The Commonwealth

CommonAge
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Dementia In The Commonwealth

A REPORT BY COMMONAGE
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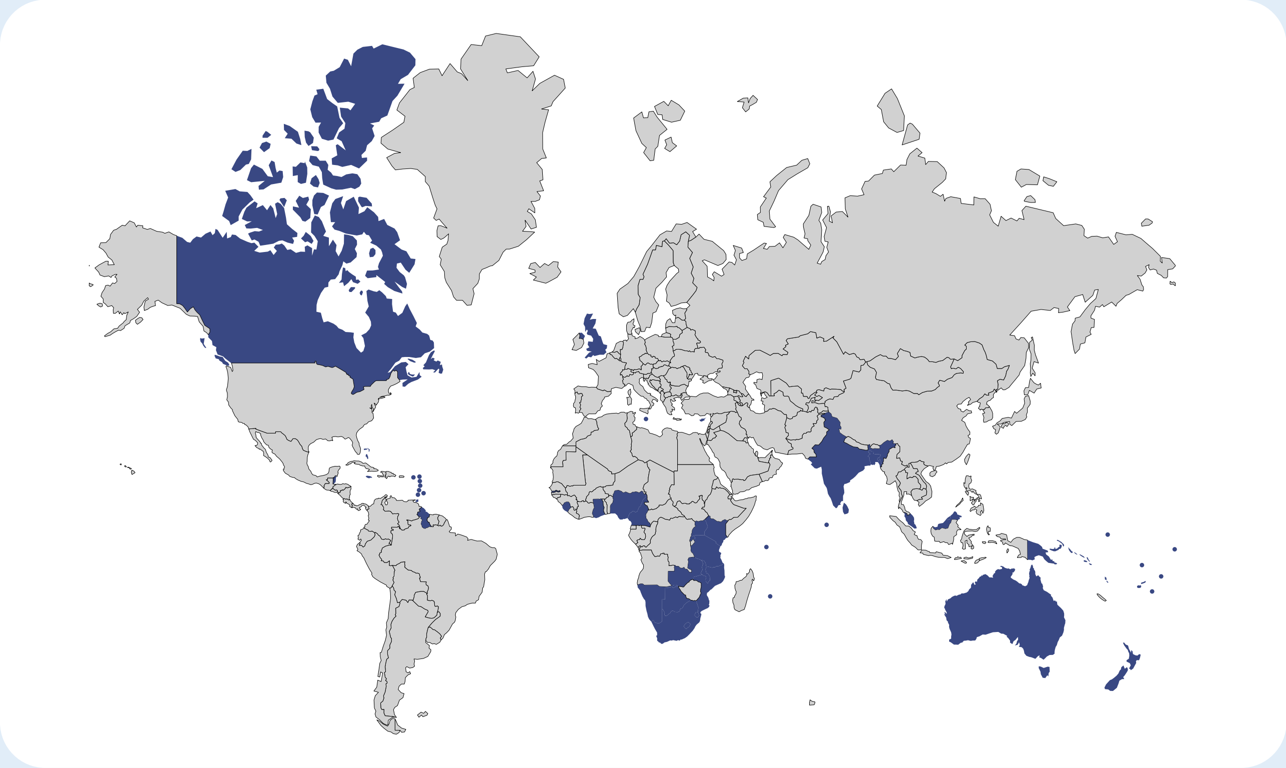
Commonwealth Association for the Ageing



The Commonwealth

The Commonwealth is a voluntary association of (56) independent and equal sovereign states, each responsible for its own policies, consulting and co-operating in the common interests of our peoples, in the promotion of international understanding and world peace and influencing international society to the benefit of all through the pursuit of common principles and values. (Commonwealth Charter)

Acknowledgements and disclaimer

This report has been made possible with great thanks to the Board of CommonAge, our sponsors, partners, supporters and the many contributing authors from across the Commonwealth. A full acknowledgements list is provided.

Thank you to our many partners who have contributed photographs for this report. First Nations people are advised that the following report may contain images of people who have died.

Most importantly we thank the many people living with dementia or caring for those that are, who teach and inspire us every day. We recognise how challenging this can be and appreciate all that you do to improve the care and support for each other and your communities.

The hard-copy printed report references the many articles written by experts in the field of dementia prevention, diagnosis, care and support. The full report, available online, includes these articles in full. For a full list of articles and contributing authors please see the summary of articles on page 4.

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Note to readers. This report is designed in two parts. The main document is a print and online report with contents as above. The online report includes all the individual articles contained in the three appendices. The online report is available via **www.commage.org**

Foreword

As the recently appointed Commonwealth Secretary General's Special Envoy for Ageing Well, I am pleased to have the opportunity to support this comprehensive report by CommonAge. Dementia is a cruel and pernicious condition that continues to be a growing threat to the health of people of all age groups, across all communities within the Commonwealth.

The demographic projections for the increasing prevalence of the condition, as highlighted in this report, continue to be of particular concern.

The World Health Organisation has called on all countries to make dementia a public health priority by the development of National Dementia Plans. Despite much progress being made, there is still a long way to go for this to become a reality.

I would like to commend CommonAge for providing this report, and for the contributors who have shared their experience and expertise for the benefit of all. The evidence of what works in practice, and what is being done in many countries to address the challenge, is encouraging and compelling.

It is hoped that this report will support many policy makers within Health Ministries and across government departments to ensure a holistic approach to one of the greatest issues for societies.

Now is the time for concerted action across the Commonwealth to ensure that every country has a co-ordinated multi-sector plan to ensure that plans are implemented without delay.

The 2.5billion people across the Commonwealth deserve nothing less.

Dame Carol Black GBE
Commonwealth Secretary General’s Special Envoy for Ageing Well

Summary of articles

The online version of this report includes a wide range of articles demonstrating innovation, progress and practice across the Commonwealth. These articles are referred to in the section titled "Innovation, practice and progress from the Commonwealth" in this report. The articles have been categorised into three broad themes and are listed here by theme and in author alphabetical order.

Appendix 1 – Focus on areas of practice and evidence base

AUTHOR	TITLE
Larpent, Andrew	Personhood in dementia
Wong, Datin Jacqueline W. M.	Women and dementia: from caregiving disparities to economic opportunities
Davos Alzheimer's Collaborative	Leading an unprecedented global response to Alzheimer's and dementia
Childhood Dementia Initiative	Childhood dementia and the urgent need for policy inclusion
Patterson, Rianna	Young people and dementia
Hobbins, Ngaire	Nutrition
Morris, Dr Tom and Alford, Marie	Design and dementia
Swinton, Professor John and the Health Television Network	Spirituality, relationships and dementia
Mishra, Sailesh	Developing and managing 'A1Snehanjali' assisted living elder care for Dementia as a Social Enterprise: Challenges and Impact
Yeates, William and Alford, Marie	Hearing the voices of lived experience in designing for dementia

Appendix 2 – Place based articles

AUTHOR	TITLE
Shamam, Femada	Dementia update – Africa
Ventry, Dr Philip	Dementia and cognitive impairment among Indigenous and Aboriginal populations: a comprehensive review
Tan, Maw Pin and AGELESS Investigator Team	A multi-institutional interdisciplinary collaboration in Malaysia using innovative diagnostic and management solutions for dementia prevention
Formosa, Professor Marvin	Malta's contribution to dementia policy
Judd, Dr Stephen	Dementia policy in Australia
Ahmad, Muhammad Hanif & Teo, Shyh Poh	Dementia initiatives and innovative practices from the Asia Pacific region
Pulugurtha, Nishi	Making meaning to lives: Alzheimer's and related disorders society of India (ARDSI) Calcutta Chapter
National Care Forum UK	Examples of dementia services in England
Collyns, John	National plan for dementia in New Zealand: An overview
Bullock, Dr Cynthia	UK Research and Innovation (UKRI), healthy ageing challenge
Blanche, Maria; Roberts, Edward and Ross, April	Multi-sector collaboration – spotlight in Essex. Coventry and Birmingham in England
Eldemire-Shearer, D	Overview of dementia in Jamaica

Appendix 3 – Solutions / case studies

AUTHOR	TITLE
Amichi, Trish	What relevance, if any, does an intergenerational program have for older people?
Mahoney, Fiona	The Archie Project – Intergenerational Awareness
Dementia Care International	The Spark of Life Model of Care
Shamam, Femada	Train the trainer programme: a practical solution using a strength-based collaborative partnership model
Dalal, Mansur	Technology/AI and Reminiscence therapy

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Care first

We remember with love the late Dr Julie Christie who contributed so much to improving the lives of people living with dementia. She would have been a key part of this project, and we miss her thoughtfulness, advocacy and friendship.


Singapore
Celebrating
Global
Spark of Life®
Month


Tania

Executive summary

The aim of this report is to provide insight to policymakers, community organisations, health and care professionals into the wide range of approaches and actions being taken across the Commonwealth with regards to improving the health and wellbeing of all those living with dementia. The hope is that the examples shared in this report provide ideas, solutions and approaches that can be adopted or adapted in a culturally sensitive way.

It is recognised that there are many competing priorities for governments, particularly for low and-middle-income countries, including water/sanitation, food distribution, climate change and education. In many of these countries there are already great examples of activities that are supporting people living with dementia and their families. For countries struggling to know where to start, there are examples throughout the report to help.

The full report which is available online at **www.commage.org** includes twenty-six articles across three broad categories a) a focus on areas of practice; b) place-based examples and c) some examples of solutions supporting people living with dementia.

The printed report includes a discussion using WHO's seven cross cutting themes as a guide; a) human rights of people with dementia, b) empowerment and engagement of people with dementia and their carers, c) evidence-based practice for dementia risk reduction and care, d) multisectoral collaboration on the public health response to dementia, e) universal health and social care coverage for dementia, f) equity and g) appropriate attention to dementia prevention, cure and care[7]. The discussion pulls out examples and key points from the articles and looks at key themes that may be helpful in developing plans and strategies.

This report highlights the progress made towards the development of National Dementia Plans (NDP) or strategies from across the Commonwealth. Based on data collected by CommonAge and Alzheimer's Disease International in their 2024 publication *From Plan to Action VII* only 11% of Commonwealth nations have a NDP in place, with 19% in the process of developing a NDP. However, 59 % of Commonwealth nations do not yet have a NDP or strategy in place[5].

It is essential that the target for all countries to have a national approach to dementia is met in order to provide the commitment, resources and approaches that can result in improvements in the health and wellbeing of people living with dementia, their carers and communities. A plan provides a mandate for implementation and raises the issues relating to dementia as a public health priority. However, not having a plan does not mean nothing is happening. Communities and civil society are mobilising to create greater awareness and dementia friendly spaces to reduce isolation and discrimination. Health and care professionals are working in partnership with other key stakeholders to find new ways of providing culturally appropriate care and support. Entrepreneurs from private and social sector, and committed enterprising individuals are also seeking solutions across key areas such as housing, residential care and technology.

Executive summary

Key themes and areas of commonality across the Commonwealth relating to:

- **Human rights**, equity and consideration for a) culturally appropriate solutions co-designed with the people they aim to support b) dementia as a whole life course disease; and c) the role of women.
- The power of **community engagement** and awareness raising using creativity, storytelling and intergenerational activities.
- The essential and varied role of community in **reducing social isolation** and support for informal carers.
- The opportunities provided by **technology as a component of culturally appropriate care** and support.
- The importance of **design** of both places to live and places to enjoy.
- **Workforce** – growing, changing and valuing a labour market able to meet the care needs of people with dementia and their families.
- A **financial model** to ensure implementation.

There are many examples in the full report that do not require huge investment, there is so much that is and can be done with the compassion and commitment of citizens. These local examples can ensure cultural understanding and raise awareness of living with dementia and what can help people to continue to live as independently and as well as possible.

> There are so many stories in the report of people doing incredible work, combining this with governmental commitment provides much optimism for the future.

Why dementia, why the Commonwealth, why now?

By Paola Barbarino,
Chief Executive Officer, Alzheimer's Disease International

Every three seconds, someone develops dementia[1]. Yet, as many as three-quarters of those who have dementia will remain undiagnosed, deprived of the treatment, care, and support they need and deserve so much[2]. Family and loved ones will also be affected, with an estimated 133 billion hours of informal care provided each year[3]. Many carers will develop physical or mental health aliments as a consequence. Many will not be able to hold a job. This is why it is crucial that dementia remains at the forefront of politics and policymakers globally, recognising its profound and growing impact on societies worldwide.

We would like to thank CommonAge for commissioning this report at a time when policymakers and governments all over the world, regardless of the wealth of countries, seem to be neglecting this very issue. The report convenes those at the forefront of this effort, amalgamating policy, research, healthcare practice with national case studies from across the Commonwealth, highlighting the necessity for intersectoral and multilateral collaboration to address this global public health issue. Most importantly, the report includes the voice of those with lived experience, reminding us that the outcomes of policy have a direct and tangible impact on those living with the condition.

In 2017, Member States of the World Health Organisation (WHO) approved unanimously the Global Action Plan on the public health response to dementia[4]. The seven action areas of the plan sought to improve the lives of those living with dementia, carers and reduce its impact on the wider society. Action Area 1, 'Dementia as a public health priority' sets the target of 75% of countries to have updated or developed National Dementia Plans by 2025. It commits each country to periodically report to the WHO on the progress of each action area of the plan between 2017 and 2025. Yet with under a year remaining until the estimated completion of the Global Action Plan in 2025, Alzheimer's Disease International's (ADI) report *From Plan to Impact VII: Dementia at a Crossroads*, published in May 2024 found that Member States are far from achieving these targets and worst still, Member States are not even reporting on their progress[5].

These facts sadly reflect Alzheimer's Disease International's and our membership's own experiences when working with national governments. Despite research overwhelmingly suggesting that the impact of dementia will only continue to worsen over the coming decades, most Governments still choose to neglect the issue or bury their heads in the sand. This inaction has lasting consequences which will become compounded in the future.

In the Alzheimer's and dementia community, hopes are running high. We are on the brink of new disease modifying therapies entering the market, and whilst these are not definite cures, they could give the individual affected many more years before the onset of cognitive decline. This means two things, the first is that more people, once aware of this, will demand to be diagnosed in the hope of accessing the new therapies. The second is that care will continue to have the utmost importance in dementia treatment as the absence of a cure will inevitably lead onto the path of care, just delayed. ADI has advocated for years for governments to improve their diagnostic and post diagnostic capacity in view of these breakthroughs but sadly most governments have failed so far to improve diagnostic rates in their countries[2, 6].

Why dementia, why the Commonwealth, why now?

Despite this situation, there is room for hope and the expert essays within the report are a testament to the work that is being conducted. We must also acknowledge governments which are prioritising dementia, there are quite a few that are doing excellent work and accordingly this report rightly highlights nations that are demonstrating leadership in this area.

ADI and our community have been advocating for a 10-year extension to the Global Action Plan on the Public Health Response to dementia. This will provide Member States the opportunity to reset and address the failures and inaction of the previous seven years. We hope the countries this report addresses will add their voice to those who have already joined our cause, at the next Executive Board of the WHO in January 2025. It is a rare opportunity to give a second chance to the countries that are lagging behind, in some cases due to COVID, lack of funds or lack of human resources. ADI helps all countries that want to embark on a National Dementia Plan but may lack expertise and require advice, we do this by sharing the knowledge we have acquired and by connecting interested individuals across the globe. There are a lot of people who have witnessed the havoc dementia causes and are willing to help. We are a civil society, and we are limited in what we can do but every day we wake up and go to work, knowing we can make the world a better place for people living with dementia and their families. The stakes are high and the stigma surrounding the disease is still a major issue, but we know we can win and with your help we can get there better and sooner!

CommonAge and dementia in context

By Andrew Larpent OBE,
Chair (Emeritus) CommonAge

The Commonwealth Association for the Ageing – CommonAge was formed as a voluntary organisation and charity in Australia in 2013. It is formally accredited by the Commonwealth as a civil society non-governmental organisation. All activity by the charity is made possible by generous donations from the individuals and organisations that constitute its membership, and through the commitment of increasing numbers of volunteers who devote their time and energy to the cause.

The Board of Commonage reflects the diversity of the organisation. Its 11 Directors are spread across seven Commonwealth countries and four continents. They are all distinguished and respected professionals in their respective countries, with deep experience in the aged care and supporting living sectors, and in international advocacy. They devote their time voluntarily to the cause of CommonAge.

CommonAge's purpose is to work for Commonwealth citizens of all ages, but with particular emphasis on the interests of older persons, working for a truly inclusive, all-age-friendly Commonwealth in which no section of society is marginalised on account of age. In doing this it has to be recognised that, despite the best intentions of governments and institutions, the Commonwealth, with its continued emphasis on youth, inadvertently projects an ageist attitude that results in the rights, interests and support needs of older citizens being accorded low priority in public policy and resource allocation. This is the case in the so-called advanced economies of the Commonwealth, as well as the rapidly developing countries of the "Global South".

Population ageing is affecting all Commonwealth countries. This fact is well known to those who work in the field of ageing and who advocate for the rights, needs and contributions of older people to be recognised and appreciated by governments and institutions. From the time it was first conceived by a group of professional colleagues working on service provision for older people, CommonAge has experienced how the interests and potential of older people are too frequently overlooked.

CommonAge's response has been to build an international network of professionals and organisations involved in ageing and aged care. Key areas of focus are:

- Advocacy for the rights of older persons.
- Working at the front line to deliver training programmes and leadership development initiatives across the Commonwealth.
- Working in partnership with many national and international organisations such as the Global Ageing Network, Age International, the International Federation on Ageing, the Global Alliance on the Rights of Older Persons, HelpAge International, Alzheimer's Disease International, the International Institute in Ageing United Nations-Malta, Dementia Alliance International, and the Davos Alzheimer's Collaborative.

CommonAge and dementia in context

- CommonAge has also recently launched a Youth Chapter to support the views and experiences of young people in shaping future approaches to care and support for people with dementia.

Much of the work of CommonAge takes place within the extensive mixed market ecosystem of public, private, not-for-profit and academic institutions, companies and NGOs that make up the global ageing economy and industry. As a civil society charity CommonAge does not specifically endorse individual commercial products and services but it recognises and appreciates the support and contributions that many private sector organisations give willingly in their efforts to promote stronger and more resilient societies. These are companies that operate for social benefit and their efforts and contributions are directed to the common good.

This report focuses on dementia, a condition that affects an increasing number of people of all ages and in all countries across the Commonwealth. Dementia is a progressive brain disorder characterised by various conditions that cause gradual brain damage, hinder normal functioning, and negatively impact social interactions. Alzheimer's disease is the most common type, accounting for 60-80 per cent of cases[8]. Currently, there is no cure for dementia, however, there are many approaches that could help individuals and their families adjust to the condition and ensure quality health and social care.

Even in countries with predominantly young populations, people are living longer, and they are developing more complex health and social needs as they age. Dementia does not discriminate, and it affects all generations; a factor that is being given too little attention throughout the Commonwealth. Dementia primarily affects older people, but it is becoming more prevalent in individuals in their 30s, 40s, and 50s. There is also a growing understanding of children living with dementia. Unfortunately, across the Commonwealth there is insufficient public awareness, and many individuals lack access to early diagnosis, proper medical services and care support, leading to poor quality of life and highlighting significant policy challenges.

In developing this report, CommonAge has aligned closely with the WHO's Global Dementia Action Plan[11] and also drawn on evidence of progress, or lack thereof, and Alzheimer's Disease International (ADI) continuous monitoring through their annual "From Plan to Impact" reports [5]. The response to the call by the WHO, for all nations to develop National Dementia Plans (NDPs) by 2025, has been slow and there are currently only a handful of countries with NDPs in place.

Globally, 48 countries and territories have adopted a plan on dementia: 39 in WHO Member States[12]. Several countries are developing their plans, but the majority have yet to respond to the challenge. CommonAge's purpose, through this report, is to support and encourage a more dynamic approach to the challenges of dementia by Commonwealth member states as they in turn support existing and growing NGO and civil society actors through the development of their own NDPs, or strategic plans. The intention is to follow up this report in 2026 with an update on progress that will be presented to governments and ministers.

In 2024, CommonAge takes up the two-year appointment as the representative civil society organisation on the Commonwealth Advisory Committee on Health (CACH). It is hoped that by the end of the time in this role the challenge of "Dementia in the Commonwealth" will be firmly established as a standing item on the agenda of the annual Commonwealth Health Ministers Meeting (CHMM).

CommonAge has developed a diverse international network of professional colleagues across the Commonwealth who, individually and collectively, represent valuable in-depth knowledge and experience in all aspects of ageing service development. CommonAge has the ability and voluntary capacity to support Commonwealth governments with the development of National Dementia Plans.

To explore further how CommonAge can assist please make contact via the website at **www.commage.org** or by email to secretariat@commage.org

It is essential that the challenge of dementia is recognised and addressed by all commonwealth countries as a public health priority.
Now is the time to act!

Key facts

55 million

people living with dementia globally

New dementia case every **3 seconds**

Worldwide cost of dementia at least **1.3 trillion** US dollars every year and will increase up to nine times by 2050[10]

Globally 3 out of 4 people living with dementia are never diagnosed

By 2050 the number of people living with dementia will triple to

139 million[9]

The number of people requiring care will increase from 2.1 billion in 2015 to a predicted **2.3 billion in 2030**

1 in every 2,900 babies born will develop childhood dementia

82 billion

hours of informal care are provided to people with dementia at home annually. Women contribute 71% of these hours

Commonwealth countries comprise over 33% of the global population

Only 11% of Commonwealth nations have a National Dementia Plan in place


Nilanjana


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Developing National Dementia Plans and setting priorities

By Glenn Rees AM
former CEO of Alzheimer's Australia
and Chair of Alzheimer's Disease International

There are four key priority areas to winning the fight against dementia, which lie in a unique combination of global solutions and local knowledge:

1. **The imperative to adopt a National Dementia Plan**
2. **Achieving a planning dynamic**
3. **Policy priorities**
4. **Engaging the support of civil society**

1. The imperative to adopt a National Dementia Plan

At the country level, experience from within the Commonwealth has demonstrated that adopting a National Dementia Plans (NDPs) provides the opportunities to:

- Promote understanding at the political, administrative and community level that dementia is a major health and social challenge in this century.
- Optimise the use of available resources to improve and coordinate care, treatment, and prevention and to invest in research.
- Reduce stigma and social isolation by promoting understanding of dementia as a chronic condition.
- Recognise the importance of family carers and their need for support if people with dementia are to remain in the community and avoid premature institutionalisation.

The failure to plan can have profound and costly consequences. For example, an under investment in home and community-based care services, including respite care, which may result in premature institutionalisation of people living with dementia and greater demands on hospitals. Underuse of the primary health system and overuse of specialist resources to diagnose dementia – resulting in higher diagnostic costs. A failure to address dementia risk reduction.

2. Achieving a planning dynamic

Creating a dynamic for change is an essential element of developing a NDP which has the active support of the national government. Situational analysis at a country level is important to increase the understanding of dementia and the needs of people with dementia and their family carers and may include elements such as:

- analysis of the prevalence, costs, and burden of disease of dementia
- the constraints across the health system in delivery of services to people living with dementia, especially in primary care, community care services and the quality of acute residential care services
- recommendations for a nationally coordinated and planned strategy around research, diagnosis, training, expansion of community care, quality dementia care and provision for special groups.

Developing National Dementia Plans and setting priorities

The challenge in every country is not simply writing a plan but making it come alive. Initiating change by:

a. providing a roadmap, setting out intended outcomes for 5-10 years' time.

b. guiding and monitoring action by government and civil society.

c. drawing on international experience through Alzheimer's Disease International.

d. improving and integrating policies, services and systems for people living with dementia, their families, and carers.

e. ensuring planning is on-going and promotes partnership between the key actors in the health and social services departments, medical professionals, service providers and care staff, and people living with dementia and their families. Alzheimer's and dementia organisations have played a critical role in ensuring the voices of family carers and people living with dementia are heard in the development of policies and services.

3. Policy priorities

The need for action in key policy areas from diagnosis and post diagnostic support to treatment and care and palliative care is now well understood. The challenge is in implementation and translating the key policy objectives into action. It is here that high-income countries within the Commonwealth can assist lower-middle income countries in undertaking situational analyses and assisting with evidence on what approaches might be most cost effective, for example in design of services to assist family carers. It is essential however that local culture and rituals are understood and that stakeholders work together to ensure culturally appropriate care and support.

The priorities in many NDPs relate well to the action areas of the Global Dementia Action Plan and include:

- promoting a greater awareness of dementia through information, the adoption of dementia-friendly projects and the potential for reducing the risk of dementia (Actions 2 and 3).
- capacity building through training and education for health professionals, care staff and family carers (Actions 4 and 5).
- expansion of community care and implementation of new models of support for family caregivers and effective approaches to diagnosis and post diagnostic support (Action 4 and 5).
- building an evidence base for the development of policy and services (Action 6).

It is noted where these priorities correspond broadly to the seven action priorities in the Global Dementia Action Plan.

4. Engaging the support of civil society

The driving force of action comes from family carers and from people with dementia themselves. People with dementia and their families are the experts!

The task is to develop a national plan that tackles dementia as both a medical and social issue in making the health and care system dementia friendly and the society inclusive of people with dementia. This will best be achieved by ensuring that people with dementia and their family carers are fully engaged from the outset including through non-government organisations such as Alzheimer's organisations.

It is important to plan and develop health and social care pathways to show how access to services is working from the perspective of government, service providers and people with dementia and their families.

Conclusion

Experience from within the Commonwealth suggests that NDPs will contribute to efficient use of resources and improved access to services for people living with dementia in developed and less developed countries. The starting point for a plan is to undertake a situational analysis by the main stakeholders (government, service and health providers, researchers, and consumers) which documents at a minimum the prevalence and costs of dementia, the constraints to dementia services and carer support and the priorities proposed for action taking a realistic view of resource constraints. Assistance for situational analyses of this kind in lower-income countries in the Commonwealth where the need is greatest might be considered by those with stronger economies and health systems.

Urgent call to make dementia a public health priority

By Emily Ong

Speaker, patient advocate, author, consultant, facilitator, and content writer on dementia-related topics based on lived experience, academic reading and grassroots involvement.

Whether people living with dementia and their informal carers can cope with a progressive chronic medical condition like dementia, depends significantly on the social determinants of health (SDOH), which have a profound effect on a person's health, including their risk for dementia. Living with dementia further compounds adverse SDOH due to stigmatisation associated with the disease creating accessibility barriers to healthcare services [13]. Yet, availability and accessibility of early detection systems, timely and accurate diagnosis, culturally appropriate information, and quality and affordable post-diagnostic interventions are prerequisites for a meaningful quality of life for people with dementia and those impacted by it. Essentially the right to the highest attainable standard of health by all without discrimination.

Dementia is the seventh leading cause of death globally and the third largest contributor to neurological disability-adjusted life years [14,15]. It is driven by global patterns of population ageing and is projected to affect 75 million people worldwide by 2030 with one new case every three seconds. Dementia is particularly prevalent in low and middle-income countries making it a significant public health concern of the Commonwealth, where most of its member countries are in this category [16]. Moreover, the absolute size of the older population in the Commonwealth countries is expected to increase by at least 100 per cent over the next 25 years, and these are mostly low and middle-income countries[17]. This is likely to have a phenomenal economic impact and needs to be addressed by policymakers as a public health priority.

Traditionally, dementia has been viewed as a gerontological issue. With the shifting demographics, it is everyone's business because dementia is an increasingly growing threat to healthy ageing and social care systems in every country[18]. The weak social health coverage and poor financial independence of older people mean they rely heavily on their children as an essential pillar of income security and providers of care. The inadequate preparedness of the healthcare systems in low and middle-income countries of the Commonwealth, coupled with the low universal coverage for essential health services, make it extremely difficult for people who live in poverty to access quality health and social care services.

The poor response to the Global Action Plan on the Public Health Response to Dementia 2017-2025 showed the underemphasis on dementia[11]. This lack of progress which indirectly perpetuates the stigma and discrimination, causes many people living with dementia, their families and informal carers to be underserved and their needs unmet. These people living with and impacted by dementia experience intersectional discrimination on multiple levels and there is an urgent need for national and local health agencies, civil societies, and other partners to work together with these people with lived experience to prepare for and reduce the impact of dementia.

Urgent call to make dementia a public health priority

Population health approach to reduce dementia risk

It is undeniable that ageing is the predominant risk factor for age-related chronic diseases and conditions including dementia[19]. Yet, the risk of developing dementia or other age-related chronic disease starts years earlier or even decades before the diagnosis as in the case of dementia, and nearly 40 per cent of dementia cases are preventable [20]. Hence, a population health and preventative approach would be more effective for people to make healthier life choices based on evidence-based interventions to achieve optimal health outcomes and maintain cognitive health.

The "Healthier SG" is a population health system that **Singapore** embarked on to shift away from reactive curative care to proactive preventive care and reshape the health-seeking behaviours and lifestyles of its people [21]. In tandem with the proactive preventive care of Healthier SG, Active Ageing Centres are a tailored approach that supports older people to age actively and healthily in their communities.

While low and middle-income countries might not have the financial and resource capacity to do what a high-income country like Singapore can do, they can adopt the shift in mindset towards preventive care for older people and empower individuals with and impacted by dementia and those at risk to take charge of their health journey by working with the people and their relevant stakeholders in the communities.

The "Dementia Café of Ipoh" in **Malaysia** is a good example of a ground-up initiative by people impacted by dementia working together with healthcare providers to empower families and informal carers with knowledge on ways to slow down the cognitive decline and reduce their risk of developing dementia. Additionally, the café also provides an assortment of activities for people with varied interests and abilities. This initiative would not be possible without the support from stakeholders in the community and healthcare professionals from the local hospitals.

Public health as a leader in addressing dementia

With myths and stigma surrounding dementia, educating the public is an effective strategy to normalise conversations about cognitive health and early detection of dementia[22]. Many people including healthcare providers would attribute cognitive difficulties or decline to the normal part of ageing or believe that nothing can be done to reduce the risk or once diagnosed with dementia[23]. Therefore, education strategies must include the voice of those with lived experience of dementia including informal carers and their families to provide a more accurate understanding of dementia to tackle the stigma.

It may also be beneficial to integrate dementia risk prevention messages into existing non-communicable disease public health messages. This would make them more accessible and comfortable in communities where dementia is a taboo topic and stigma is pervasive. Healthcare and public health curricula must be revised to incorporate modules on dementia to improve the knowledge competencies of healthcare providers and public health professionals to achieve a dementia-prepared future[24]. These education strategies are doable with knowledge sharing and dementia advocates with lived experience from high-income countries of the Commonwealth.

Dementia-inclusive communities

Regardless of which Commonwealth countries they stay in or whether they are from high-income countries like **New Zealand** or low-income countries like **Namibia**, people with dementia mostly live in community settings either with their families or staying alone. Therefore, creating supporting communities and workplaces for people with dementia and their carers is essential to empower them to continue leading independent, dignified and purposeful lives in their neighbourhood and familiar surroundings.

The dementia-friendly community, also known as the dementia-inclusive community, has two core components – the "hardware" and the "heartware." The "hardware" refers to the infrastructure and the "heartware" is about the community engagement spirit and cultures.

The Yio Chu Kang pilot project was the first local dementia-friendly neighbourhood study and started in 2019[25]. A prototype design known as "Blue Zone" is a community leisure space co-created through a whole-of-society approach to ensure that the custom design improvement caters to the needs of older people living with dementia. The "Blue Zone" is open to the public and provides a range of opportunities for cognitive stimulation activities, big enough to have physical exercise for a small group of people and sitting places for social interaction. The availability of this leisure space within the neighbourhood is beneficial to people with dementia to feel 'being in the world' with their neighbours and the choices of activities enable them to exercise their autonomy[26].

In addition, a supportive neighbourhood can help to reduce the risk of limitations in life-space mobility experienced by people living with dementia due to driving cessation and safety reasons. Often their life space is restricted to their own home or the place they sleep towards the later stage of dementia. Without having the possibility to visit other people and no access to social activities, the risk of social isolation and loneliness may exacerbate their cognitive decline and hasten the need for institutional care.

The *"Find Your Way"* initiative by a local transport provider, SBS Transport in **Singapore**, aimed to help people with mild dementia to continue taking public transport confidently and safely by having coloured-coded nostalgic murals and directional floor arrows to assist in wayfinding and orientation at bus interchanges and MRT stations[27]. Initiatives like this help to support life-space mobility, making it possible for people with mild dementia to travel independently and safely across the island city.

Advocacy with lived experience to tackle stigma

The biggest barrier to tackle is the pervasive nature of this stigmatised health condition and discrimination against people living with dementia. Despite Alzheimer's disease having been defined since 1906 and other related dementias were subsequently discovered, the myths, misconceptions, negative attitudes, and discrimination towards people with dementia have not changed much.

Even in this century, people with dementia continue, too often, to be regarded with suspicion and superstition in some countries, particularly in **Africa**. Meanwhile, older people with dementia in high-income countries of the Commonwealth continue to experience abuse in nursing and residential homes. During the COVID-19 pandemic, the death rate for older people with dementia was high due to multiple factors and among them was the unpreparedness of healthcare to protect this vulnerable population group from getting COVID-19 and the poor design of dementia nursing homes to control the spread of infection. The long social isolation and restriction protocol accelerated the cognitive and functioning decline of this group even though the intention was to keep them safe[28].

Without their voice, the struggles and discrimination experienced by those living with dementia and informal carers remained unheard. Dementia advocacy must have the voice of those with lived experience to lead and call for change in the systemic issues. The eBook project, *"Voices of Asia"*[29] is a good example of advocacy by people with lived experience and two of the co-leads are advocates from Taiwan and Brunei Darussalam (and Malaysia), respectively. An excerpt from the eBook:

"As a person with dementia [Emily Ong], I experience stigma and discrimination firsthand but also see the adverse impact on families, particularly those from minority groups or with low and middle socio-economic status. There are over 38 million people with dementia in the Asia Pacific region, with the majority in low and middle-income countries. Stigma and discrimination against people with dementia are both pervasive in these countries due to a lack of dementia awareness, and a cultural context in which not only is the existence of dementia denied; rather it is assumed to be a natural process of ageing and not a result of a brain degenerative disease. Furthermore, the inadequate preparedness of the healthcare systems in resource-poor settings worsens the situation." [30, p. 8]

Urgent call to make dementia a public health priority

The way forward

As an advocate living with dementia, I believe that more can be done to reduce the modifiable risk factors for dementia and address the underlying social determinants of health through collaboration at multi-sectoral levels within the country and across the Commonwealth. The time to act is now because it has been for too long that people living with and impacted by dementia have been underserved and left out of decision-making processes that affect their quality of life. Inclusion and valuing people with lived experience of dementia is pivotal to reaching the vision of the global dementia action plan *"a world in which dementia is reduced and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality."*

The development of National Dementia Plans in the Commonwealth

By Rianna Patterson
Founder, Dominica Dementia Foundation

The WHO Global Action Plan on the Public Health Response to Dementia urges governments to have a National Dementia Plan (NDP) in place by 2025[7]. "From Plan to Impact VII – Dementia at a Crossroads" demonstrates that this target will be missed and calls for an extension[5].

The implementation of a NDP is expected to yield favourable outcomes for individuals affected by dementia, as well as their families, friends, and communities. A NDP will enable them to gain access to enhanced support, timely diagnosis, and improved treatment options. Additionally, the plan underscores that dementia does not have to be an unavoidable consequence of ageing and emphasises the importance of providing those affected by dementia with the essential support to help them lead fulfilling lives[5].

Countries are urged to develop a comprehensive national dementia strategy to address the substantial gap between the demand for dementia prevention, treatment, and care, and the actual provision of these services[7]. Dementia is often underdiagnosed, leading to fragmented or absent long-term care pathways. The lack of understanding and awareness of dementia results in stigmatisation and barriers to diagnosis and care, depriving individuals living with dementia of their human rights. Furthermore, dementia imposes significant financial burdens.

> A NDP plays a vital role in ensuring that individuals living with dementia have access to necessary support and services including governmental interventions. It is essential for strengthening preventive measures, enhancing diagnostic capacities, and amplifying care services for individuals with dementia and their carers on a nationwide scale[7].

There are many challenges and government priorities across the Commonwealth, on which dementia has an impact, including wider health outcomes, the labour market and the economy. It should be recognised that some countries are facing greater cultural, economic and resource challenges than others when it comes to prioritising and developing a NDP. The time taken to produce and publish a NDP should not be underestimated. For some countries, particularly those with a smaller population dementia is inserted as a component in a national ageing plan (or a national active or healthy ageing plan). For example, **Brunei** (with a 450,000 population) and nearly 2,000 people living with dementia, has two geriatricians, and no care home, or aged care facility in the country. For countries with larger populations. **Malaysia** (32 million population), a separate and specific NDP is required with an estimated 320,000 people living with dementia and 39 geriatricians.

In producing this report, CommonAge surveyed all Commonwealth member states via High Commissioners in London, local governments, NGOs and inter-governmental officials. Unfortunately, only 14% of Commonwealth nations responded to the survey; however, the responses received added rich data in relation to dementia engagement and local activity as well as governmental structures that have taken dementia engagement into consideration.

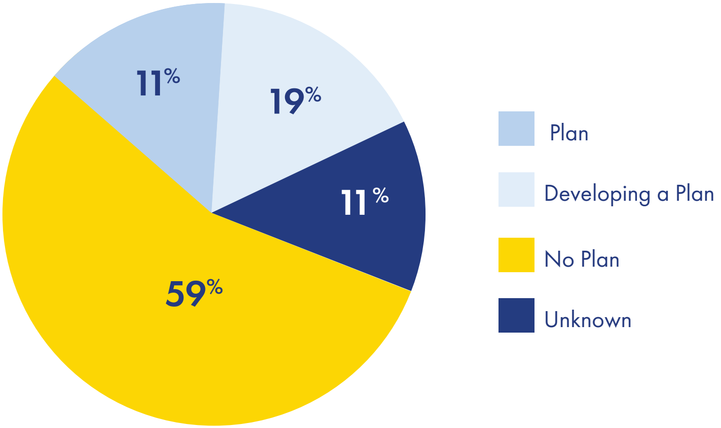
The survey data combined with the extensive global picture contained within *"From Plan to Impact VII: Dementia at a Crossroads"* enabled an overall view of the Commonwealth's progress towards having NDPs in place[5].

The development of National Dementia Plans in the Commonwealth

These charts below focus specifically on the existence of a NDP, the activities happening across the Commonwealth are discussed later in the report.

The first chart shows the overall position of NDPs across the Commonwealth, it is a stark reminder of the work yet to do, however as you will read in this report, not having a NDP doesn't mean there is no activity in relation to supporting people living with dementia.

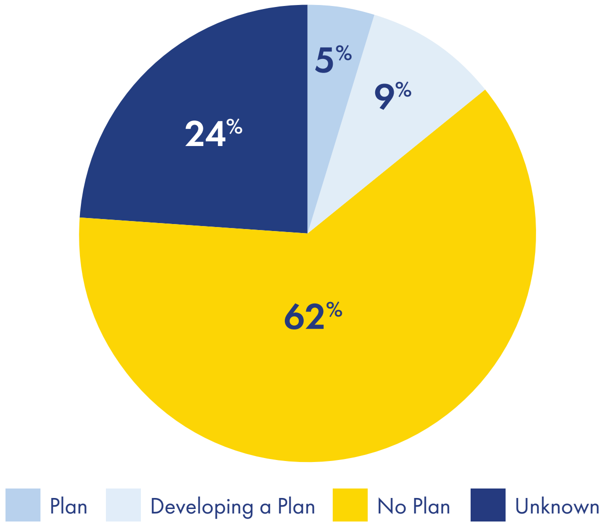
Summary of status of Commonwealth National Dementia Plans



The following charts are a breakdown by Commonwealth region.

Africa

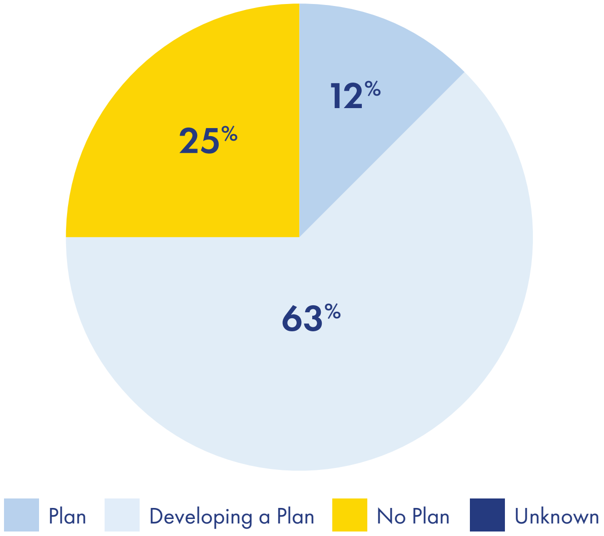
There are many positive contributions from Africa within this report, however there are still several countries where little is known about their approach to developing a NDP. Whilst South Africa, Botswana and Uganda are listed as having 'no plan' there are pro-active organisations leading the call for a national strategy. In addition, the African Union protocol will support the prioritisation needed for development of national plans or strategies for dementia[31]



Country	Status of National Dementia Plan
Botswana	No plan
Cameroon	No plan
Gabon	No Plan
Gambia, The	Unknown
Ghana	Developing a plan
Kenya	Plan in Place
Kingdom of Eswatini	Unknown
Lesotho	Unknown
Malawi	Unknown
Mauritius	No plan
Mozambique	No plan
Namibia	No plan
Nigeria	Developing a plan
Rwanda	No plan
Seychelles	No plan
Sierra Leone	No plan
South Africa	No plan
Togo	No plan
Uganda	No plan
United Republic of Tanzania	Unknown
Zambia	No plan

Asia

Good progress is being made across Asia with regards to the development of National Dementia Plans. Several examples from Asia are included throughout this report.

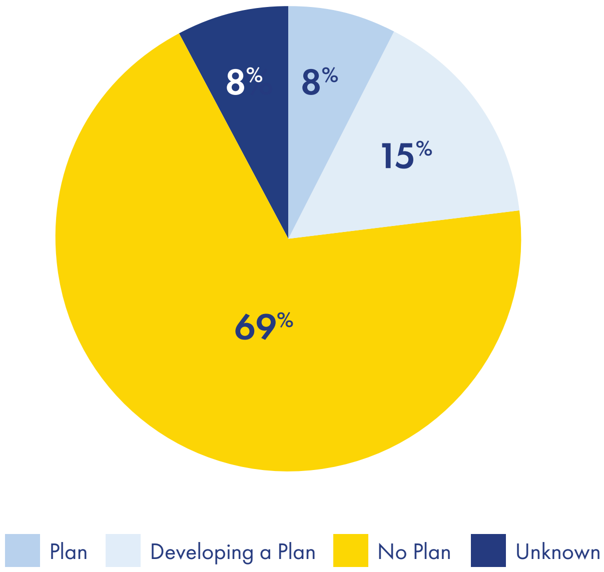


Country	Status of National Dementia Plan
Bangladesh	No Plan
Brunei Darussalam	Developing a plan
India	Developing a plan
Malaysia	Developing a plan
Maldives	Developing a plan
Pakistan	Developing a plan
Singapore	Plan in place
Sri Lanka	No Plan

The development of National Dementia Plans in the Commonwealth

Caribbean and Americas

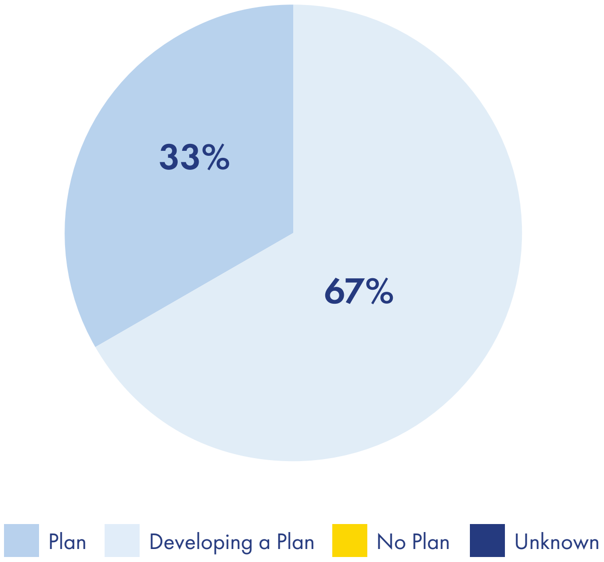
Further exploration is needed to understand the approach to dementia in this region of the Commonwealth.



Country	Status of National Dementia Plan
Antigua and Barbuda	No plan
Bahamas, The	No plan
Barbados	No plan
Belize	No plan
Canada	Plan in place
Dominica	Developing a plan
Grenada	No plan
Guyana	No plan
Jamaica	No plan
Saint Lucia	No plan
St Kitts and Nevis	No plan
St Vincent and The Grenadines	Unknown
Trinidad and Tobago	Developing a plan

Europe

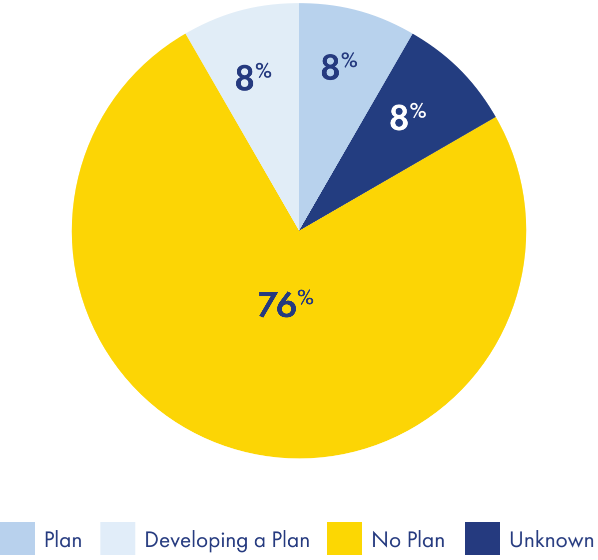
There are only three countries within this Commonwealth region, there is good progress with all either having or developing a plan.



Country	Status of National Dementia Plan
Cyprus	Plan in place
Malta	Plan in place
United Kingdom	Developing a plan

The Pacific

The approach to dementia for Australia and New Zealand in the Pacific Commonwealth region is well documented however, more exploration is needed to understand the approach or progress towards NDP for the remainder of the Pacific region.



Country	Status of National Dementia Plan
Australia	Developing a plan
Fiji	No plan
Kiribati	Unknown
Nauru	No plan
New Zealand	Plan in place
Papua New Guinea	No plan
Samoa	No plan
Solomon Islands	No plan
Tonga	No plan
Tuvalu	No plan
Vanuatu	No plan

In addition to the progress towards having a NDP in place, the CommonAge survey asked about specific barriers, the challenges highlighted included:

- There is no overall geriatric plan.
- Lack of support for developing one.
- Not considered as a priority by the government.
- Lack of political will and funds.

What is clear in this report, is regardless of whether a government supported plan is in place or not, incredible efforts are happening in communities across the Commonwealth to raise awareness and support improvements in care and support for people with dementia and their families.

NGOs, healthcare organisations and other interested stakeholders have a key role in working with government to support the development of a NDP, for example Alzheimer's Disease and Related Dementias in Zambia (ADDIZ) is a registered not for profit organisation. They are currently in talks with the government with regards to the development of a NDP as there is currently no policy direction[32].

Grass roots and community-based NGOs must work together to make change happen, with or without governmental leadership, with or without NDPs. This is the power of civil society and voluntary activism. If leadership at the national level is lacking, it needs to come from within at the regional, local and community level to challenge governments to improve their approach to this issue. CommonAge is keen to encourage and support grass roots organisations to build local capacity and best practice through community action in support of people living with dementia. Civil society should take the lead in many Commonwealth countries and governments need to be challenged and encouraged to follow by shaping what already takes place into developing their NDPs.

The following section and the articles in the full report online, demonstrate many examples of the engagement and the power of civil society to support people and communities with regards to dementia.

Innovation, practice and progress from the Commonwealth

By Dr Emma Hodges

The WHO Global Action Plan, in establishing a vision and goals of a public health response to dementia, has outlined seven cross cutting principles[7]. This section of the report highlights examples of work across the Commonwealth demonstrating how these principles are being applied in practice. Each sub-section includes the principle and the wording according to the Global Action Plan. Further details about the projects and approaches summarised in this section can be found in the full report online which can be found on CommonAge's website.

Principle 1: Human rights of people with dementia

Policies, plans, legislation, programmes, interventions, and actions should be sensitive to the needs, expectations, and human rights of people with dementia, consistent with the Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments.

The 30 articles that make up the Universal Declaration of Human Rights all, apply to people with dementia. To further strengthen this, the Convention on the Rights of Persons with Disabilities (CRPD) was adopted in 2006 as an additional treaty to specifically protect and promote the human rights of disabled people. This includes eliminating discrimination, protection from exploitation, violence and abuse, enabling independent living and inclusive education[33].

> Implementing a human rights-based approach, the development of policies, legislation, regulation, institutions and budgets related to dementia prevention, diagnosis, care and support should be anchored in a system of rights and corresponding obligations that States have agreed to comply with under the international human rights framework[34].

The African Union (AU) is close to ratifying the AU protocol to the African Charter for Human and People's Rights on the Rights of Older Persons which will serve as a legally binding instrument highlighting the limitations of relying solely on family care for older people including those living with dementia[31].

It is worth reviewing the list of Human Rights articles specifically through the lens of dementia and reflecting where urgent attention is needed. As discussed further under the principle of 'equity', dementia is not experienced equitably and specific recommendations should be included in NDPs for those people who are often underserved, considering intersectionality, that will compound the impact of dementia some groups of people. In particular there needs to be consideration of the human rights of women; a marginalised majority.[35].

Research is indicating that ensuring that peoples human rights are met alongside the United Nations sustainability goals can reduce the risk of dementia. A study in **Australia** discovered that the long-term impact of early life experiences impact cognitive health, and trauma, neglect and socio-economic disadvantage was found to be significantly associated with an increased risk of dementia in later life [36, 37].

In the context of dementia and human rights it is important to position dementia as a whole life course disease including children, younger onset in adults and older people. Policy, research, and support needs to be tailored to the individual needs of all people with a recognition of the different impacts on family at different stages of life. The recognition of childhood and younger onset dementia as specific areas of focus further challenges the engagement and innovation needed to ensure human rights are being met.

Innovation, practice and progress from the Commonwealth

Personhood

A key concept in the field of dementia that is key to a human rights approach is that of 'personhood'.

"The pernicious and irreversible nature of dementia is that it too often deprives the individual, not only of their memory, but also of their personality, their individuality, their dignity, their self-esteem and their status as a consequential member of society and of their community" [38].

Dalal (2024) describes how his mother who had Alzheimer's would hum a particular song and when devotional hymns were played, she would sit up straight in a pious respectful position, demonstrating a connection to memories. There are many examples of how people with dementia can engage in culture, music, art and community enabling them to enjoy things that are central to their personhood. Assuming, that people with dementia do not have the capacity to enjoy culture and community is a breach of their human rights under Article 27 *"The right to enjoy the cultural life of the community"*.

Larpent (2024) describes the difference between the experiences of people in institutionalised care and the risks of loss of individuality as care settings are challenged by regulations and routines, he states:

"In communities in the 'global south' which continue to place greater reliance on traditional family and community-based support, the position of older persons in society is more firmly rooted in respect for the individual and their status as respected elders" [38].

This shows how different cultural support structures affect experiences of dementia in society. However, regardless of the status of care and support for people with dementia the challenges ahead mean that all policies, approaches, models of care, community and institutional models will come under pressure.

The promotion of personhood using stories and film is evident in many Commonwealth member states such as South Africa via the use of storytelling, Rwanda in the recording of life stories, Australia and Canada in life story research with indigenous communities[38] and the UK with the Archie Project[39]. The eBook, "Voices of Asia" is a good example of advocacy by people with lived experience[31]. Film is being used in Kolkata, India including as part of a film festival to raise awareness[40].

Human rights and design

Although design will be discussed further under principle 7, it is worth noting the ability for someone to stay in their own home for as long as possible via the many innovations and evidence base that can enable support to be put in place is also a matter of human rights; articles 3 "the right to life, liberty and security of person" and 17 "the right to own and not be deprived of one's property". Research demonstrates that environmental impacts are a significant contributing factor to behaviours that can easily be mitigated with alignment to dementia design principles. Appropriately designed homes, also supports family carers most often the role of women, positively impacting their experience of life and human rights[41,35].

The **Wales** Cooperative Centre and Bron Afon Community Housing are examples of innovative housing designs that explore introducing a co-housing model for older adults. This model allows people to 'live together, apart', so that they can enjoy the benefits of eating together and socializing, and use shared facilities such as washing machines, tools, and vehicles[42].

This section has highlighted the relationship between dementia and human rights and provides insight into the importance of personhood being at the centre of approaches to care and support. This section also flags how design can support the human rights of people with dementia. **A recommendation for policy makers and healthcare professionals would be to consider each of the human rights articles specifically through the lens of dementia.**

Principle 2: Empowerment and engagement of people with dementia and their carers

People living with dementia, their carers and organisations that represent them should be empowered and involved in advocacy, policy, planning, legislation, service provision, monitoring and research of dementia.

Informal carers

Informal carers are family members or friends who provide care with no remuneration. Data from 64 countries shows 16.4 billion hours per day are spent in unpaid care work – equivalent to 2 billion people working eight hours a day with no remuneration. Such services, valued on the basis of an hourly minimum wage, would amount to 9% of global GDP, or USD 11 trillion (purchasing power parity in 2011)[43].

It is essential that NDPs consider how to support carers and how to better balance the roles of informal and formal care. There are many examples in the full report online, that support carers. For example, various approaches to training and in addition, much of the work on dementia engagement and dementia friendly communities will indirectly support carers. However, it also recognised that in some countries, the responsibility for care lies with the family and carer

The report "Global estimates of informal care" reveals that around **82 billion hours** of informal care are provided to people with dementia at home annually. **Women contribute 71% of these hours**. The study highlights the disproportionate impact of dementia on women and the significant societal cost of informal care. This leads to reduced work hours, career interruptions, or complete work cessation to care for persons living with dementia[45].

Women play an essential role in society as carers. According to Wong (2024) this commitment is undervalued stating that women contribute USD 3 trillion to healthcare annually[35]. Women provide two thirds of informal care and are disproportionately affected by caregiving and dementia. This represents an unfair distribution of labour and will be discussed further under Principle 6 on Equity.

On average, people spend 50% of their lives in less-than-good-health and 12% in poor health, this figure has not changed significantly in the past 50 years[46]. However, the number of people requiring care has increased from 2.1 billion in 2015 to a predicted 2.3 billion in 2030. If investments were doubled in education, health and social work by 2030, 269 million new jobs could be created in addition to supporting women who are currently unable to work due to carer responsibilities[35]. Wong's (2024) article in the full report online, provides more details on the specific issues relating to women and caring responsibilities[35].

There is a clear call for action in relation to supporting carers both in terms of psychosocial support as well as practical skills. Education and skills development of informal carers is important to support their health and mental wellbeing. For example, providing advice on nutrition, using assistive technology, household design adaptions can have a significant impact.

There some positive examples in the Commonwealth, for example the **Dominica** Dementia Foundation aims to raise awareness of dementia, raise funds for families affected and provide emotional support to families and carers. Their most recent work involves providing bursaries to care providers and residential homes so carers can undertake carer training[47]. demensia **Brunei**, a non-governmental non-profit organisation, provides dementia care skills training workshops for carers, healthcare workers, and allied professionals who assist in the care of older individuals who are ill, frail, or who are living with dementia. The training enables informal carers and family members to better manage and support others, especially during the COVID-19 pandemic[48].

Other examples of support for informal carers are the dementia respite cottages in **Australia**[41], the TRIBE project in the **UK** supporting an increase in the numbers of community carers[42], ARDSI **Calcutta** provide regular carer support meetings[40]. Other models of support can be found in the full report online.

"As a caregiver myself, one of my takes from the first carer support meet that I attended at ARDSI Calcutta Chapter was that I was not alone. Being together in a room with other caregivers, listening to their stories, seeing them share their pain and tears and yet holding on with some smiles on this journey was something that gave me much hope"[40].

Innovation, practice and progress from the Commonwealth

Awareness raising and community engagement

There is a rich range of examples across the Commonwealth of activities raising the awareness of dementia and engaging community in discussions and solutions. The principle of raising awareness and engaging communities is embedded in some strategies and NDPs. For example, in **Malta's** plan there is a specific goal around raising awareness and understanding with the creation of a dementia-friendly society, creating opportunities in community settings for inclusivity and accessibility[49]. However significant challenges relating to people's perspective about dementia remain.

Stigma and attitudes

The stigma around dementia is preventing people from seeking the information, advice, support and medical help that could dramatically improve the length and quality of life for people living with dementia. The attitudes to dementia were revealed in the World Alzheimer Report 2019: *Attitudes to dementia*[50] revealed that:

- Nearly 80% of the general public are concerned about developing dementia.
- 1 in 4 people think that there is nothing we can do to prevent dementia.
- 35% of carers have hidden the diagnosis of dementia of a family member.
- Over 50% of carers say their health has suffered because of their caregiving responsibilities.
- Almost 62% of healthcare providers think that dementia is part of normal ageing.
- 40% of the public think doctors and nurses ignore people with dementia.

While the findings of the largest survey conducted, with almost 70,000 people across 155 countries and territories spanning four demographic groups: people living with dementia, carers, healthcare practitioners and the public - are powerful in themselves, they need to stimulate action[51].

Five years on, ADI has once again commissioned the London School of Economics and Political Science (LSE) and together they launched the 2024 Attitudes Towards Dementia global survey, to update and build upon the survey conducted in 2019. The findings will be presented in the 2024 World Alzheimer Report, along with expert essays and case studies that will provide further depth and detail of global attitudes to dementia [52].

In **South Africa**, a range of organisations are working to emphasise the importance of creating inclusive societies where people with dementia can live with dignity and flourish. They also highlight the need for targeted education and awareness programmes that reduce stigma and promote understanding.

The ARDSI Calcutta Chapter, **India** offers awareness programmes in clubs, schools, colleges, government offices, hospitals and social organisations. Reaching out to young members of society and using social media is helping people to be "tuned in sensitively to the cause and spread the word around[40].

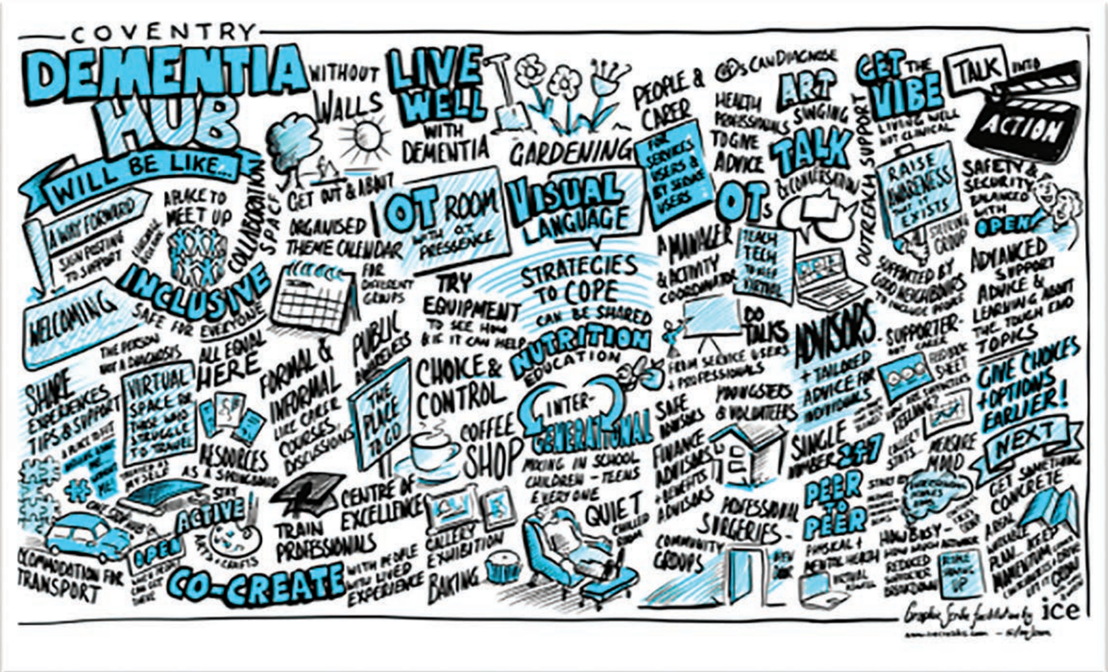
In **Brunei**, demensia Brunei (dB) offers medical and nursing students' sessions about dementia and dementia care skills. These students are then involved in public awareness roadshows, community screening programmes and the use of art, and media channels to raise awareness of the *10 Signs of Dementia*. There are also opportunities for students from the Faculty of Arts and Social Sciences of the Universiti Brunei Darussalam to be involved[48].

The Alzheimer's Disease Foundation **Malaysia** has collaborated with the Atria Shopping Gallery to create a neighbourhood community corner. A dementia-friendly space sharing ideas, raising awareness, promoting regular programmes and weekly activities for older people and their carers. The programme of health and wellbeing, movement and crafts are provided with voluntary support from doctors, practitioners and facilitators. Atria Shopping Gallery was the first dementia-friendly mall in the Asia Pacific region (Hanif Ahmad & Teo, 2024).

The Coventry Dementia Partnership Hub, **England**, was co-produced with people with dementia and their carers (via Alzheimer's Society Focus groups). Two engagement workshops were held, one for people with dementia and their carers and one for stakeholders that was led by people living with dementia. The discussions were captured as visual image based on the vision of people living with dementia and their carers. The Coventry Dementia Partnership Hub includes a wide range of partners across sectors, community groups, statutory services, people living with dementia and their carers. The members of the Board are people living with dementia and their carers[53].

Art is a great way of engaging people in discussion as can be seen in some of the examples such as BOLO described in later sections. Dementia NI is a member led charity which provides a range of support runs a Real Lives Arts Exhibition aimed at challenging the misconceptions relating to dementia and has been on tour across **Northern Ireland**. The exhibition consists of 45 pieces of art made by people living with dementia[54].

Co-design of activities is a key theme in many of the examples shared in this report, this is essential to ensure the programmes and approaches are culturally appropriate and aligned with the needs and values of different communities. For example, the DAMPAA programme, Australia, was co-designed with Aboriginal Australians, this example highlighted the importance of ongoing community engagement in the sustainability and success of innovations to support people living with dementia and their families[37].



Innovation, practice and progress from the Commonwealth

Intergenerational activities

There is a strong connection between the role of personhood, storytelling and helping reduce the stigma and social isolation associated with dementia. Intergenerational programmes of young people being involved in creating digital life stories can be a rewarding and enriching process for everyone involved. For example, the Essex Intergenerational Age-Friendly Program, **England** and the BIG ONES LITTLE ONES© **Australian**-based international visual art and literacy program both aim to connect older people with services and integrate them into the centre of community[53, 55].

The BIG ONES LITTLE ONES© (BOLO) program focuses on fostering positive interactions between adults (BIG ONES) and children (LITTLE ONES) and aims to give children a voice while allowing them to shine[55]. Atria Shopping Gallery in **Malaysia** collaborated with BOLO to host a 2-day program for Universal Children's Day 2018. Twelve aboriginal representatives from the Yurungai Learning Centre (Barnardo's Australia) presented a hands-on "sharing and caring experience" for children, young and older people, including those with dementia and different abilities. The event aimed to help participants understand the benefits of making good choices and respectful behaviour. The cultural exchange activity was particularly successful, as participants learned about another person and country, gaining a better understanding of commonalities despite living in different communities.

The Essex Intergenerational Age-Friendly programme aims to create a wide variety of activities that are friendly to all ages. The programme goes beyond simply providing services to older people and instead focuses on integrating older individuals into the heart of the community. This involves connecting them with people of all ages and interests and placing importance on interventions that are aligned with social determinants of health [53].

There are the many examples for policymakers and healthcare professionals in this summary and in the full report to provide ideas and inspiration of how to empower and engage people living with dementia, carers and the wider community. Many of the ideas shared across the Commonwealth are culturally appropriate and relatively low cost.

Principle 3: Evidence-based practice for dementia risk reduction and care

Based on scientific evidence and/or best practice, it is important to develop strategies and interventions for dementia risk reduction and care that are person-centred, cost-effective, sustainable, and affordable, and take public health principles and cultural aspects into account.

This section will focus on the evidence base in the terms of research into dementia risk reduction and care taking place in the Commonwealth.

Hobbins (2024) outlines some of the risk factors that form part of an evidence base regarding food and dementia risks as a growing area of discourse[56]. Sharing information on nutrition is being used as part of workshops in **Australia**[57].

Other research relating to risk reduction is AGELESS combining two **Malaysian** longitudinal studies aiming to address early detection, gut-brain axis, mobility difficulties and digital phenotyping in cognitive frailty using online and face to face sessions. The Malaysia AGELESS study applies the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) recognising the cultural diversity, health awareness, digital literacy that can make implementation difficult. Preliminary results suggest that cognitive frailty may be reversed through multimodal interventions[48, 58].

Jamaica was one of seven sites that participated as part of the Davos Alzheimer's Collaborative Healthcare System Preparedness (DAC-SP) Early Detection flagship programme that implemented a digital cognitive assessment in primary care. **Jamaica** leveraged the research infrastructure and stakeholder relationships that were developed from prior projects such as the STRiDE initiative. The programme was implemented in the private healthcare system in the Kingston, St. Andrew and St. Catherine parishes and via direct-to-consumer recruitment drives in communities, with a focus on patients 60 and older. The research team functioned as Brain Health Navigators, completing the digital cognitive assessments, and coordinating the blood and ECG tests for reversible causes of impairment with local laboratories and medical facilities. The post screening care pathway and management was co-developed between the research team and the health and allied care practitioners whose patients participated in the initiative.

Four key lessons from the Jamaica early detection programme include:

1. Creating pathways to get people into the healthcare system
2. Leveraging early-stage health and allied professionals
3. Building relationships with community organisations to raise awareness
4. Using the research staff roles flexibly

There is sufficient evidence of the importance of detecting dementia risks ahead of symptoms and at the early signs of the disease. There is acknowledgment that for low and middle-income countries the resources and infrastructure to support early detection is challenging[58].

Culturally appropriate evidence is essential in ensuring that all people can have access to the best support regarding prevention, diagnosis, care and support. For example, a culturally appropriate dementia screening tool was developed for use with Aboriginal Australians. The KICA screen considers cultural differences in communication styles and health beliefs providing a more accurate assessment of cognitive function [59, 37].

United Kingdom Research and Innovation (UKRI) is a public body enabling multi-disciplinary research approaches to various challenges and priorities. The Healthy Ageing Challenge aims to find new services and products along with innovative business models that can be adopted at scale. This approach is enabling a wide range of evidence-based solutions supporting people with dementia, carers, and families. For example, "Read Clear" is an app that has been proven via randomised clinical trials to bring reading back to people's lives. The aim is for the app to be universally available, free of charge.

In terms of providing care and support for people with dementia there is significant evidence regarding how the design of environments impacts on health and wellbeing. This evidence ranges from the design of villages, residential care facilities, the outside environment and changes to individual homes, [60, 41, 61, 62, 26].

Technological solutions to support risk reduction, support and care for people living with dementia and their carers are part of the range of interventions available. Ensuring that new technical solutions have a strong evidence base along with access to all people across all Commonwealth countries is essential[42, 63].

There is growing evidence on the impact of social connectedness on living a longer, improved quality of life[64]. There are many examples across the Commonwealth of activities that are about engaging people living with dementia in their communities, reducing loneliness, focusing on personhood and spirituality[53, 38, 65, 49, 31, 48]. The impact of social connectedness is not always considered as part of evidence-based care, however, there is increasing research in this field.

In summary, there is a call from contributors to this report for additional funding for research across all elements of dementia care and support and for all people including children to be given culturally appropriate support[66]. The ongoing importance of research across risk reduction, cure, care and support is essential, however there are significant challenges with regards to access, support for carers and the labour market and without these having equal focus, any benefits of research findings may struggle to be implemented.

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Principle 4: Multisectoral collaboration on the public health response to dementia

A comprehensive and coordinated response to dementia requires collaboration among all stakeholders to improve prevention, risk reduction, diagnosis, treatment, and care. Achieving such collaboration requires engagement at the government level of all relevant public sectors, such as health (including alignment of existing non-communicable disease, mental health, and ageing efforts), social services, education, employment, justice, and housing, as well as partnerships with relevant civil society and private sector entities.

There are several examples of multi-sectoral collaboration across the Commonwealth some of which are highlighted in the online report and summarised below.

A1Snehanjali (India)

A1Snehanjali's case study in establishing assisted living demonstrates an example of multisectoral collaboration[67]. During their project they connected and supported:

- employment generation for the local tribal community.
- introduction of innovative therapeutic interventions.
- promotion of a non-pharmacological approach.
- participation in community work with the local population.
- working with a primary school.
- creation of advocacy and networking for dementia; and
- supporting college students with empowerment, internships, and hands on training.

Essex, Coventry and Birmingham (England)

The National Health Service (NHS) established Integrated Care Systems in July 2022. This created an expectation in law that separate parts of the statutory health, local authority and care system, along with the voluntary, community, faith and social enterprise organisations form a formal structure to plan and deliver care. Most Integrated Care Systems will have several 'place-based partnerships' recognising both local strengths and gaps, in addition to system wide delivery. This move to Integrated Care Systems provide many examples of multi-sector collaboration in the UK with Coventry, Birmingham and Essex being highlighted in this report.

In Essex, Dementia Friendly Community Networks aim to increase dementia awareness in local areas through place-based approaches, to enable communities to be accessible and support people living with dementia, including carers and families. The locality approach with a focus on 'Let's talk about dementia' raises awareness including changing people's perceptions of dementia and the way they think, act, and talk about dementia, creating communities that are inclusive and part of enabling environments[53].

To help build these communities, work is needed across both public and private sector such as: local community organisations, businesses, schools and places of worship. This work also includes working with District Councils as part of planned communities such as new housing and care developments. People living with dementia feel safer in a community that is understanding and supportive of their needs, with feelings of safety increasing a sense of maintaining independence and empowerment to be able to continue to take part in activities that are meaningful to the person, within dementia-aware, caring, and compassionate communities.

The Coventry Dementia Partnership Hub featured earlier in this report is also an example of multisectoral collaboration including people living with dementia and their families alongside statutory and voluntary sector services[53].

The Birmingham Dementia Strategy launched March 2023 and will run until March 2028. It was co-produced involving people with dementia, their carers, and people from across, health, care and community organisations.

The city has a Steering Group that covers Birmingham and Solihull which includes over 30 organisations. Birmingham is one of the most diverse cities in the UK and has identified the following groups as demonstrating greater difference with regards to accessing support for dementia:

- Asylum seekers and migrant communities
- Ethnic minority communities
- Gypsy, Roma and Traveller communities
- Homeless communities
- Learning disability communities
- LGBTQIA+ communities
- Prison communities

The strategy is made up of six parts: Preventing Well, Diagnosing Well, Treating Well, Supporting Well, Living Well, and Dying Well.

Essex, Coventry and Birmingham are all engaged in the Compassionate Cities movement which encourage wide multi-sector collaboration on issues relating to serious illness, loss and caregiving[68, 69].

This section has provided some examples of multi-sector collaboration, with further detail included in the full report. Dementia is a disease that impacts everyone, either directly or indirectly, ensuring engagement across all sectors and all civic life provides the best chance of improving prevention, awareness, diagnosis, care and support. A key recommendation to policymakers and healthcare professionals is to seek out all the community groups, active citizens and build on what is already happening at a grass roots level, building a multi-sector collaboration out from here can provide access to knowledge to aid an effective NDP.

Principle 5: Universal health and social care coverage for dementia

Designing and implementing health programmes for universal health coverage must include financial risk protection and ensuring equitable access to a broad range of promotive, preventive, diagnostic and care services (including palliative, rehabilitative and social support) for all people living with dementia and their carers.

The issue of universal health and social care coverage covers a range of component parts and overlaps with other components in the cross-cutting themes such as engagement, equity, multi-sectoral collaboration and appropriate attention to prevent, cure and care.

The *"Health Justice and The Commonwealth: A Progress Report on 12 Recommendations Advancing Universal Health Coverage"* by civil society was presented to Commonwealth ministers and senior health officials at the side of the World Health Assembly. The discussions first took shape in February 2023 when a group of 220 health experts and civil society leaders from 35 countries participated in a series of sessions to draft these recommendations. This resulted in the *12 Key Asks* and were presented to ministers and senior health officials at the Commonwealth Health Ministers Meeting (CHMM) in May 2023. And *Key Ask 12: There is no health without mental health* [70].

It is essential that NDPs and strategies are holistic and comprehensive. For example, **Malta's** plan "Reaching New Heights" built on novel approaches and evidence-based practice[49]. The strategy spans a range of action areas including awareness, risk reduction, timely diagnosis, living well, workforce development, management and care, research, and IT. 'Reaching New Heights' provides a framework for quality improvement and addressing health inequalities. The strategy is built on empathy and a person-centred approach recognising some of the challenges of maintaining this approach alongside the medical sector[49].

New Zealand's plan also provides a holistic and cohesive response, the plan was developed collaboratively with a range of stakeholders to create a framework from diagnosis to end of life care for people with dementia ensuring that personal wishes, cultural preferences, and lifestyles were considered. Key components, as in Malta's strategy plan include early diagnosis and intervention, carer support, public awareness, and research[71]. The New Zealand plan aims to provide universal coverage; however, challenges remain with regards to equity of access. Although the plan is in place, there is a question with regards to measurement and review of its effectiveness. Effective evaluation is important to understand impact and reach, as well as learning important lessons from the work.

There are challenges in achieving universal health cover which impacts access to diagnosis, care and support for people with dementia. In many countries healthcare is provided by a range of providers. For example in **Jamaica** there is a combination of public, where healthcare is free at the point of service, and the private system which is not. Unfortunately, insurance coverage is low (20%) and does not cover long-term care. Universal healthcare coverage (UHC), one of the targets of the Sustainable Development Goal 3 (SDG 3) is estimated at 65% and is lower than the mean for the Region 75.4% [72]. While healthcare in the public health system is free, out-of-pocket expenses can be costly[44].

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Africa has a range of examples related to the aim of Universal Health and Social Care shared in the *Dementia Update* – Africa report in the full report online, examples include:

Uganda community-based organisations such as MY GRANDMAA-PAA-UGANDA are focused on raising awareness and providing support to families and individuals affected by dementia. They are emphasising the need for a holistic approach that includes medical care, social support (including recognition of spirituality) and community education. **Uganda's** approach is based on (i) community-based care models, (ii) public awareness campaigns, and (iii) policy advocacy, consistent with the WHO expectations of dementia planning[7].

Botswana is also being led by community-based organisations advocating for NDPs that provide universal coverage. A key element is again educating the public and reducing stigma. This is key as the provision of universal cover is of course essential; however, ensuring that barriers to accessing support are removed is critical. Botswana's strategy focuses on (i) capacity building – training healthcare professionals and carers, (ii) rural outreach programmes and (iii) collaboration with traditional healers[31].

A key element in this principle is financial risk protection. This is multi-faceted including funding for sufficient and appropriate services, protection for family carers, support for people living with dementia.

"A country prioritising health for all will enjoy prosperity: better health promotes progressive economic growth and yields. Expansion of the labour workforce boosts productivity whilst also delivering immense benefits and societal wealth"[35].

Dementia costs the global economy USD 1.3 trillion every year; a number that will increase up to nine times by 2050[10]. Ideally the economic and social arguments for investing in health would be sufficient to ensure appropriate level of funding for care. However, this is not the case and the ability to fund care and provide support to families is a key challenge.

The mixed market ecosystem where private sector organisations and NGOs work alongside government care provision does provide a wider range of support to people living with dementia and carers. However, this can also result in inequitable access to support either due to some areas having more service provision than others or due to the ability to pay for private care.

There are also financial challenges for many of the organisations supporting activities in dementia, reliance on charitable funding can be problematic and impact capacity as seen with the ability of UK Hospices to support palliative care needs for people with dementia[73]. Mishra (2024) provides a useful insight in his article for this report, into the challenges of developing a centre for people with dementia as a social enterprise in **India**[67].

In **England**, social care is means tested, therefore some people will pay for all their residential or domiciliary care, this results in some people selling their home in order to cover costs. Successive governments have struggled to agree on an adequate solution to the provision of social care for an ageing population.

The NDP for **Canada** references an investment of USD 50 million over five years to achieve the aspirations in their plan. The NDP for **New Zealand** references that delivery of their plan is reliant on the government providing sufficient financial resources[12]. In **South Africa**, advocacy efforts focus on securing government funding for respite care programmes alleviating the financial burden on families.

However, whilst the reports show various strategies and national approaches, they are largely silent on the issue of financing the changes that need to be made.

This section has highlighted the challenges of universal health cover. In the context of dementia there are a range of issues impacting this principle, including community awareness, clear pathways of diagnosis and support, capacity and financial resources. **Whilst governments do not have to meet the challenge of dementia alone, strategies need to be in place to manage some of these barriers.**

Principle 6: Equity

All efforts to implement public health responses to dementia must support gender equity, taking a gender-sensitive perspective and keeping in mind all vulnerabilities specific to each national context. This approach should be consistent with the 2030 Agenda for Sustainable Development, which recognizes that vulnerable and underserved populations, including people with disabilities, older adults, and migrants, must be empowered.

Many of the organisations highlighted in this report are committed to inclusivity whilst recognising the challenges that this brings. For example, Mishra (2024) in describing this for Silver Innings in **India** states:

"In India we have a melting pot of cultures and religions. language, climate, tradition, religion, dressing, greetings: all so different. From diets to traditions, from festivals to social interactions, there is a great range of preferences in the population and at old age people get more selective. In such circumstances, creating occupational activities, recreational activities, daily food menus, décor and a harmonious environment for all residents is a consuming task" [67].

Although Africa has the youngest population globally, increasing life expectancy means dementia is becoming more visible. In Femada Shamam's article Dementia update Africa, she highlights the specific challenges in parts of Africa and the intersection between alcohol abuse and the prevalence of HIV/AIDS and the increasing number of people with dementia. In many traditional cultures there is not a word to describe dementia and cultural perceptions of dementia being attributed to witchcraft or punishment by God creates additional challenges. Examples from **South Africa, Uganda and Kenya** demonstrate that the narrative is slowly changing, and a range of community-based organisations are at the forefront of creating partnerships and solutions to support people with dementia, their families and communities[31].

The Philip Ventry's article "Dementia and cognitive impairment among Indigenous and Aboriginal Populations: A comprehensive review" provides an in-depth review of many of the aspects related to dementia. Studies demonstrate that Aboriginal Australians experience higher rates of dementia compared to their non-Indigenous counterparts. The disparity is attributed to a range of factors including lower educational attainment and socio-economic disadvantages in addition to higher prevalence of other chronic diseases[74]. Torres Strait Islanders also face a significant challenge with regards to prevalence of dementia, with additional challenges due to geographical isolation and limited healthcare access. Russell et al's research (2020) emphasised the importance of the integration of traditional knowledge and practices in health interventions to enhance their effectiveness and acceptability[75, 76].

There are many disparities within the intersection of dementia and women. Datin Jacqueline Wong's article on Women and Dementia: From Caregiving Disparities to Economic Opportunities highlights women as a 'marginalised majority' and describes in detail the disproportionate impact of dementia on women both as carers and the numbers living with the disease.

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> "Older women are discriminated against because of their age, gender, condition and role as carer and, or, if diagnosed with dementia. Extreme discrimination can lead to women with dementia facing neglect, abuse and even violence"[35]. These negative and discriminatory experiences of women is an infringement of their human rights. It is essential that NDPs have specific gender sensitive approaches to dementia including women being more involved in research, development and decision making.

The issue of equity should include all people with dementia. According to Childhood Dementia Initiative, 1 in every 2,900 babies born will develop childhood dementia, with half dying before the age of 10[66]. The number of children dying with dementia is very similar to those dying with childhood cancer. The complexity around childhood dementia needs to be recognised in national frameworks.

Scotland referenced childhood dementia in its 2023 strategy and **Australia** in 2024.

The report by the Childhood Dementia Initiative calls for further research to better understand the specific requirements of children with regards to prevention, cure, care and support.

There are many groups who experience specific challenges with regards to equity of access to healthcare including for dementia. Dementia UK highlight the specific challenges of people who are part of the LGBTQIA+ community[77] and Marie Curie highlight some of the experiences of care towards the end of life and the impact of bias and key relationships not being recognised[78].

> Some LGBTQ+ people may not remember that they have 'come out' and re-live fears and concerns about their sexual orientation including internalised homophobia or biphobia. For some older people, this could include experiences related to conversion therapy. Transgender people may not remember transitioning and again struggle to relate to their acquired gender or feel triggered by pictures, early memories and experiences prior to transitioning. Similarly, if their partner has transitioned, they may not remember this[79].

New Zealand's plan has a specific focus via the involvement of Te Whatu Ora to ensure an understanding of the Indigenous context of Māori individuals[71]. This active engagement is essential in creating culturally sensitive policies and appropriate support.

Access to care is often dependent on locations with different resources being available in different parts of countries. 'Tribe' is an artificial intelligence solution that builds pictures of regional landscapes using multiple data source[42]. The aim of the founder of Tribe is to eliminate care inequalities in later life. The Tribe Project via identifying gaps in resources supports the upskilling and accreditation of a new workforce **via** micro-enterprises. The model is currently being tested in several areas in **England** supported by UKRI[42].

In Coventry, **England** as part of the Dementia Partnership Hub there is a Culturally Inclusive subgroup led by local people including from the Coventry Muslim Forum, Lions Club of Coventry Godiva and the Tamarind Centre. The subgroup work is primarily focused on addressing the barriers preventing people from diverse communities accessing support and services at the Dementia hub. The subgroup raises awareness and works with communities on obstacles to dementia care for those diagnosed to have dementia from a diverse community or for care providers in this section of population[53].

It is clear in this section that equity of access to care and support is a significant issue across the Commonwealth, regardless of economic status. Whilst there are some differences across the Commonwealth member states, all have challenges on meeting this principle. The issue of equity and dementia is compounded by existing inequities in accessing health and care. This document and further information in the full report highlights issues of equity for women, young people and people from the global majority. As described by Birmingham in the multi-sector collaboration report there are many groups for which equity is not being achieved[53]. For many people the issue of intersectionality creates multiple inequities e.g. women who have disabilities and/or carers combined with being from the global majority in relation to ethnicity.

The issue of equity is significant, and **a recommendation would be for policymakers and healthcare professionals to engage widely in order to co-design solutions that recognise the various inequities related to dementia.**

Principle 7: Appropriate attention to dementia prevention, cure, and care

Steps to realise this focus include using existing knowledge and experience to improve prevention, risk reduction, care and support for people living with dementia and their carers and generation of new knowledge towards finding disease-modifying treatments or a cure, effective risk reduction interventions and innovative models of care.

This principle spans all stages of a dementia pathway from prevention to diagnosis, to cure, care and should also include palliative and end of life care. As is clear in the principle, the pathway should consider the impact on carers and this term should be seen as wider to include the close family and friendship unit of the person living with dementia.

Prevention and risk reduction

Several of the articles reference the need to raise awareness on what can reduce the risks of dementia. Lifestyle choices such as those around food and nutrition is a growing area of interest [57]. **Malta** have embedded risk reduction into their strategy with the aim of helping the population understand the potential of preventative lifestyle changes[49].

There is some evidence of risk reduction that relates to prevention social connectedness [64, 80, 81, 82]. Many areas across the Commonwealth are doing some fantastic work in this area highlighted in the online reports which can be an effective low-cost intervention.

Care and support

A1Senhanjali, **India** is an assisted living elder care home for people who do not need nursing home care but do need support with dementia or Parkinson's disease. Mishra (2024) highlights the advantages of understanding the Indian context towards dementia and ageing but also the challenges of running a social enterprise model of care in **India**.

Mishra describes:

"a society where elders are respected and part of the family. Whilst urban areas are warming up to the idea of retirement homes, from our experience there is still a social stigma attached towards children whose parents are in retirement homes. Older adults too feel that it is their children's "responsibilities", however, there is a need for specialised care homes for dementia or retirement homes" [67].

Mishra's article demonstrates many of the challenges of establishing care for people living with dementia in a context of changing societal perspectives with regards to residential care and the contribution of social enterprises and NGO as service providers.

There are a variety of approaches and models of therapeutic support for people living with dementia, often demonstrating benefits to the wider care circle of formal and informal carers. For example, RenCi Nursing Home in **Singapore** implemented Spark of Life, a neuro-rehabilitative programme that supports care staff to "shift their mindset from impossible to possible" and reports benefits to residents, family, and staff members with improvements in cognitive and social skills[83].

Hebron Love and Care Centres are based in **Nigeria** and describes:

"what started as two monthly meeting outlets has since burgeoned into a network of six branches across two cities by 2024, with an annual conference of over eight hundred individuals including people with dementia" [83].

The services are focused on "empathy and compassion and provide the skilled care that enabled them to re-engage with life again"[83]. This demonstrates how the organisations align itself with a more holistic approach.

The Caring for the Spirit programme, **Australia**, is an online dementia education and training initiative for Aboriginal and Torres Strait Islander Australians. The programme aimed to enhance carers' knowledge and skills, promoting better dementia care practices. This programme also highlighted the need for co-design and culturally appropriate content [84, 37].

Radford et al (202 collaborated on the co-design of an active and healthy ageing programme using mobile technology to reduce dementia risk with Indigenous communities in **Australia**. The programme highlighted the potential use of technology to deliver care and support to remote areas[85, 37].

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The stories of services and support for people with dementia across the Commonwealth are filled with inspiring individuals doing what they can within the cultural context. The story of Mrs Shefali Chaudhuri can be read in full via the full report online. Mrs Chaudhuri started Alzheimer's and Related Disorders Society of India (ARDSI) Kolkata Chapter, India in 1999, age 81 in her home in. Her daughter had been diagnosed with dementia in her fifties and, as she cared for her daughter and explored other services such as the one in Kerala, she started her own chapter organisation. The members of the chapter include family carers, professionals, doctors from different fields, social workers and anyone interested in supporting. Offering awareness sessions, memory screening, counselling in the community, a daycare centre and home companionship[40].

Initiating conversations about palliative and end of life care is of course sensitive and has many cultural and spiritual considerations. For people living with dementia, conversations about what matters most towards the end of their life often needs to take place earlier in the disease trajectory when cognition enables this to happen. There are approaches to having these conversations available online for example Dementia UK[86].

The Advance Project (General Practice) in **Australia** is a practical, evidence-based resource toolkit and a training package, specifically designed to support Australian general practices to implement a team-based approach to initiating advance care planning (ACP) and palliative care into everyday clinical practice.

It was informed by literature reviews and extensive input and feedback from our expert advisory group, general practitioners (GPs), general practice nurses, practice managers and consumer representatives. Three different eLearning courses, specifically tailored to the unique learning needs of Australian GPs, nurses and general practice managers, explain how to use the evidence-based resources in general practice.

The Advance Project eLearning courses for General Practitioners, General Practice Nurses and Practice Managers are currently being refreshed and will be available in 2024[87].

The Dementia Strategy for **Canada** also references the importance of care up to and including end of life. In 2017, the Canadian government invested funding including for access to palliative care[8]8. The issue of access to or support from hospice care for people living with dementia was highlighted by Hospice UK in 2015[73].

There are some simple and effective approaches that can provide support for people living with dementia, for example in **Northern Ireland** via Dementia NI. Dementia NI is a member led charity which provides a range of support including:

- The Herbert protocol, developed in partnership with the police service, department of health and the policing and community safety partnership. The Herbert protocol was developing in response to people living with dementia who go missing. It is a form, that people living with dementia (or their carers) complete which is kept in a prominent place – often in the fridge. The form is handed to the police if someone goes missing to aid a speedy response.
- Dementia JAM card is a card someone with dementia can carry. JAM stands for 'just a minute' and people living with dementia can show their card to flag they need a bit of patience when going about their daily lives e.g., when shopping. JAM awareness sessions are available to organisations.

To find out more about Dementia NI, visit their website www.dementiani.org/what-we-do

Design

Design is a key component of care and support and there are examples of consideration of design in several of the articles in the full report, online.

It has been almost 30 years since the work of Stephen Judd, Mary Marshall and Peter Phippen in their book Design for Dementia (1998) which, back then, for the first-time showcased dementia design principles across the world in practice[89]. Yet organisations are still struggling to implement core elements into day-to-day environments that create enabling (not disabling) places for people with dementia to live. What is known is, when correctly implemented – the outcomes for people living with dementia create a quality of life everyone would want, and that all deserve.

Stephen Judd said of the eight case studies from across the world in his book:

> *"they are separated by distance, by language, by culture, by climate, and by laws. They are different, with distinctive features. And yet their smallness and sensitivity to scale; their focus upon familiarity, as culturally appropriate homes with which the residents can personally identify; their legibility being understandable and orientating; their promotion of self-esteem, autonomy and individuality; and their appreciation of safety, within an environment of manageable risk, demonstrate the providing the best physical environment for people with dementia is not a question of money or luck, but of good, thoughtful client-concerned design"* [89].

The Dementia Centre's article on design in the full report online, demonstrates the many benefits of dementia inclusive design on the lives of people with living dementia across a variety of settings including the importance of outdoor spaces[41].

An example of how housing can support social connectedness is cohousing the following example from Wales. The **Wales** Cooperative Centre, Bron Afon Community Housing is exploring the introduction of a cohousing model for older adults.

> *"Allowing people to 'live together, apart', people can enjoy the benefits of eating together and socialising, using shared facilities such as washing machines, tools and vehicles...reducing or delaying the need for access to costly health and social care interventions. Living in cohousing has had a positive impact on residents by enhancing their sense of wellbeing, reducing loneliness and isolation, and providing continued activity, engagement, personal autonomy and independence"*[42].

The Designing Homes for Healthy Cognitive Ageing is a multidisciplinary team involving stakeholders from all areas of housing provision including people experiencing ageing and cognitive change. The demonstrations and test beds have resulted in a range of tools, information, training materials and resources for people thinking about housing design. This includes use by the Scottish Government City Region Deal for Central Scotland, University of Stirling Dementia Service Development Centre the Royal College of Occupational Therapists[42].

The World Alzheimer Report 2020, *'Design, dignity, dementia: Dementia-related design and the built environment'*, offers a global perspective on dementia-related design, highlighting the importance of innovation, entrepreneurship, and aesthetics. It compares dementia-related design to the physical disabilities movement and calls for design solutions to be included in national governments' responses to dementia. The report includes 84 case studies and examines design in various settings, including homes, day and residential care, hospitals, and public buildings. It states that dementia design is 30 years behind the physical disabilities movement and calls for change[60]. Environmental factors are a crucial component of the International Classification of Functioning, Disability and Health (ICF), influencing an individual's functioning and disability. These interactions, influenced by their health condition, personal factors, and environment, significantly impact a person's quality of life, affecting their ability to function in a standard environment and participate in their usual environment.

Dementia Alliance International (DAI) has established an Environmental Design Special Interest Group (ED-SiG) to promote design that respects dignity, autonomy, independence, and equality of opportunity for people living with dementia. The group includes clinicians in neurology and ophthalmology, researchers in environmental design and architecture, and other fields of gerontology and occupational therapy. The group addresses the World Alzheimer Report 2020 on dementia-related design[60].

The WHO and the United Nations have endorsed the creation of a supportive environment for older people, encouraging discussions on all-age-friendly cities and communities. The *"Age-friendly Cities and Communities: A Global Perspective"* provides a comprehensive view of developing urban environments designed to improve the lives of older persons, allowing them to co-produce all-age-friendly policies and practices. Case studies from Europe, Asia, Japan, Korea, Thailand, Singapore, China, and Australia cover social inequality and community empowerment. However, there is a need for increased discussion on strategies and best practices to ensure services and products meet the specific needs and life situations of older people, particularly those living with dementia and different abilities. Access to health and social care services is severely impacted by lack of infrastructure, transportation, communications, and government agencies[90].

In addition to full report online report further information regarding design can be found via the recent Australian Government report National Aged Care Design Principles and Guidelines[91].

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Technology

There is an expected rise in the relationship between technology and care. The digital care market in **India** for example recorded a revenue of INR 440.49 billion (USD 5.30 billion) and is expected to reach INR 1.16 trillion (USD 14 billion) by 2028 [63].

Dalal (2024) describes the increasing appetite in **India** for assistive technology, telemedicine, social networking and media amongst the older population. Due to memory loss being a main symptom of dementia, there is a significant opportunity for technology to support people living with dementia and their carers.

As with many services, during the COVID 19 pandemic ARDSI Kolkata Chapter started using virtual platforms to continue to support people with dementia and care givers. Continuing to use these, ARDSI was able to offer more support online and reach out to a much larger number of people outside the city of Kolkata, other districts of West Bengal, other parts of India and abroad[40].

Dementia **Singapore** supported by the National Council of Social Services and the Agency of Integrated Care launched a programme called CARA (community, assurance, rewards and acceptance). In 2021, membership of the programme, via an app on Apple and Google stores, offers rewards, lifestyle benefits and safety features. The app includes a 'connected care circle' and a 'safe return feature'[48]. Further information regarding CARA is available in the online report.

> Telementoring such as ECHO has been demonstrated, with First Nations-led health services in Australia to improve healthcare providers' confidence and competence in managing dementia, fostering professional development and knowledge exchange among healthcare providers. Telementoring provides solutions across remote areas[92, 37].

A **United Kingdom** project supported by UKRI is "Connecting Through Culture" meeting an increased demand for digital innovation whilst also tackling loneliness and increasing social connections. The project, "Tabletop Travel" emerged from the "Connecting Through Culture as We Age" project through a process of co-design with older adults. A prototype has been built which pairs a meal kit with food stories from **India** through a technology-enhanced meal box containing visual, audio and tactile interactions" this technology enables people to connect to their hobbies and interests particularly when then are unable to leave home[42].

Technology will form an increasingly integral part of providing better prevention, diagnosis, care and support for people with dementia. The examples shared in this report demonstrate the wide range of ways technology can provide culturally appropriate solutions to many of the challenges faced.

Workforce

Workforce is a common theme across the articles contained in the full report online. The ability to recruit, train and retain sufficient people is a challenge across the Commonwealth. There is, according to the World Economic Forum, an estimated global shortfall of 10 million healthcare workers by 2030, primarily in low and middle-income countries. A separate report suggests a shortage of 13 million nurses in the same period[93, 94].

The challenges have become worse since COVID-19 pandemic, with a reported increase in burnout. There are specific challenges mentioned for some Commonwealth countries; in **India**, 75% of doctors have experience violence whilst at work[93]. In **Canada**, since the pandemic 50% of nurses meet the criteria for PTSD 40% of nurses in **Uganda** recorded experiencing burnout. In **Australia**, 17% of nurses had sought mental health support. International recruitment encouraging workers to move from low and middle-income countries to those that can provide better pay is also contributing to shortages[94].

Ensuring that NDPs are backed up with a practical and deliverable workforce plan is essential for meeting the labour market challenge associated with dementia. Malta highlights workforce development in their strategy with a commitment to establish a workforce capable for providing the type of high-quality services it desires[49].

> Day to day care for people living with dementia is primarily provided by care workers, rather than healthcare professionals such as doctors, nurses and therapists. However, these roles are often undervalued and not necessarily seen as attractive. This needs to be tackled to expand the labour market to the level it needs to be.

Mishra (2024) in writing about his experience of financing, building, and operationalising an assisted living facility in India, states that the biggest challenge was finding the right workforce.

"There is no incentive to work in the elder care sector because the work can be challenging and there are limited growth prospects. There are many opportunities for young people in malls and call centres which they find preferable, often paying more money than care for less challenging work". [67]

These examples are not limited to **India** and is part of a global skills shortage.

Providing new and innovatives ways of training people to engage them in the dementia labour workforce can provide solutions to recruitment and retention. There are a range of approaches to training within the online reports in particular "The Archie Project", "Spark of Life" and "Train the Trainer". These approaches report improvements in confidence and understanding in their role supporting people living with dementia, this improves job satisfaction and retention [83, 39, 95].

There are several examples where young people have been engaged in intergenerational community activities or have had personal experience of a relative with dementia that they want to continue to make a difference. The examples in Rianna Patterson's report 'Young people and dementia' (2024) demonstrate some of the entrepreneurial approaches that may create new models of care for future generations. In developing workforce plans, the different expectations of workers from different generations, cultures, etc should be a key consideration. Two examples are:

- Rahat Hossain was motivated to co-found AYAT Care while working in the home healthcare services industry in **Bangladesh**. He recognised a significant need for support and care in the country, particularly for those suffering from dementia. AYAT Care aims to develop young carers to provide care to people with dementia and raise awareness regarding dementia at home. To date, they have provided service to more than 50 people with dementia, and his work has empowered 60 young people to support people with dementia in Bangladesh[47].

- Rianna Patterson's grandfather passed away with dementia in **Dominica**, as a teenager she would spend her time at the hospital with her grandfather. This experience drove her to establish a youth-led dementia charity called the Dominica Dementia Foundation at the age of 18. The Dominica Dementia Foundation aims to raise awareness of dementia, raise funds for families affected, provide emotional support to families and carers, as well as facilitating dementia related research. Their most recent work involves providing bursaries to care providers and residential homes so carers can undertake caregiving training. The team is currently working with the Ministry of Health to solidify a national plan for dementia in Dominica[47].

There are many examples of approaches in the full report online, that suggest an improvement in staff morale and job satisfaction. More work in this area is needed resolve the workforce crisis facing dementia care.

This section for principle 7 "Appropriate attention to dementia prevention, cure, and care" covers a wide range of areas and for this specific report themes of prevention and risk reduction, care and support, design, technology and workforce. The full report provides further information on the range of examples and issues raised in this summary. Many of these themes rely on other principles being considered as part of a NDP, for example prevention and risk reduction is aided by awareness and engagement. There are a range of examples relating to the use of technology and design which can provide some ideas and direction. The issue of workforce is a common theme across the Commonwealth and one that without progress will undermine many of the NDP aspirations and therefore should be included in all dementia plans and strategies.

Innovation, practice and progress from the Commonwealth

Conclusion

The aim of this section was to provide insight into the wide range of approaches to dementia from across the Commonwealth and how these support the seven cross-cutting themes highlighted by the WHO. The examples shared can be read in more details in the full online document.

The hope is that this report provides healthcare professionals and policymakers ideas, solutions, key points of consideration, shared challenges and approaches that may be relevant to their setting.

Several key themes have emerged from the reports received from across the Commonwealth and this discussion section that might be helpful as part of the development of approaches to NDP or strategy development:

- **Human rights**, equity and consideration for a) culturally appropriate solutions co-designed with the people they aim to support b) dementia as a whole life course disease; and c) the role of women.
- The power of **community engagement** and awareness raising using creativity, storytelling and intergenerational activities.
- The essential and varied role of community in **reducing social isolation** and support for informal carers.
- The opportunities provided by **technology as a component of culturally appropriate care** and support.
- The importance of **design of both places to live and places to enjoy.**
- **Workforce** – growing, changing and valuing a labour market able to meet the care needs of people with dementia and their families.
- A **financial model** to ensure implementation.

Dementia affects over 57 million people and impacts millions more, where over 60 per cent are living in low and middle-income countries. There is increased awareness of early-onset dementia, i.e. in individuals in their 30s, 40s and 50s and more recently, some awareness of childhood dementia. COVID-19 has exacerbated mental health issues in youth, including brain fog, cognitive impairment, and early-onset dementia. The recovery rate from the virus may be subpar due to the prevalence of non-communicable diseases (NCDs) and long-term symptoms. A study reveals that 1 in 3 COVID-19 patients experience brain fog and mild cognitive impairment, highlighting the significant burden of mental and neurological conditions in young people. The study also found that among 236,379 COVID-19 patients, the incidence of neurological or psychiatric diagnosis in the following six months was 0.11% for Parkinson's, 0.67% for dementia, 17.39% for anxiety disorder, and 1.40% for psychotic disorder[28].

While ageing is the strongest known risk factor for dementia, however, with the long-COVID symptom an unknown variable, it is a Trojan horse. We must consider healthy populations through an intergenerational lens (and this means mental wellbeing and risk-reducing dementia). Adolescence is a critical period for the development of adult NCDs and dementia, with rising trends indicating a need for integrated diagnosis and treatment of chronic conditions. These behaviours and health risks impact health, productivity, and lifelong consequences, making it crucial to incorporate NCD diagnosis and treatment into national programs to prevent young-onset dementia in adulthood[96].

The Commonwealth of 56 member countries with a population of 2.5 billion comprises over 33% of the global population: with 1.5 billion people in the Commonwealth under 30, making up 60% of its total population. There is a critical need for public response, resources and support, particularly in Africa, Asia and the Pacific, especially for those who are living with the multi-morbidities of NCDs and dementia.

CommonAge encourages and strongly supports intergenerational initiatives, and programmes. Young people can be part of the solution and can be agents of change, initiating healthier actions, choices and behaviour. In other words, they can be the catalyst for social movements that reinforce healthy lifestyles. Early intervention is key in making a difference: empower the young people to be healthy, have productive adulthoods and future generations and society, as a whole, will benefit.

CommonAge stands ready to assist the Commonwealth Advisory Committee on Health (CACH) and the Commonwealth Health Ministers Meetings (CHMM) in addressing the revision of existing policies, guidelines and plans, strategies particularly for low and middle-income countries across the Commonwealth and beyond.

CommonAge recognises that each country will need to tailor culturally sensitive responses to the challenges of dementia in their communities.

It is clear from the evidence above in this report, and from research into activity across the Commonwealth, that attention is being paid to the challenges of dementia by many NGOs, community groups, national and international organisations and individuals. Research into the condition continues in many academic and medical research institutions throughout the world. The ways and means to tackle the challenge, both medically and socially, are understood and the search for cures and therapies continues. However, the capacity of the international efforts to find and implement solutions is compromised by insufficient priority being given by governments.

The WHO has recognised the need for greater coordination and collaboration in the Global Dementia Action Plan. This plan requires that all states develop their own National Dementia Plans or strategies. Those few countries that have done so have given the lead and now offer models for other countries to follow. The path forward has been created and it should not be difficult, or expensive, for others to follow. The seven principles outlined above offer the framework. The methodology and practice-based evidence of what works, and what can relatively easily be implemented, is increasingly well established. A National Dementia Plan or strategy offers a way forward and the result will be greatly improved outcomes for people living with dementia now, and the millions who will be living with the condition in the future.

Collaborations and partnerships are key. Governments do not have to do all the work – however, they do need to have a plan and implementation framework, make dementia a public health priority, and ensure the legislative mandate is in place to drive and accelerate progress.

NOW IS THE TIME TO ACT!

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Appendix One

This section includes a range of articles on key topics and areas of practice including personhood, women and dementia, young people, nutrition and design.

Appendix One

Personhood in dementia

By Andrew Larpent

"What matters in life is not what happens to you but how you tell the story"
Gabriel Garcia Marquez

Personhood – the quality or condition of being an individual person.

The pernicious and irreversible nature of dementia is that it too often deprives the individual, not only of their memory, but also of their personality, their individuality, their dignity, their self-esteem, and their status as a consequential member of society and of their community. From the moment of diagnosis at a meeting with a physician or consultant the individual is, all too frequently, no longer identified as a 'person' but as a 'patient'; frequently talked over rather than talked with and progressively deprived, by health and care systems designed to support them, of their personhood as the disease progresses. This is the experience for so many people living with dementia, particularly when they are citizens of the so called 'Global North'; countries with advanced systems put in place by governments and civil societies to provide care and support services. Despite the dedication and professionalism of care and support staff in care settings, the systemic and procedural nature of the care environment can result in the loss of the characteristics of individuality and personhood for residents and persons living with dementia.

There has been significant and substantial research on the subject of Personhood in Dementia in recent years and the pioneer of research and prvactice in this area was by Tom Kitwood in the 1990s[1]. It is not intended in this article to revisit aspects of the subject that has been extensively explored and researched by others, but that the examples outlined below open a window of potential study and deeper research for readers and scholars. The findings and implications of established research activity that should be noted by policy makers and practitioners are effectively summarised as follows:

"The research has important implications for practice, regulation, and policy. The person and their personhood should be protected rather than undermined, and relationships should be enhanced not diminished by the formal care process. The focus should be on creating and living the self through interactions with others and engaging in occupational and social roles to ensure continuity of self"[2].

In so called 'advanced' economies and societies, where greater reliance is placed on institutionalised care and support services, it is frequently the experience for persons living with dementia that they are congregated in care homes. In such settings of communal living their conditions and support needs can most efficiently be managed by multi-disciplined teams of professional and semi-professional care staff. However, in such situations connections to families and loved ones are inevitably challenged by the routines, requirements and regulations for infection control, medication, congregate living, management systems and cost-effective utilisation of staff resources. There is a tendency in such situations to depersonalisation and loss of identity.

Much progress has been made in recent years in recognising the person, and life story enhancement examples can range from the inclusion of memory boxes outside the bedrooms of residents in care settings to the use of photo albums and other reminiscence tools. The potential of the use of technology applications is also becoming more mainstream and is likely to play an increasing role with advances in artificial intelligence.

In countries and communities of the 'Global South', which continue to place greater reliance on traditional familial and community-based support, the position of older persons in society is firmly rooted in respect for the individual and for their status as respected elders, endowed by virtue of age and experience with wisdom and respect as custodians of tradition and community values. It is more frequently the case that persons living with dementia in such societies will continue to live out their lives at the heart of families and communities, connected to their life experiences and traditions.

As longevity increases in all societies, the prevalence of cognitive decline and age-related dementia is set to increase. Social scientists and demographers have used the term "tsunami of dementia" to describe the challenges ahead. The race is on to find cures and improved medical interventions and therapies. Many governments are in denial about the challenges ahead and are relying on civil society, institutions and organisations to address and meet the support needs of current and future generations. There is a major international effort underway, led by the World Health Organisation and non-government organisations such as Alzheimer's Disease International, to raise awareness and encourage the development of National Dementia Plans. The world is looking for answers to the growing dementia crisis.

Appendix One

The power of the storytelling in preserving personhood

Among the therapeutic answers in helping persons with dementia to live as well as possible, is the power of reminiscence, the positive retention of memory and the recognition of the importance of protecting and valuing individual personhood. The basis of the approach is on non-medical interventions designed to promote self-esteem and protect personhood. The answer is as old as the hills. It lies in the power of storytelling. A recognition that lies at its heart is the simple fact that "every person has a story" and for those living with dementia a simple truth in terms of personhood is that "I am my story, and my story is not over yet!"

There are many ways in which personhood can be promoted and protected through life stories. Every person living with dementia has a life story and there are many ways, both traditional and modern, in which the personhood of an individual living with dementia can be maintained and enhanced.

In tribal Zulu communities in South Africa, when an older person celebrates a significant birthday, it is not uncommon for the younger members of the family to enact a play for the community, based on the life story of the celebrant. The process of researching and rehearsing the play and the story can assist greatly in ensuring that the individual whose story is being told is accorded the respect of the family and community. The process of learning and understanding the life story of the older person is central to the traditional oral story telling process.

In Rwanda in 2022 at the time of the Commonwealth Heads of Government Meeting the TEGA Girl Effect organisation conducted an oral history project, supported by CommonAge, that enabled the recording of life stories of older women by their granddaughters. The project resulted in a greater understanding of recent history on the part of the students. It also affirmed the dignity of the subjects of the study, enhanced their personhood and contributing strongly to intergenerational communication and understanding.

In Australia an extensive programme of life story research has been undertaken by the Museum of the Moving Image in Melbourne to capture on film for posterity the life stories of Aboriginal elders, thus contributing to, and enhancing, the oral story telling tradition and promoting the dignity of the individuals whose stories have been recorded and told. Similar projects have been undertaken within First Nation communities in Canada by the Centre for Personhood in Dementia at the University of British Columbia.

Enhancing personhood in dementia care

In formal institutional care home settings, every resident will have a "care plan" – terminology that should be discarded in favour of the more positive and life affirming term – the "wellness plan". In what can too frequently be procedural documentation of the support needs of the individual resident, the most important component should be the person's life history. This should be as comprehensive as possible and is frequently drawn up by those most closely associated with the person whose story is recorded. The story should be recorded in as much detail as possible to include family history, career details, artistic, musical, and cultural preferences, likes and dislikes, positive and negative story components that can guide care givers towards helpful and meaningful conversations.

The process of digitally recording life stories can be an important method of promoting intergenerational connection and understanding. The experience of children and teenagers visiting grandparents in care homes can often be a challenging. A solution to this is by encouraging them to take part in capturing their family members story, scanning images and creating a digital life story of their grandparent, overlaid with the subject's favourite music and oral descriptions of shared experiences. This is effectively downloading the personal story from the brain to the computer. It can also be a positive and effective way in which generations can be connected by the process of recording the life story. It can promote conversation and understanding between the older person and the family, enhancing connections and cohesion. Pioneering work in this area has been undertaken in many countries.

In a separate article in this report, the concept of digitisation of life experiences to enhance memory is explored further in the context of augmented reality to stimulate memory and reminiscence. These are powerful tools that are becoming daily more readily available. The challenge is to continue to explore ways to enhance and protect the personhood of those living with dementia. Such therapeutic interventions will not prevent or slow the progressive decline of cognitive function. It is however possible to enhance and protect the quality of the person's life throughout most of the journey of cognitive decline. Services need to ensure that such therapeutic use of life stories to protect personhood, is incorporated as a core component of policies and procedures to enhance the wellbeing of persons living with dementia.Those responsible for governing and regulating dementia care services must ensure that the concept of personhood is understood and firmly embedded and promoted in staff training and in care standards.

Appendix One

Women and dementia: from caregiving disparities to economic opportunities

By Datin Jacqueline W. M. Wong

Background

Women's health has always been seen through the lens of their healthcare needs. However, women play an important role as both providers and recipients of healthcare in their families and communities. Economically, politically and culturally, this commitment is undervalued. Women contribute approximately USD 3 trillion to healthcare annually. Caregiving responsibilities are typically associated with societal norms, leading to women becoming de facto carers despite lack of experience, or skills.

Accounting for nearly two-thirds of primary carers, women are disproportionately affected by caregiving and dementia. Women who care for others with dementia are more likely to develop dementia and experience more severe symptoms. Dementia is one of the leading causes of death in women. Older women in poverty are most affected and impacted by lack of government assistance; a significant factor in low and middle-income countries in the Asia Pacific region, which will experience 71% of global dementia cases by 2050.

In 2020, 9.2% of the world (689 million people) live in extreme poverty, on less than USD 1.90 a day, increasingly concentrated in sub-Saharan Africa and South Asia. The COVID-19 pandemic has exacerbated challenges, reversed years of progress where over 97 million people are back into extreme poverty. Millions, mostly women, lost their jobs and livelihoods.

This article aims to shed light on the unique impact of caregiving and dementia on women, address the often-overlooked caregiving role (formal and informal) and emphasise the need for investment in women, because this will help build social capital; contribute to a more sustainable economy; and ensure a more equitable and inclusive society.

Introduction

Although women make up 39% of global employment, they account for 54% of overall job losses [3]. While working on the front lines (supporting care systems, economies, communities, etc.) women also undertake most of the unpaid care work. Thus, gender and age-responsive policies should be included in measures that governments adopt to mitigate the impact of the pandemic (e.g. on employment and income) if women's contributions to the workplace, their inherent right to work and other workplace-related rights are to be a central feature of recovery.

Dementia is not an equal opportunity disease

The World Health Organization (WHO) estimated 57 million people live with dementia worldwide. Two-thirds are women – individuals who face the highest levels of stigma and discrimination. Rates of dementia in older people (71-plus) are also higher in women (16%) than men (11%)[4].

Women are disproportionately impacted by dementia and caregiving

Disability-adjusted life years attributable to dementia are around 60% higher in women. Women also account for 65% of total deaths due to dementia but provide most of the informal care for people with dementia (viz. 70% of carer hours). Despite the disparity, there is little evidence of policy development or action taken to address these issues[5].

Many societies expect families to care for older unwell relatives

Many high-income countries support older people (including those with dementia) via community services. Few low and middle-income countries have similar support systems, as traditionally, family (especially women) and community take care of older relatives. Changes to family structures and migration, result in the gradual weakening of these informal support systems, yet governments fail to 'fill the gap'[6].

Lack of health and social care services in rural and remote areas

Access to health and social care services (including for those living with dementia), particularly in rural and remote areas, are severely impacted by lack of infrastructure, transportation, communications and government agencies, etc. It is critical that community services are made available and accessible, including and especially for women with little or no education[7].

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Need for professional health care workers and skilled carers

To provide effective advice and support, dementia care skills training should be in place for all community-based health professionals, to enhance understanding of behaviours of people living with dementia, and the impact the disease has on their carers. Currently, healthcare and social support systems have limited capacity and are inadequate to meet demands for geriatric and dementia care. Furthermore, perceived low status (of a carer role), lack of financial reward, inadequate training and lack of support for carers continue to impact negatively on women, their families and people with dementia [8].

Key highlights and statistics

Dementia is a public health issue: one increasingly visible in low and middle-income countries as the populations age. Policymakers need to understand the implications of current and predicted dementia statistics; acknowledge that dementia affects women disproportionally and assess the impact, review any support currently available in their country, and ensure policies are in place to meet both current and future needs.

Dementia affects over 57 million people, with a new case every 3 seconds

Approximately 60% of people with dementia live in low and middle-income countries. This number is expected to increase five-fold by 2050 [9]. Although dementia mainly affects older people, there is increased awareness of early-onset dementia, i.e. in people in their 30s, 40s and 50s.

Perceptions of dementia

In many countries, from the community members to the policymakers, there is a lack of acknowledgement and/or understanding that dementia is a medical condition - not a 'normal' part of ageing. In some countries, 'dementia' is not even a word. Stigma and discrimination exist (and can be rife) with those having the disease, accused of witchcraft and/or threatened with violence and receiving sub-standard, if any, care. Furthermore, young people with dementia have reported being laid-off or unable to access jobs due to discrimination or a lack of understanding, and this impacts on their social welfare and/or disability benefits[10].

Attitudes towards dementia

In 2019, Alzheimer's Disease International (ADI) conducted the world's largest survey on attitudes to dementia. The study, involving over 70,000 people across 155 countries, revealed astonishing attitudes towards dementia, including more than half of the healthcare practitioners surveyed, agreeing that their own colleagues ignored people with dementia[10].

Risk reduction programmes

Only 1 in 10 individuals receives a diagnosis for dementia in low and middle-income countries. Targeted programmes and early dementia diagnosis could save government expenditure by reducing high costs of emergency and health treatments, improving care and increasing the effectiveness of social, community and other care services[11]. '*Prevention is better than cure*'.

A marginalised majority

Living longer does not equate to living healthier or better lives. By 2025, the number of older women in the population will increase (13.2% compared to 11.6% for men), posing further challenges and impacting health, welfare, care and financial systems. By 2050, one in four people will be 80 years or older[12] and 71% of people with dementia will be living in low and middle-income countries in the Asia Pacific region. Changing family structures – coupled with changes to migration trends – continue to weaken informal support systems, shifting the burden of care towards an (unprepared) wider society. According to a report on *Women & Dementia: A Global Research Review*, there is a critical need to understand the main issues affecting women in relation to dementia[13].

Key highlights:

Dementia is listed by the WHO as the fifth-highest cause of death and disability for women.

Deaths due to dementia more than doubled (2000 to 2016), with dementia the 14th cause of global deaths in 2000 but the 5th leading cause in 2016. It was the leading cause in the UK (O'Dowd, 2017, The Guardian) and second leading cause in Australia[10]. Of the 48 countries and territories with dementia plans adopted, only 12 considered gender-sensitive issues. Furthermore, there is no systematic data collection to disaggregate prevalence, diagnosis rates or impact of dementia on women, locally or globally.

More women than men live with dementia

At the age of 65, women have a 1 in 5 chance of developing Alzheimer's disease (for men, 1 in 11). Symptoms women experience and live with are also more severe.

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Women make up two-thirds of dementia carers

Women carers provide 71% of the global hours of informal care; the highest proportion being in low and middle-income countries. They contribute over 58 billion hours globally per year to caring for people living with dementia yet receive no wage. For young girl carers, this is a 'quadruple jeopardy', as they are likely to be discriminated against because of age, gender, race and lack of education. Furthermore, lack of access to education before girls reach the age of 20 is now recognised as a risk factor for poor health and wellbeing[14].

Women impacted by dementia receive little, if any, health care

Caregiving impacts wages, retirement, promotions and ability to remain employed. Women caring for family members are 2.5 times more likely to live in poverty compared to non-carers. If diagnosed with the disease, they are likely to receive little if any appropriate care and must support themselves. As women make up 70% of the world's 1.3 billion poor, the level of poverty can become even more extreme in old age[15].

Older women are discriminated against because of their age, gender, condition and role as a carer, and or, if diagnosed with dementia

Extreme discrimination can lead to women with dementia facing neglect, abuse and even violence. Not only is there stigma attached to the disease, women who are widows face a 'triple jeopardy' - they are older people, have dementia and are alone[16, 17, 18].

Barriers to accessing justice and legal support lead to isolation and exclusion - even more so for women with dementia and a disability

It is estimated that women with disabilities are 1.5 to 10 times more likely to face abuse (physically or sexually) by a family member, or her carer, and have little if any access to legal support [9].

Women with disabilities are often excluded from national laws, policies and remain marginal to global discussions

The global women's agenda seldom considers issues and concerns of women with disabilities, let alone of women with dementia.

Women are often sidelined with respect to policy and decision-making processes

Although WHO's Global action plan on dementia stipulates equality as a cross-cutting issue, only 12 national plans offer gender-sensitive responses to dementia. For many women, there remain barriers to their participation in science, research, development, decision and policy making; all areas that could have a positive impact on global health outcomes[20].

Women face barriers to participating in clinical trials and research

While dementia affects the lives of millions of people, little is known about the real impact it has on women, especially those in low and middle-income countries. Too often, women carry responsibility and burden of care for loved ones with dementia, only to find themselves in the same situation later in life[13]. Clinical trials for women living with dementia remain an under-funded and under-researched area. The impact of limited knowledge about women's health (relative to men's) is far-reaching. Research funders, policymakers, and business leaders apparently lack a basis for altering research investments[21].

Women carers at the forefront of the COVID-19 pandemic

The UN Women's Regional Office for Asia and the Pacific (ROAP) conducted surveys to assess gender-related consequences across the region in April 2020 (two weeks after COVID-19 was declared a pandemic). The surveys, distributed among millions of people, revealed how differently women and men experience effects of the pandemic[22].

Women, work and caregiving

Improved living standards and medical advances mean people generally now live longer. By 2030, people aged 60 years and older will outnumber children under 5 years old[12]. This has financial implications for the working population, particularly older women. With longer life-expectancy, more people will leave the workforce to care for elderly parents; this is especially pronounced in Asia, where women are more likely to take on the caregiving role than men.

The physical, emotional and financial impact of caregiving on people's lives prior to COVID-19 has been further exacerbated, with healthcare workers facing unparalleled demands since the pandemic. For example, according to US surveys (February and November 2021), 32% of registered nurses questioned, said they may now leave their current direct-patient-care role[23].

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COVID-19 has also heightened the intensity of stress, including in the workplace and in personal relationships, thereby impacting mental and physical health. Women in informal care and young carers are disproportionately affected by these and other factors[24]. Globally, women's mental and emotional health is at its lowest in 15 years and gaps in gender-related needs, remain[25].

Besides older people and persons with disabilities, older women, older people with a migrant or refugee background, and/or of a different race, ethnicity, or with an indigenous heritage and those living in poverty are the people most negatively impacted by the pandemic and lack of appropriate government responses. The prolonged situation, with on-going physical/social distancing has further aggravated the wide range of issues and challenges faced by such individuals[26].

In 2015, unpaid carers provided over USD 471 billion in uncompensated labour. These informal carers have skills of value 'in the (labour) marketplace', and alternative mechanisms to fund, support and provide access to paid care work (especially for young carers), should be considered. Employers, health systems, the community and those who can afford paid help, are key access points for bringing about this much needed change, especially given current shortages in the labour market[27]. *Archangels Work* (www.archangels.work/about-us) is changing the way employers and job seekers view a caregiving role. Informal carers can help drive culture change by showcasing their skill sets on their resumes or CVs and encouraging employers to recognise those skill sets. In Malaysia and Singapore, *Homage* (www.homage.com.mHyy/) provides on-demand home and community-based caregiving by trained local carers (and retired nurses) to assist with daily living for safe and independent living at home.

In terms of home and community-based care; in Brunei Darussalam, there are 1,200 people with Alzheimer's disease and over 2,000 people living with dementia. People living with dementia' struggle with isolation, loneliness and faced worsening symptoms during the COVID 19 pandemic. Incepted in 2018, focused on building local capacity through sustainable practices, *demensia Brunei* (a non-government non-profit organisation) works to provide dementia care skills training workshops for carers, healthcare workers and allied professionals who support caregiving for older people who are ill, frail or who are living with dementia. The training enables informal carers and family members to better manage, cope, and help others, including during the pandemic. So far, 400-plus carers, healthcare workers, and related professions have attended 23 dementia care skills workshops and a Train-The-Trainer Programme. These figures may seem insignificant, but when Brunei's population (less than 500,000) is compared with Malaysia's (32 million), this translates to an equivalent of 28,000 people in Malaysia having received dementia care training.

In Australia, *Dementia Australia* offers a carer support group; knowledge, tips and strategies being shared with others involved in the caregiving experience. Education programmes specifically designed for families and carers are also offered on a regular basis (www.dementia.org.au/support/family-and-carers). In the United Kingdom, research has resulted in *Living with Dementia: My Life, My Goals* (www.alzheimers.org.uk/blog/life-after-dementia-diagnosis-guide-setting-reaching-goals), a practical self-help guide enabling people living with early-onset dementia to manage and enjoy independent living by adapting cognitive rehabilitation therapy to real-life scenarios.

Societal costs of caregiving

On average, people spend about 50% of their lives in less-than-good health and 12% in poor health, a ratio that has not changed in the past 50 years[28]. In 2015, 2.1 billion people required care: 1.9 billion children under 15, 200 million older people. By 2030, this could be 2.3 billion. Global data from 64 countries shows 16.4 billion hours per day are spent in unpaid care work – equivalent to 2 billion people working eight hours a day with no remuneration. Such services, valued based on an hourly minimum wage, would amount to 9% of global GDP, or USD 11 trillion (purchasing power parity in 2011). Globally, women perform 76.2% of total hours of unpaid care work. In the Asia Pacific region, this increases to 80%. Female migrants often work under poor conditions and for low pay in the informal economy[29].

In 2018, 606 million working-age women were not able to work because of unpaid care. For most women working at paid jobs, some of the biggest challenges were lack of work-family balance and unequal pay for similar work. It is estimated that 300 million people aged 65 and older are in need of long-term care currently[30]. The increasing numbers of carers needed (especially for dementia) and evidence-based interventions to support carers, should be part of any comprehensive plan to address increases in growing numbers of people needing care[31]. If investments were doubled in education, health and social work by 2030, 269 million new jobs could be created. According to a World Bank report on the global care crisis, increased investment in the care economy would not only result in a total 475 million jobs by 2030, but would also lead to overall better health, education, equality, decent work and real economic growth[32].

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That said, the gender wage gap for women working in health and social care means that a woman's average hourly earnings are least 10% less than her male equivalent's. For some women this means adopting multiple roles: employee, mother, homemaker, primary carer, etc. It has already been noted that approximately 70% of family carers of people living with dementia are women (wives, daughters, daughters-in-law), but too many countries lack effective support care policies, programmes and services, for those living with dementia and their (informal) carers. This adds to the burden of women providing critical services to the community.

Minority women in particular, experience the challenges of unpaid caregiving. For example, in the United States, 30.7% of African American and 40.8% of Hispanic single women over 65 years of age live in poverty, as caregiving impacts not only wages but also retirement, promotions and ability to remain employed[33].

Evidence shows redistribution of care responsibilities between men and women has become ever more critical and urgent. In the United Kingdom, almost 80% of all care is provided by informal carers, with women providing the lion's share. Care duties often fall to family members who have lower opportunity costs. Caregiving tends to exacerbate gender wage and pension gaps[34].

In Asia, the cost of elderly care contributes to gender inequality. In Hong Kong (2018), 342,000 people received eldercare (subsidised or non-subsidised residential care or home care). 58% were women. The cost was HKD 38.8 billion per year. But carers will double to 89,000 in the next 20 years and increase to 97,000 by 2060. The opportunity cost for informal working carers who lose both income and career advancement are estimated to quadruple from HKD 1.8 billion in 2018 to HKD 7.2 billion by 2060. In Singapore, the number of elderly carers is projected to double in 20 years' time and increase 2.6 times to 890,000. The average retirement savings gap between low-income working men and women is 32% in studied Asian markets: Malaysia, Indonesia and Thailand having the largest gap of 44%. The main reasons for this disparity include women have shorter working periods (due to family-related career breaks) and early-age retirement. Furthermore, women are generally more risk-averse and have lower financial literacy levels than men[35].

Global healthcare spending is often over USD 8 trillion each year and increases faster than GDP [36]. In 2021, a podcast by the International Monetary Fund (IMF) captured the contributions of unrecognised carers - disproportionately women and girls who form the economic base for global societies: *"... our whole notion of productivity is skewed because most care work is not captured in GDP..."*[37]. In addition to the enormous health and societal burden, dementia is an economic nightmare about to metastasize as the world, especially poorer countries, experiences unprecedented population ageing[38].

An equitable, sustainable and inclusive future

Working together to create a society that is more inclusive, equitable and sustainable post-COVID-19 must also include a future where no woman (or girl) is left behind.

1. Invest in Research on women. It contributes to the economy

Women's health is an economic issue policymakers cannot afford to ignore. Funding research into women's health could improve the lives of millions of people living with dementia, especially women, but discrimination around dementia is a barrier to advances in this area. However, when USD 280 million is invested in Alzheimer's disease research for women, the outcome means 4,000 years of life are reclaimed. 6,500 years with dementia are eliminated. USD 930 million added to the US economy. In short, a 224% return on investment. Women's health is global health.

According to research, humanity may add up to 45 billion more years of higher-quality life over the next decade (approximately six years per person on average), and significantly more in some countries and populations. A culture that adapts to innovate health systems; decisive leadership in public health policies; and scaling effective solutions will be required to achieve this goal.

More effective and beneficial outcomes for older women have emerged from the use of timely and high-quality gender-data in driving policies and crisis recovery strategies/plans. For example, statistics from UN Women's rapid gender assessments indicated that during the pandemic, women were more likely to offer additional unpaid care, which influenced Colombia's national care policy. In Albania, the data contributed to the expansion of farm subsidies to better reach women. And in Senegal, it fuelled the new Resilience-Building Programme for Households and Vulnerable Groups (PAREM) by the Ministry of Women, Family, Gender and Child Protection's (MFFGPE)[39].

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2. Invest in Equality. It truly builds better forward

Over the last three decades, there has been much discussion, and little action, regarding the disproportionate burden and challenges to women (and girls) at home and in the workforce, especially those living on low wages or in poverty. For instance, the *Beijing Declaration 1995* was endorsed by over 180 countries. Progress on pledges has ranged from slow (at best) to zero. Women remain disproportionately disadvantaged across all sectors: the informal economy, long-term care needs, healthcare, and education. COVID-19 has increased hardship, starvation and domestic abuse, for both the impoverished in low and middle-income countries, and the vulnerable and marginalised in high-income countries.

Acting now could add USD 12 trillion to the global GDP by 2030 (McKinsey, 2015). In a "full potential" scenario in which women play an identical role in labour markets to that of men, as much as USD 28 trillion, or 26%, could be added to global annual GDP by 2025. Investing in women's education, healthcare skills training, science and research has excellent outcomes for the global economy. Women must be involved in future economies, policies, action plans and strategies as they offer unique perspectives and capacities that enable inclusive development and sustainable progress.

The 'new *fairer* normal' requires the international development community to learn from the experiences of grassroots networks and recognise what collective learning and problem-solving can achieve. It also requires partnering with, and investing in community-led solutions, guided by principles of human rights and dignity[40].

Building on information gathered from the Organisation for Economic Co-operation and Development (OECD) members in 2020, a brief provided recommendations to promote equality as part of the recovery process, including use of tools for planning, regulations, budgets and public procurement. The OECD survey *'Mapping good practices and challenges faced by the Institutions in tackling the effects of COVID-19'* conducted at the start of the pandemic, included a snapshot of early efforts as of April 2020[41].

Despite recent gains, the number of people living in poverty remains unacceptably high across the world, with concerns raised about eradicating poverty by 2030. The human cost of COVID-19 is immense, with millions in developing countries sliding back into poverty. Evidence also showed the pandemic exacerbated women's inequality, with an estimated 70% of the female population adversely affected. This calls for governments to re-commit to long-term development strategies that include investing in human capital, especially for older women, women and girls. The IMF has worked with 113 member countries to develop gender-equal budgeting processes, allocations, and tax policies to assist governments and countries in focusing resources on women. The findings conclude the policies were effective, increasing women's employment and improving their economic wellbeing. Such measures should be implemented on a larger scale[42].

3. Invest in Health. It yields return and societal wealth

With disparities in access and outcomes (within and across countries, regions; and across gender, wealth and other demographic variables) health inequity remains a persisting major issue. When lockdown measures began in early 2020, the biggest issues revolved around impact and effects on health and care[43]. Aside from physical health, the pandemic's toll on millions of older women and women (including girls) will have long-term consequences in terms of mental health and economic wellbeing[44].

Dementia has significant social, economic and financial implications and costs. The estimated global societal cost of dementia was USD 1.3 trillion (2019). This is expected to surpass USD 2.8 trillion by 2030. By 2050, the cost will conservatively reach USD 48 trillion[45]. Irrespective of method of cost calculation, the contribution of informal care, particularly from women and young carers, is substantial. A grave concern is ageing populations; this being particularly acute in the Asia Pacific region. By 2050, the global ageing population is estimated to reach 2.1 billion. Two-thirds of the world's elderly are living in the Asia Pacific with one in every four persons over the age of 60. Globally, 48 countries and territories have adopted a plan on dementia: 39 in WHO Member States, with 12 considering needs of women and none, young carers[46].

In 2021, a dialogue at the International Monetary Fund-World Bank Group (IMF-WBG) Civil Society Policy Forum on *Building back better health systems: Lessons from the WBG's COVID-19 response and recovery plans* focused on redesigning health care systems. Most governments are reducing funding on health for the next 2 to 5 years. This is not only a huge setback. It also poses additional challenges and implications to economic, social, welfare, health and care. Aged care, health assistance initiatives and care programmes will suffer because of the domino effect. This only serves to underline (to decision- and policymakers) the importance of universal healthcare coverage as a basic right for all, especially older women[47]. A country prioritising

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health for all will enjoy prosperity: better health promotes progressive economic growth and yields. Expansion of the labour workforce boosts productivity while also delivering immense benefits and societal wealth. Prioritising good health enables social development and spurs economic growth - two of the top three drivers of life satisfaction for individuals[48].

While women account for 70% of healthcare workforce, fewer than 20% of the world's health ministers are women. Amid COVID-19, women are on the front line, responding as heads of state and government, legislators, healthcare workers, carers at home and community leaders and mobilisers. It is therefore critical that women continue to lead as well as participate fully in decision-making on crisis response, recovery and beyond. Women's leadership and participation can provide more effective, inclusive, and fair policies, plans and budgets to address the pandemic. For example, the Minster of Health of India's state, Kerala, has been hailed as the reason that a state of 35 million people has only lost four people to COVID-19 [49]. The former Prime Minister of New Zealand and leader of Labour Party (Jacinda Ardern) and several women leaders have been recognised as providers of global best practice in response to the pandemic[50].

4. Invest in Education. It supports creation of quality employment

Investments in the STEAM and care economy have the potential to be at the core of inclusive, job-rich recovery policies. Health, social work and education sectors are important generators of jobs, especially for women in low and middle-income countries. *When women thrive, all of society benefits and succeeding generations are given a better start in life.*

In 1995, the *Beijing Platform for Action* identified 12 key areas where urgent action was required to achieve greater equality and opportunities for women, girls, men and boys. For women to achieve equality and become change-makers, they need an education [51]. While educated women benefit communities and societies, contributing to thriving economies and improved health, nutrition and education of their families, gaps and disparities still remain and need to be addressed.

Older women are majority of learners in later-life learning programmes[52]. Women's re-integration into productive employment must continue to be supported by active labour market policies. Gender- and age-responsive national employment policies can support to balance gender-specific impacts of the pandemic and create conditions to support creation of quality employment for women on multiple fronts [53]. Full employment and decent work are required to break the cycle of poverty. Underprivileged women and youth have benefited from entrepreneurship programmes that have helped them [54].

5. Invest in youth. It is building better forward for future generations

For young people, especially for vulnerable youth (girls and young carers), COVID-19 has disrupted education and employment, impacted mental health and diminished disposable income. While youth and future generations will shoulder much of the long-term economic and social consequences of the pandemic, their health and wellbeing may be impacted in the short-term. An inclusive response requires an integrated approach to public governance that anticipates the impact of response and recovery measures across gender and different age groups.

When young people are considered the 'link' between short-term concerns and long-term goals in public consultations, decision-making processes and public dialogues, this results in more equitable and inclusive policy decisions and societal resilience. Therefore, empowering young people and involving them in building societal resilience should be twin goals. After all, this population group is forecast to reach 1.4 billion in 2050, and account for 40% of the global workforce by 2050 [41].

To address the key concerns raised particularly regarding older women (and including young carers), recommendations include (but are not limited to) the following:

- Initiate Public-Private Partnerships that help develop sustainable models of caregiving (including for older people and for those with dementia).
- Foster collaborative processes between Government, public and private sectors towards developing and accelerating action, improving public policy strategies that support ageing populations, those with dementia, families, carers and the community.
- Use evidence-based models to help build capacity; ensure development and application of quality standards/guidelines for best practice in all health professional and care services, up-date and standardise training models, provide learning and development opportunities (for health professionals, volunteers, family members, other carers) including in rural/remote areas.

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- Provide incentives (including financial) for care service providers, including family members, organisations, etc., for instance: tax breaks, subsidies, free legal/emergency/administrative support, flexible work arrangements, extended care/compassionate leave, mental health support.
- Encourage an open, supportive workplace culture that adapts to the needs of the workforce; encourage employees to 'future proof' by addressing matters relating to health, accommodation, legal issues, etc.
- Raise public awareness on cost of caregiving being a challenge to the whole of society, work with public agencies, NGOs, media, etc. to better educate the public about dementia as a global health priority and address discrimination/stigma associated with a medical condition disproportionately affecting women.
- Invest in funding research, development and implementation of innovative solutions ensuring gender-perspectives are discussed and acted on at every level, with women fully represented and involved at every stage in decision and policy making. Greater investment in research along with innovation, has been the driving force behind most advances in health.
- Provide practical and tangible support, 'safety-nets' for women living with dementia, living alone or in rural and remote areas and/or as unpaid carers. The COVID-19 crisis has demonstrated the relevance of telehealth and created a window of opportunity to modernise the care delivery system. New analysis indicates telehealth use has increased thirty-eight times from pre-COVID-19 [55, 56].
- WHO Secretariat of the *Global Plan of Action on the Public Health Response to Dementia* implementation to monitor impact on women with countries, regional bodies and international bodies to collaborate, share best practice and collectively develop comprehensive gender-responses to dementia.

While it is important to learn from achievements and progress, it is equally important to recognise every institution, leader and individual has a critical role to play.

An urgent priority

Seven goals for improved policy, awareness, prevention and diagnosis, research, care and treatment of dementia and dementia care were included in the WHO's global action plan on the public health response to dementia 2017–2025, which was adopted in May 2017.

'Dementia as a public health priority' is the first aim urging *75%* of Member States (146 countries) must develop a customised response to dementia by 2025.

In the Commonwealth, *12 Key Asks* were formulated resulting from a landmark roundtable *Critical Conversation:* '<u>Advancing Universal Health Coverage Through Gender Equality</u>'. Discussions first took shape in February 2023 when a group of 220 health experts and civil society leaders from 35 countries participated in a series of sessions to draft these recommendations. The *12 Key Asks* were presented at the Commonwealth Health Ministers Meeting in Geneva in May 2023 and in 2024, a progress report on *12 Recommendations* for advancing universal health coverage from Commonwealth civil society was presented to Commonwealth ministers and senior officials in May 2024 at the side of the World Health Assembly. *Key Ask 12 is that: "There is no health without mental health"* [57].

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The Davos Alzheimer's Collaborative: Leading an unprecedented global response to Alzheimer’s and dementia

The idea for developing a global mechanism of action was first raised at the 2019 Lausanne Workshop. It was taken forward at the World Economic Forum's Annual Meeting in 2020, where a diverse group of private-sector executives, government leaders and NGOs came together with a singular goal: *How can we mount a global response to Alzheimer's by orchestrating game-changing solutions to end the suffering, financial burden and stigma around this disease?*

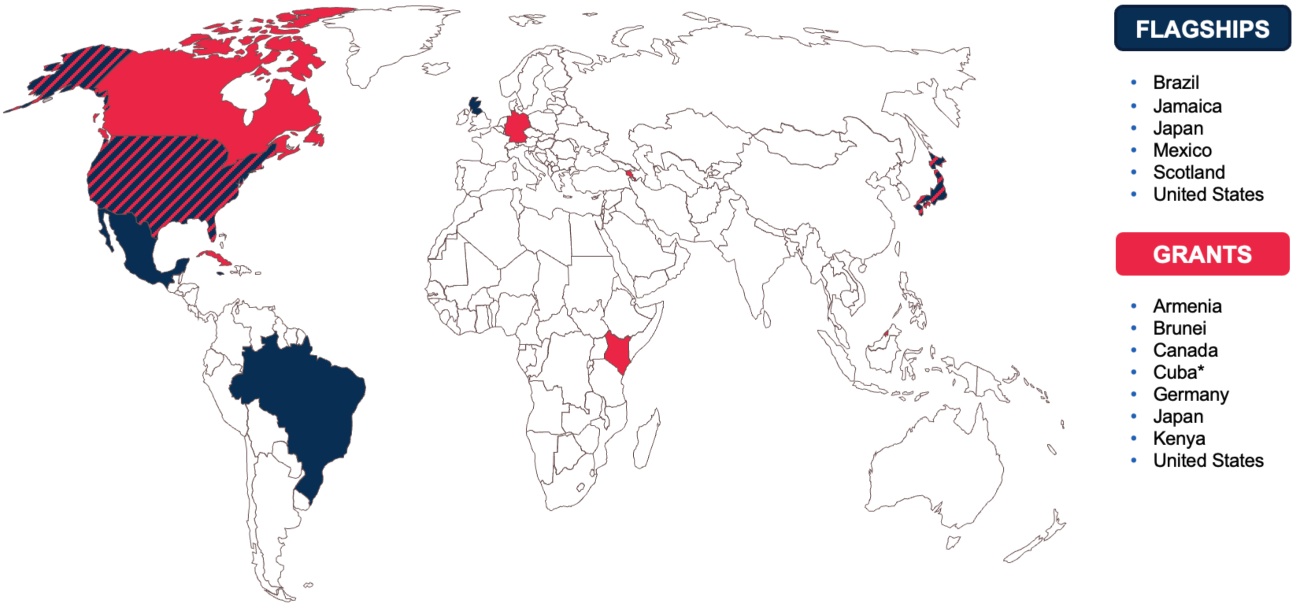
Led by the World Economic Forum (WEF) and The Global CEO Initiative on Alzheimer's Disease (CEOi), the Davos Alzheimer's Collaborative (DAC) seeks to invest over $700 million to accelerate innovation in drug development and transform the way healthcare systems diagnose and treat Alzheimer's for all people in all places.

The challenge

The incidence of Alzheimer’s disease and dementia is increasing, but healthcare systems are not prepared to meet today’s challenge, much less the coming surge. The number of people living with dementia is projected to triple from 55 million at present to over 139 million by 2050. Annually, dementia costs the global economy more than USD 1.3 trillion. Globally, 3 out of 4 people with dementia are never even diagnosed, much less treated. This number will increase by up to nine times from 2020 to 2050.

Healthcare systems face significant challenges evaluating and adopting novel interventions in real-world practice. There is a 17- to 20-year gap between clinical innovations and widespread adoption, with less than 50% ever becoming part of real-world practice.

Dementia does not discriminate and recognises no borders, neither can solutions to diagnosis, care, support and risk-reducing the disease. One of the DAC programmes is the Healthcare System Preparedness supporting multiple, diverse implementation programmes focused on seeding healthcare system change with clear actions and goals aimed at sustainable solutions.



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Healthcare system preparedness

DAC Healthcare System Preparedness aims to catalyse healthcare system transformation that allows people living with Alzheimers and their families quicker access to life-changing innovations. To achieve this ambition, DAC Healthcare System Preparedness is implementing and evaluating global programmes focused on increasing rates of cognitive screening, early detection, and accurate diagnosis of Alzheimer's disease and related disorders.

The first programme focused on early detection of cognitive impairment, which is a critical building block for healthcare system preparedness, including identifying the right patients for the right intervention at the right time.

- Flagship Programme: The Early Detection Flagship Programme included seven flagship healthcare systems across six countries: Brazil, Jamaica, Japan, Mexico, Scotland, and two sites in the US. This program was designed to increase early detection of cognitive impairment in non-specialty settings by implementing a digital cognitive assessment and a blood-based biomarker test.
- Grant Programme: The Early Detection Grant Programme awarded grants to 12 healthcare systems in 8 countries for projects related to the early detection of cognitive impairment symptoms. Grantees were in Armenia, Brunei Darussalam, Canada, Cuba, Germany, Japan, Kenya, and the United States.

Over 75 applicants from 24 countries responded to DAC Healthcare System Preparedness's inaugural grant funding for improving early detection of Alzheimer's disease and dementia.

*Cuba is a non-funded DAC Healthcare System Preparedness collaborator

DAC projects in the Commonwealth are listed in the following:

Brunei Darussalam

Brunei has a high prevalence of non-communicable diseases, which are risk factors for dementia. Despite this, the country has a low rate of dementia diagnosis, with detections often delayed until complications like falls, immobility, and aspiration pneumonia arise. The Global Burden of Disease Study 2019 predicts that the number of people living with dementia in Brunei will increase by 365% by 2050. However, there are currently no validated tools available for cognitive screening in the country. To address this, a pilot project supported by the Davos Alzheimer's Collaborative Healthcare System Preparedness (DAC-SP) programme was conducted to test community screening. This included training field workers in community screening and cognitive assessment, as well as organising workshops for primary care providers and relevant specialists.

This project involved a community survey using cluster sampling to target older individuals. Specifically, the survey focused on those aged 60 and above, as well as those aged 50 and above with non-communicable diseases or risk factors for developing dementia. Participants were recruited from various community sources, including senior citizen activity centres, village heads, and community centres. They were given a questionnaire that covered dementia risk factors, symptoms of dementia, indications of concern regarding these symptoms, and a brief cognitive assessment tool (Mini-COG).

A total of 1,962 participants were screened at various locations, including Senior Citizen Activity Centres, Health Centres, marketplaces, public awareness booths, public events, village head pension collections, dialysis centres, RIPAS Hospital, and various government departments or ministries. Commonly identified risk factors included hypertension, high cholesterol, diabetes mellitus, and kidney disease. Reported symptoms of dementia included misplacing things, memory loss, visuospatial difficulties, and mood or behaviour changes. Among those with symptoms, 14.5% believed their condition was worsening, and 12% felt that their symptoms affected their activities of daily living. Additionally, 14.5% of participants showed possible cognitive impairment based on Mini-COG scoring.

Canada

Context and project goal

In Canada, there is a critical need to improve cognitive and biomarker assessments for Alzheimer's disease (AD) in people aged 65 and older. Currently, many cases of dementia are underdiagnosed or diagnosed late, as seen in an Ontario study where 31% of nursing home residents with cognitive decline were undiagnosed. The diagnosis challenges are due to AD's complexity, the large, affected population, and limited access to diagnostic tools and specialists. To address these issues, the project explored training social workers at Alzheimer Society chapters and involving optometrists to conduct retinal imaging to screen for the presence of AD retinal biomarkers using RetiSpec's AI.

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Project description

This project evaluated the effectiveness of using community-based settings to increase cognitive assessments and detect AD through an AI-based eye test by RetiSpec. Adults aged 55 and older with memory concerns underwent cognitive assessments at local Alzheimer Society chapters or had retinal imaging at optometry clinics. Results from these assessments were shared with primary care providers or nurse practitioners, who then discussed the findings with the participants.

Impact

A total of 916 individuals were screened, mainly from optometry settings (60.2%). Of these, 124 underwent cognitive assessments. Following these assessments, 88.7% discussed results with clinicians, and 39.6% consulted the study's Nurse Practitioner. Notably, 52% of those with memory concerns showed signs of cognitive impairment. Participants who received RetiSpec scans rated them positively and expressed willingness for future scans, especially if covered financially. Interviews revealed benefits like comfortable screening and early detection, alongside risks such as follow-up delays, and highlighted facilitators including accessible settings and staff training, as well as barriers like stigma and communication gaps.

Jamaica

Jamaica was one of seven sites that participated as part of the Davos Alzheimer's Collaborative Healthcare System Preparedness (DAC-SP) Early Detection flagship programme that implemented a digital cognitive assessment in primary care. Jamaica leveraged the research infrastructure and stakeholder relationships that were developed from prior projects such as the STRiDE initiative. The programme was implemented in the private healthcare system in the Kingston, St. Andrew and St. Catherine parishes and via direct-to-consumer recruitment drives in communities, with a focus on patients 60 and older. The research team functioned as Brain Health Navigators, completing the digital cognitive assessments, and coordinating the blood and ECG tests for reversible causes of impairment with local laboratories and medical facilities. The post screening care pathway and management was co-developed between the research team and the health and allied care practitioners whose patients participated in the initiative.

Four key lessons from the Jamaica early detection program include:

1. Creating pathways to get people into the healthcare system

In Jamaica, this programme represented a novel care pathway with emerging infrastructure. To ensure the programme was appropriate to the local context and accessible to patients, the Site Lead leveraged partnerships with local health and civil society organisations. An unanticipated barrier to the feasibility of the programme was the cost of tests for reversible causes which would have been prohibitive for patients to cover out of pocket. The site lead was able to secure additional funds to overcome this barrier.

2. Leveraging early-stage health and allied professionals

To help support staffing and operationalising the programme, the Jamaica site leveraged many health and allied professionals in the early stage of their careers. Some were medical professionals, and some were undergraduates trained in psychology. These early career professionals were looking for applied research experiences outside of the typical academic environment. They functioned in many on-the-ground roles, including serving dual roles as researchers and brain health navigators for the program.

3. Building relationships with community organisations to raise awareness

The Jamaica site invested in building relationships with key community organisations, such as places of worship and community leaders, to raise awareness about the importance of brain health and healthy aging. The site, built trust with the local partner organisations over a long period, in many cases prior to the start of the DAC-SP initiative, understanding the community's needs for healthy aging in each community context. This approach helped meet potential patients where they were.

4. Using the research staff roles flexibly

Many primary care providers found it challenging to incorporate the new workflow for the early detection programme as they were pressed for time with other priorities when seeing a patient. The Jamaica site was able to use their research assistants in a flexible way (akin to Brain Health Navigators) to support the implementation of the programme and address bottlenecks in primary care workflow.

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Kenya

Sub-Saharan African countries have the fastest-growing rates of older populations among lower and middle-income countries. In Kenya, the proportion of people aged 60 and older is expected to more than double by 2050 compared to 2017. However, limited data on dementia prevalence and a shortage of healthcare staff highlight the challenges faced by Kenya's health system. Community Health Workers (CHWs), with their strong community ties, have been effective in delivering health interventions within Kenya. Leveraging this, a project supported by the Davos Alzheimer's Collaborative Healthcare System Preparedness (DAC-SP) programme aimed to deliver dementia screenings to adults aged 60 and above over six months. This initiative sought to improve early detection and intervention for dementia in rural areas.

This project redeployed volunteer staff from the Strengthening Responses to Dementia in Developing Countries (STRiDE) initiative and trained community health workers to screen 2,400 people aged 60 and above. The workers were equipped with tablets to conduct the Cognitive Screening Instrument for Dementia (CSI-D) assessment, which included an informant interview, a word list recall task, and the Euro-Dementia scale.

A total of 3,521 older adults took part in the screening process, with 636 testing positive (18%) and subsequently referred to a hospital. Most participants approved, welcomed, and responded positively to the dementia screening. Most also found the duration of the testing suitable. Overall, there was an increased awareness among participants resulting in more referrals to hospitals and clinics.

Scotland

Brain Health Scotland; Alzheimer Scotland

The Scotland Flagship site has a strong partnership with the National Health Service (NHS) in Scotland. Brain Health Services are being created in partnership by Alzheimer Scotland and NHS colleagues as part of the Scottish Government's programme for brain health. The Scotland Flagship programme involved engagement with several NHS areas and was established across clinical settings (nurse-led assessment team, psychology and primary care) in one NHS board as well as at a new employer-led Brain Health Clinic at Scottish Rugby, which commissioned brain health services for its former elite athletes. Depending on the setting, the digital cognitive assessment was conducted by a nurse, healthcare support worker, psychologist, assistant psychologist, general practitioner, or healthcare assistant. The blood test was facilitated on a case-by-case basis between nurse and consultant psychiatrist as part of the assessment pathway.

Universal healthcare is provided by Scotland's public health service, NHS Scotland.

What are the key lessons learned from the site?

1. Gaining buy-in at the policy level

Recognising the importance of brain health, the Scottish Government provided funding and Brain Health Scotland was established in partnership with Alzheimer Scotland in 2020, prior to implementing the Early Detection Programme. This meant that the flagship programme was well aligned with the existing policy and movement and was able to gain buy-in from the government stakeholder, NHS Scotland.

2. Aligning on policy and sustainability of the Quality Improvement project

The Scotland site ran the DAC-SP Early Detection Program as a Quality Improvement (QI) project. As a QI project, they did not need research ethics approval to implement newer tools such as the Digital Cognitive Assessment (DCA) and blood-based biomarkers (BBMs). All necessary healthcare system approvals were gained. These tools were implemented in clinical practice in one NHS Board Area in Scotland with transferable learning to other NHS Areas in Scotland.

3. Co-designing the workflow

The site leads focused on a relational approach from the outset, working together with all the key stakeholders including the clinicians, the information governance team, local Alzheimer Scotland consultants and senior managers. The approach taken was to work with the early adopters who were invested in early detection, to co-design the programme workflow and spread within the system. This allowed the workflow to incorporate different perspectives and accommodate existing practices.

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Childhood dementia and the urgent need for policy inclusion

by The Childhood Dementia Initiative

Overview

Childhood dementia is devastating and particularly under-recognised. It's caused by 100+ neurodegenerative life-limiting genetic disorders.

An estimated 1 in every 2,900 babies born will develop childhood dementia. There are no cures or treatments and all children with dementia die prematurely, half before the age of 10 and most before reaching adulthood.

Before dying, children with dementia experience chronic, increasingly severe symptoms as well as progressive intellectual and physical disabilities. They live with growing levels of confusion, distress, unhappiness, and pain.

Including childhood dementia in national dementia policy frameworks is essential to improve outcomes for children with dementia. Policy inclusion for children with dementia is needed to meet this cohort's unique needs, improve support, increase research, and ensure that children can benefit from advancements for all people living with dementia.

Research funding, efficiency and equity are urgently needed. Despite the severity and impacts of childhood dementia, research to date has been fragmented and grossly underfunded. As a result, no notable improvements in survival for children with dementia have been achieved.

Ongoing research inequity is particularly evident when comparing global childhood dementia research activity to childhood diseases with far better survival rates. Large-scale research funding alongside an increase in collaborative research and shared infrastructure is required to accelerate the development of treatments and cures.

Families need access to tailored health care and support. Emerging research is revealing disability and health systems don't cater for children living with dementia and that families are experiencing significant psychosocial challenges. Greater awareness and education are required to improve early diagnosis and ongoing responsive care. Additionally, further research is urgently needed to understand and address families' care and support needs.

It's time for a new approach. The Framework for Childhood Dementia Systems Change outlined below gives policymakers, researchers, and health and social care professionals across the world a framework to improve the lives of children with dementia.

Childhood Dementia Initiative invites conversation with policymakers and decision makers on sustainable health solutions for childhood dementia.

What is childhood dementia?

Dementia is often associated with adults, however, an estimated 1 in every 2,900 babies born will develop childhood dementia[58].

Over 100 life-limiting , neuro-degenerative rare genetic conditions have so far been identified as causing childhood dementia[58]. They are particularly under-recognised and have attracted very little research. As a result, there are no cures or treatments. **Half of the children with dementia die by the age of 10 and 71% of children with dementia die before reaching their 18th birthdays[58]. All will die prematurely.**

Estimated in Australia every year

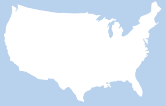
91 deaths in people with childhood dementia

92 deaths from childhood cancer (0-14 yrs)

Estimated in the UK every year

204 deaths in people with childhood dementia

260 deaths from childhood cancer (0-14 yrs)



Estimated in the USA every year

1,077 deaths in people with childhood dementia

1,050 deaths from childhood cancer (0-14 yrs)

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In countries where data is readily available, the significant impact of childhood dementia relative to other childhood diseases is clear. For instance, an estimated 91 people in Australia, 204 in the UK and 1,077 in the US died in 2021 due to childhood dementia respectively. For comparison, 92 children aged 0-14 years die annually in Australia from childhood cancer, 260 in the UK and 1,050 in the USA [58],

Not only are the lives of children with dementia short, but they are also extremely difficult [59, 60, 61, 62]. **Children live with chronic, increasingly severe symptoms as well as progressive intellectual and physical disabilities until they die prematurely**. Over months, years or even decades, as their young brains are damaged, children lose their cognitive and physical functions. They lose their speech, their ability to learn and concentrate, and their ability to move. They also live with growing levels of confusion, distress, unhappiness, and pain. The complex childhood dementia disorders can also cause seizures, loss of vision and hearing, and problems with bones, joints and cardiovascular, respiratory, or digestive systems.

Childhood dementia: it's time for a new approach

Compared to adult-onset dementia, childhood dementia has received little recognition. This is because each of the genetic conditions causing childhood dementia has been considered and viewed individually based on the underlying biological cause, rather than as a broader group with common presentation as the adult dementias are. This siloed approach resulted in a lack of appropriate care and support for children and their families, insufficient research and inadequate inclusion in health policies worldwide.

Collectively addressing childhood dementia gives greater visibility of this cohort's unique needs, and opportunities to improve support services and research.

Dementia policies must include children with dementia

National policy frameworks established to address the needs of people with dementia must be inclusive of all people with dementia and not exclude anyone based on age or any other attribute. Until recently, not a single national dementia policy anywhere in the world recognised childhood dementia. Additionally, where data is collected, this cohort is excluded from national data sets that monitor people with dementia.

With growing awareness and increasing calls for action, this is starting to change. Scotland referenced childhood dementia in its Dementia Strategy in 2023 [63] and Australia included children in its draft National Dementia Action Plan released in 2023[64], with a final plan due to be published in 2024.

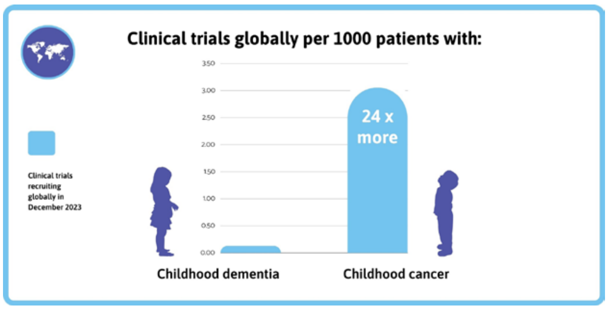
Opportunities for change

Including childhood dementia in national dementia policy frameworks is essential to improve outcomes for children with dementia. Policy inclusion will ensure that their health and wellbeing are prioritised and that children can benefit from advancements for all people living with dementia.

Research funding, efficiency and equity is urgently needed

Research is inadequate, fragmented and grossly under-funded. There has been no notable improvement in survival rates for childhood dementia. All children with dementia die prematurely, half by the age of 10[58].

This is unlike other severe conditions such as childhood cancer. Due to intensive medical research in recent decades, there have been impressive gains in childhood cancer survival. Most children were previously not expected to survive cancer. Today in high-income countries, more than 80% of children with cancer are cured[65].



A 2024 analysis of global research revealed significant inequity in research and activity into the development of treatments and cures for childhood dementia globally. The study found that, per person, there were over 20 times more clinical trials for childhood cancer than childhood dementia[66].

The analysis also revealed that clinical trial activity has slowed over the last 5 years despite the continued growth of activity overall and opportunities to enrol in clinical trials are lacking. Childhood Dementia Initiative identified that regulatory hurdles, lack of funding, a dearth of infrastructure and fragmented research are exacerbating this inequity.

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Opportunities for change

Large-scale funding is urgently needed for research that concurrently studies multiple childhood dementia disorders and develops new therapeutics. This will enable more clinical trials, and ultimately, accelerate the development of treatments and cures.

Collaboration and shared resources and infrastructure are required to accelerate the development of new treatments and cures. This is especially important for advanced therapeutics, which have enormous potential but are costly. Economies of scale can be created by sharing platform technology and infrastructure across disorders, giving children access to treatments that otherwise would have been too expensive to develop.

Quality care and support is inaccessible

Emerging research, including a review of global literature on the psychosocial impact of childhood dementia on children and families[59] reveals that childhood dementia is associated with significant carer stress and anxiety, and challenges accessing necessary support. Psychosocial challenges are numerous and encompass physical, economic, social, emotional, and psychological implications.

As the childhood dementia cohort has attracted little attention, disability and health systems don't cater for the unique needs of children living with dementia. Insufficient inclusion of childhood dementia has multiple outcomes including:

- Delays in diagnosis and misdiagnosis[60, 59, 67]. This results in insufficient or inappropriate care, children missing out on the chance to be included in clinical trials (the only chance of survival for them and future generations), and families having multiple children without understanding their genetic risk.
- A lack of care pathways leaving families to figure out what care and support their children need and how to access those services [59, 67].
- Lack of awareness, knowledge, and expertise of childhood dementia across systems of health, dementia, and disability.
- Lack of standardised, consistent processes including diagnosis pathways, clinical care guidelines, care pathways, and models of care.
- Lack of infrastructure such as registries, information resources, clinical trial networks, care coordination, and multidisciplinary care teams.
- Lack of access to emerging therapies and clinical trials.

Like adults with dementia, children experience behavioural and psychological changes and challenges such as anxiety, hyperactivity, hallucinations, aggression, as well as sleep disorders so severe that some children are unable to sleep for extended periods. In the absence of dedicated dementia support for children, behavioural and personality changes can contribute to their exclusion from education and paediatric health services, including palliative care. These symptoms also place immense pressure on families caring for children with dementia [60, 59, 67].

It is important to note that there is little to no data on family experiences with disability, health and education support in lower income countries or the specific experiences of First Nations or Culturally and Linguistically Diverse families. There is significant risk that the level of care children receive is dependent upon their families' resources and ability to advocate for support.

Opportunities for change

- **Broad awareness and education resources are required across health and disability settings to support early diagnosis and ongoing responsive care.** Those working with children with dementia need a deep understanding of family needs, emerging research and changing policy and practice. Workforce education must be embedded in systems and structures ensuring ongoing sustainable change.
- **Access to early diagnosis through newborn screening and rapid diagnosis pathways is needed to improve the development and access to emerging therapies as well as optimal care and support.** Earlier diagnosis also informs future reproductive and other planning decisions for families that have a child diagnosed with dementia.
- **Further research into the psychosocial impacts on families and their experiences of health and social care systems is urgently needed** to address families' care and support needs. Outcomes of this research will inform the development of frameworks for care that will guide improvements in systems and services to better meet needs.

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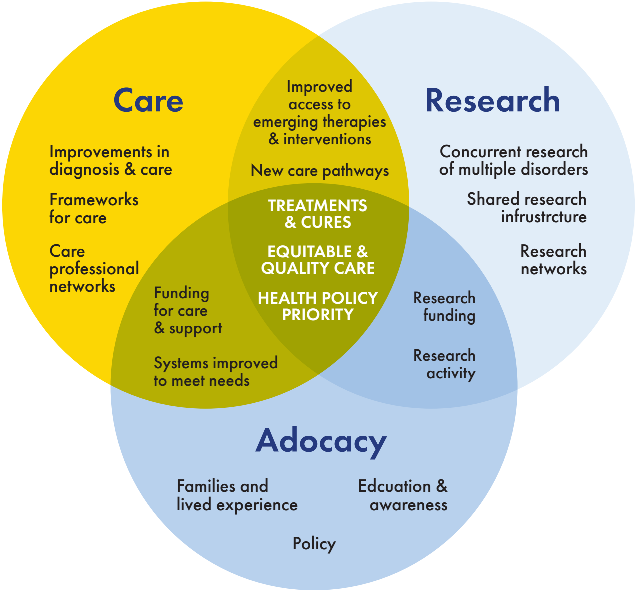
Framework for childhood dementia systems change

The evidence-informed framework for change for childhood dementia outlined here was developed by Childhood Dementia Initiative. It incorporates care, research and advocacy. The intersection between each of these areas is critical to achieving the outcomes needed:

- Treatments and cures for childhood dementia
- Equitable and quality care for people with childhood dementia
- Recognising childhood dementia as a health policy priority



The interdependent nature of the three areas is key to the model. For instance, increased funding and activity in the research space are necessary for the development of treatments and cures. However, awareness, policy change and the inclusion of families' perspectives and needs are also critical to enabling research.

The Framework for Childhood Dementia Systems Change is underpinned by the key principles of evidence, people, and co-design. To drive system change, the body of comprehensive evidence must first be developed and validated by three key sources: the lived experience of the families of children with dementia; experts working in the field; and empirical data. Evidence required to drive system change for childhood dementia ranges from psychosocial impacts, epidemiological and health system data, research benchmarks, current system issues and opportunities, policy frameworks and funding.

Systems primarily consist of people, so gathering the right organisations and stakeholders to co-design, implement and embed sustainable solutions is critical. The networks required to drive system change for childhood dementia are diverse and evolving. It includes, but is not limited to, families, researchers and research institutions, health and social care service providers, dementia specialists, policymakers and funders.

Childhood Dementia Initiative

Childhood Dementia Initiative is the for-purpose organisation transforming research, care and policy responses for all children with dementia. The organisation leads a paradigm shift by driving solutions for all conditions that cause childhood dementia as a collective. This new approach compels awareness and allows for greater efficiencies, scale and impact.

Childhood Dementia Initiative's leadership, Board, and advisory committees represent both lived experience and extensive professional experience across rare, chronic and terminal disease. Cross-disciplinary experts from research, healthcare, social services and policy are engaged to drive change through strategic collaboration and the organisation is guided by the voices of families who have children with dementia.

Childhood Dementia Initiative invites conversation with policymakers and decision makers on sustainable health solutions for childhood dementia.

Appendix One

Young people and dementia

By Rianna Patterson

Introduction

This report highlights the views and involvement of young people with regards to dementia, providing examples from across the Commonwealth. It draws on experiences from members of CommonAge's Youth Chapter.

Survey results

An online survey was sent out to young people via known networks and members of the CommonAge Youth Chapter, there were 17 responses across several Commonwealth countries. The results revealed the most crucial area that needs to be addressed is making dementia a priority in their respective countries. While information systems for dementia were considered to be the least important area. Dementia awareness and diagnosis, treatment, care, and support were ranked as the second most important area.

A key recommendation from one participant was that governments should provide cost-free screening for older people, to enhance the rate of diagnosis for individuals affected by dementia:

"The most important issue at hand right now is the implementation of the National Dementia Plan. Emphasis ought to be placed on free health screenings for these individuals as well as others to properly diagnose. This is extremely important as one believes dementia is on the rise and we are not taking it as seriously as we ought."

Most young people (n=6) from our study were not aware of whether their country had an active national plan on dementia. The respondents were asked what issue they would address if they were to meet their local government regarding people living with dementia. Most individuals mentioned the need for more awareness efforts and programmes for older people.

Three respondents from the Caribbean (Dominica, Bahamas and Trinidad & Tobago) emphasised the need for developing a national plan on dementia and government engagement. Social Entrepreneurs and carers for older people with dementia, seek government support to navigate operational challenges and develop national programmes that raise the profile of dementia in their communities in the Asia and Caribbean region. A key barrier to young people engaging in policy advocacy involves the cultural attitudes towards younger professionals. It was also expressed that competing agendas from a governmental level makes it challenging for other causes to be seen as a priority.

In summary, the survey highlighted that young people want local governments to work towards creating a welcoming environment that respects young people's views and encourages their engagement in discussion on key issues including dementia. It also highlighted that participants believe that a national plan on dementia would support the key challenges and barriers of dementia care such as delayed diagnosis and support for carers across Commonwealth countries.

Social entrepreneurs

This section highlights the activities of young people in their communities seeking to tackle challenges related to dementia. Several youth-led organisations have impacted more than 30 older people in their communities.

United Kingdom

Charlie Blair, the founder of The Blair Academy, shared her experience of caring for her grandmothers and how it led her to start a business where she could support people, in her way. The Blair Academy has a team of fourteen young people who lead hip-hop dance classes for older people living with dementia, and they also have six young people who help lead an intergenerational social club. Charlie and her team have been actively involved in shaping local policies by working with Age UK, local politicians, and the local authority. In addition, they have been campaigning for national policies to help improve the lives of older people.

Lizzie is the founder of Women in Neuroscience UK (WiNUK), WiNUK is a youth-led volunteer organisation of 40 with aims to 'connect, inspire and advocate for female-identifying neuroscientists' through events, blogs and social media in the UK and beyond. Women in Neuroscience UK also aims to advocate for individual-led improvements to inclusivity in dementia research culture. Lizzie's grandmother died from Alzheimer's disease, as well as her other grandmother from the disease. Lizzie recognises dementia as one of the biggest health and care challenges faced in the UK.

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Africa

Comfort Mwanza, the founder of Youth Changing the Mindset (YCMO) organisation in Zambia, decided to dedicate himself to the field of work dealing with dementia due to personal experiences of witnessing the impact of the disease on loved ones. He developed a genuine passion for improving the lives of those affected. They are also engaging in conversations with policy makers and local leaders.

Roberta Adutwumwaah Ntem is the founder of the Good Old Age Golden Foundation. She was inspired to launch this charity to learn more about dementia in Ghana. The Good Old Age Golden Foundation aims to raise awareness about ageism and elder abuse. The voluntary organisation also promotes intergenerational contact between younger and older people. Currently, there are 37 young people involved in this organisation.

Asia

Rahat Hossain was motivated to co-found AYAT Care while working in the home healthcare services industry in Bangladesh. He recognised a significant need for support and care in the country, particularly for those living with dementia. AYAT Care aims to develop young carers to provide care to dementia patients and raise awareness regarding dementia at home. To date, they have provided services to more than 50 people, and his work has empowered 60 young people to support people living with dementia in Bangladesh.

Caribbean

Rianna Patterson's grandfather passed away with dementia in the Commonwealth of Dominica, she would spend her time at the hospital with her grandfather. This experience drove her to become the founder of a youth-led dementia charity called the Dominica Dementia Foundation at the age of 18. The Dominica Dementia Foundation aims to raise awareness of dementia, raise funds for families affected, provide emotional support to families and caretakers as well as facilitate research towards dementia. Their most recent work involves providing bursaries to care providers and residential homes so carers can undertake caregiving training. The team is currently working with the Ministry of Health to solidify a national plan for dementia in Dominica.

Darren Leblanc, is also from the Commonwealth of Dominica, is the founder of Golden Saints Foundation, formally known as H.T.S.E (Helping the Schools and Elderly) at the age of 21. HTSE is a non-profit organisation based in Penville, Dominica. They have organised meet and greet events, where members would visit care homes to have a conversation with residents about their past lives. They have also delivered care packages to older people in the community.

Angela Symonette is a member of the Bahamas Alzheimer's Association. She organised an event on 'moments of the past' where it provided a nostalgic experience for the older people living with dementia, revisiting pleasurable memories. She also founded a small healthcare organisation called United Healthcare Innovators, that consisted mostly of college, nursing and medical students. She has had the opportunity of educating younger people around her by sharing resources on hospice care and mental health.

Conclusion

According to this report, young individuals are eager to collaborate with their local government to create a national plan. They are also actively involved and passionate about working with people living with dementia in their community from Hip Hop Classes in the United Kingdom to carer training in Bangladesh. Furthermore, there are numerous young individuals who are pursuing mastery and PhD degrees in dementia across the Commonwealth countries. For instance, Lizzie English is currently pursuing a PhD in dementia at the University of Cambridge.

Although there is still a lot of work to be done, young individuals have already taken the initiative to enhance the quality of care for people living with dementia.

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Nutrition

By Ngaire Hobbins APD,
Author: Brain Body Food – the ultimate guide to thriving into later life and reducing dementia risk.

It is vital that everyone addressing the needs of people living with dementia; whether they be policy makers, carers, or governments; understands that nutrition needs and eating preferences can be quite different following a dementia diagnosis to what they may have been before that.

The influence of certain dietary patterns and specific nutrients in either increasing or decreasing the risk is driving research across the world. It is prudent of course that policy makers, as much as individuals, pay heed to the wealth of research which seeks to reduce the incidence, prevalence, and potential impact of dementia on families, societies and countries. But, for the millions of people already living with or caring for someone with a dementia diagnosis, awareness of the challenges dementia can pose in achieving adequate nutrition and of the altered nutritional priorities unique to people living with dementia is essential.

Following diagnosis, people can continue to live independently with dementia for many years. This not only enhances quality of life for individuals and their families but reduces the impact on health and care systems. It is therefore imperative that there is strong awareness of how best to support people living with a dementia diagnosis.

Risk reduction

This section outlines some considerations in reducing an individual's risk of developing dementia:

- **Cardiac risk factors:** In everyday terms, anything that is known to increase the risk of cardiac disease, also increases the risk of dementia. Obesity, hypertension and elevated cholesterol in early and mid-life are associated with an increased incidence of dementia in later age. Managing these by dietary intervention and medication as appropriate is also crucial in reducing the risk of cognitive decline.
- **Weight loss – early and middle age vs later age:** Obesity in early life and middle age is associated with a greater risk of developing dementia later in life so efforts to lose excess body weight in these years are central to risk reduction strategies. However, it is also important to note that once individuals reach later age the situation is not as clear cut. In later adult years, unless weight loss is accompanied by significant, intentional resistance exercise, dieting to lose weight, or experiencing unintentional weight loss results in loss of lean body mass (largely body muscle). This is undesirable because body muscle forms a protein reserve for many other body functions including the immune response, tissue repair and cell maintenance, so weight loss (and thus muscle loss) can not only reduce physical strength and capacity but can also precipitate ill health and ongoing frailty. People living with dementia are more likely to experience weight loss than other older people so a focus on weight maintenance rather than weight loss in later years is vital.
- **Physical activity:** Regular exercise is powerful both in prevention of dementia and in maintaining health and quality of life when living with dementia, no matter an individual's age. Physical activity helps maintain elasticity in blood vessels, improving blood flow through the brain to deliver nutrients and remove potentially toxic substances efficiently and is also known to helping reduce chronic inflammation which is considered to contribute to the cell damage and the accumulation of substances within the brain associated with living dementia.
- **Maintaining lean body mass (muscle):** While this is mentioned above, the central importance of muscle warrants additional discussion.
    - **Physical Function:** Maintaining muscle strength and function minimises the impact of issues common in dementia including difficulties in walking, standing and carrying out the basic skills of daily living including dressing and maintaining personal hygiene.
    - **Fall Prevention:** Individuals with dementia have a high falls risk and this is exacerbated by loss of body muscle.
    - **Joint Support:** Muscles provide support to the joints, helping to alleviate strain on the joints, particularly in weight-bearing areas such as the hips, knees, and spine. This support is essential for preserving mobility and reducing the impact of conditions like arthritis.

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- **Heart and Lung Function:** Muscle health is closely linked to cardiovascular fitness and respiratory function, with regular physical activity enhancing circulation, oxygen delivery, and overall cardiovascular and cognitive health.
- **Swallowing and Eating:** Muscle strength in the throat and mouth is essential for effective swallowing and eating. Individuals with dementia may experience difficulties with swallowing, known as dysphagia, which can lead to choking, aspiration, and malnutrition. Maintaining muscle tone and coordination in the oral and pharyngeal muscles is crucial for safe and efficient swallowing in individuals with dementia.
- **Insulin Sensitivity:** Muscle tissue plays a key role in insulin sensitivity and glucose metabolism. Maintaining muscle mass and function can help regulate blood sugar levels and reduce the risk of insulin resistance and diabetes in individuals with (and without) dementia.
- **Independence and Quality of Life:** Preserving muscle strength and function enables individuals to perform daily tasks, engage in social activities, and participate in recreational pursuits, enhancing autonomy, confidence, and overall well-being.
- **Cognitive Benefits:** Physical activity and muscle-strengthening exercise has been found to stimulate neuroplasticity and therefore enhance cognitive resilience and function.

Optimising diet for brain health

The relationship between food and dementia risk reduction is complex and multifaceted. While there is no single food or nutrient that can guarantee the prevention of dementia, a balanced and nutritious diet can certainly contribute to overall brain health and potentially reduce the risk of cognitive decline. Simplified messaging offering 3 main factors in food selection is useful:

Food to minimise damage to brain cells:

- All cellular activities create oxidative waste products which, if allowed to accumulate can be harmful to brain cells. Antioxidant substances in foods reduce the impact of oxidative waste and thus foods containing these are central to brain cell protection. There are hundreds of different types of antioxidants, and they also provide foods with their natural colours. It can be tempting to rely on promoting one or two foods with high antioxidant content to help reduce dementia risk, but it is better to encourage the intake of as wide a variety of different foods each day, of many varying colours as possible, ensuring a wide variety of antioxidants are made available to the body and brain.
- In addition, the same foods rich in antioxidants – fruits, vegetables, herbs, nuts and seeds - also help reduce the impacts of chronic inflammation.
- Omega-3 fatty acids, which are concentrated in oily fish, like salmon, mackerel, and sardines, in nuts and seeds and in oils. These play a crucial role in maintaining the structure and function of brain cells and in the efficient supply of fuel to brain cells.

The negative impact of ultra-processed foods:

- Research evidence is mounting that the processing of foods can have negative health consequences and higher intakes of ultra-processed foods have been associated with cognitive decline and an increased risk of dementia. The reasons are not yet entirely clear, but the messaging is consistent: mostly eat foods that have been minimally changed from their original state to reduce dementia risk. Ultra-processed foods generally contain ingredients that are rarely or never used in home kitchens and usually have long lists of ingredients that might include any or all of flavour enhancers, emulsifiers, bulking agents, colours and sweeteners. Some of these foods are also high in sugars and excessive consumption of these compared to minimally processed foods can contribute to chronic inflammation as well as cognitive ill health.

Stay hydrated

- Proper hydration is essential for brain function. Even mild dehydration can impair cognitive performance, memory, and attention. Older adults may be at a higher risk of dehydration due to decreased thirst sensation, and people with dementia might fail to recognise or act on thirst signals effectively. For individuals living with dementia and especially those who have lost weight or are at risk of weight loss, nourishing fluids such as milk drinks, soups or fruit juices, provide nutrients as well as fluids.

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Addressing food and eating challenges

For people living with dementia, food choices and eating habits can be impacted by various cognitive, physical, and emotional factors. Short-term memory loss, altered sense of taste and smell, a dysregulated appetite and impaired executive functioning, judgement and decision making, can significantly impact food intake and create unintentional weight loss.

Inadequate nutritional intake and weight loss accelerate the loss of capacity and ability to maintain independence for people living with dementia, so it is vital that policies are developed, and carers understand how best to assist individuals to eat as well as possible.

- **Assistance with access to and preparation of meals**: Individuals living with dementia may struggle with tasks like grocery shopping, reading labels, remembering what items to collect or buy, getting groceries home and meal preparation. Development of strategies to assist in all these tasks is helpful. In the earlier stages of dementia this should focus on side-by-side assistance to facilitate independence as long as possible.
- **Dysregulated appetite and thirst cues:** While some individuals living with dementia may lose awareness of hunger or thirst cues, others may have unchanged sensations of hunger or thirst but be unable to express their need for food or drink effectively. Carers should encourage intake at usual mealtimes and make a variety of food and drinks available. Encouragement and social interaction at mealtimes can be helpful, while monitoring food and fluid intake to ensure adequate nutrition and hydration will often be required, especially where there has been weight loss.

  Occasionally, dysregulated appetite may cause excessive food intake causing weight gain. While this is best minimised, the reality is that most individuals with dementia will ultimately lose weight as the dementia progresses, so active measures to encourage weight loss in such a circumstance are not warranted.
- **Support with eating skills:** As dementia progresses, individuals may experience difficulties using utensils, chewing, or swallowing. This can result in frustration, slow eating, partial meal intake, avoidance of certain foods that require more effort to consume and potentially dysphagia and choking. It is important to provide aids to assist with eating or foods which can more easily be eaten with fingers or simplified cutlery.

  Where there are issues with swallowing food the input of a qualified speech pathologist (speak and language therapist) is essential. Modification of the texture of foods and drinks can be helpful where some foods or liquids are not able to be swallowed safely. However this should be with the guidance of an appropriate healthcare professional
- **Behavioural changes:** People living with dementia can experience changes in behaviour such as agitation, aggression or wandering. Carers may need to implement strategies to manage these behaviours during mealtimes. Foods that can be eaten 'on the go' can be helpful, as can using a family meal set up which can tap into old memories of mealtimes and encourage participation.
- **Safety concerns:** Dementia can increase the risk of accidents in the kitchen, such as forgetting to turn off the stove or using kitchen appliances unsafely. Assistance with meal preparation (which may progress to covert supervision) allows for an individual's continued involvement in cooking and food preparation as long as possible.
- **Emotional factors:** Dementia can cause emotional changes such as apathy, depression, or anxiety, which can impact appetite and eating habits. Emotional distress may lead to changes in food preferences, comfort eating, or loss of interest in food. Medical management of depression may improve food intake while efforts to reduce social isolation can be extremely helpful.
- **Focus on recognisable, familiar foods and drinks:** Food preferences in people living with dementia often reflect long term food memories. In addition, some familiar foods may not be recognised, or desired options are not able to be described adequately to carers. It is vitally important that people providing food and drinks to people living with dementia understand their food preferences, including their traditional or cultural origins. When food is prepared, it is also important that dishes look like what is expected of the recalled dish. It may not always be possible to recreate traditional dishes, but every attempt should be made to make dishes as memorable as possible.

  If modification of texture of foods is required, clear description of the food being offered is important and where possible, arrangement of foods to make them look as much like the original as possible can greatly assist intake.network.

In conclusion there are a variety of ways that nutrition is an essential consideration for both risk reduction and for people living with dementia and their family/social network.

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Design and dementia

By Dr Tom Morris and Marie Alford,
The Dementia Centre, HammondCare

The well-worn pathways of the hallway in your home. The heart of your family and a place where your friends gather. The place you feel safe. One day, you wake in an unfamiliar home. With other people. And other belongings. You no longer feel safe. You are confused and alone. Which way to go when you leave this unfamiliar room? How to get outside to the garden where you enjoyed a daily cup of tea? This is aged care. This is the experience of many people that we support. We can do better.

It's been almost 30 years since the work of Stephen Judd, Mary Marshall and Peter Phippen in their book ***Design for Dementia*** (1998) which, back then, for the first-time showcased dementia design principles across the world in practice [68]. Yet here we are still struggling to implement core elements into our day-to-day environments that create enabling (not disabling) places for people living with dementia to live. What we know is, when we get it right – the outcomes for people living with dementia create a quality of life we all want, and we all deserve.

In Australia since July 2024, the Department of Health and Aged Care has made a part of the landscape the Design Principles and Guidelines that will focus on creating more accessible, dementia-friendly and home-like living environments. But this is almost 30 years after the first evidence-based research landed based on international knowledge and perspectives. We welcome this change and challenge but how far does this go, what does this mean and internationally what do we need to do to meet the current needs of people living with dementia and those that care for them?

Notwithstanding the amount of time since the original design principles and features were launched, good dementia design remains just good design. Because, in an ideal world, we all age and we should live in a society that supports us as we age, regardless of disease or disability. And there are simple things we can do to support and maintain wellbeing for people living with dementia. From living at home, to supported living and residential aged care.

A person living with dementia, regardless of age, can experience changes due to the disease process. These can include impacts to vision, hearing, mobility, and balance. Add these to the range of challenges associated with dementia such as memory loss, poor concentration, difficulty learning new information, changes in personality and mood and you get to understand why it is so important to focus on design and environment that enables people with dementia to live well. Dementia Support Australia, An Australian Government funded program led by HammondCare that supports people living with dementia where behaviour impacts their care, lists environmental impacts as a significant contributing factor to changed behaviours that can be mitigated or modified with alignment to the dementia design principles.

When design goes wrong for a person living without dementia, we become frustrated. Think about the airport with poor navigational signage or the hotel with patterned carpet that makes us feel discombobulated. Add a diagnosis of dementia and bad design quickly becomes confusing, dangerous, stressful, degrading and may lead to unintentional restraining. Prof. Mary Marshall in developing the first International Dementia Design Schools said, *"Dementia as a disability is characterised by an acute sensitivity to the built and social environment"*. Confidence and self-worth which is key in maintaining personhood is impacted and yet we still don't always consider the small changes that can get us closer to better in terms of enabling dementia design.

Dementia design features and principles work hand in hand with models of care that empower the use of their environments. All can be interpreted in ways that suit local, regional, cultural, national and international environments, an important consideration when we not only look to build new environments but work to retrofit existing environments to be more enabling.

The interpretation of environments that are *domestic and familiar* speaks to the feeling of hearth and home. For each of us this will have a different meaning depending on where we live in the world, and what brings us comfort – that *feeling* of home that is familiar. It is the creation of spaces that consider scale – from dining rooms to bedrooms to living areas. Taps and door handles that are reminiscent of an era that we are more familiar with, not the most modern, architecturally designed. Familiar items in public spaces such as living areas or private spaces will help people with dementia identify purpose and in doing this, we can promote independence, enhance self-esteem and confidence. In the HammondCare's Dementia Centre, we ask ourselves in our Dementia Design Schools, would you find that in your house? This speaks to the challenge of unfamiliar equipment that slips into care environments –

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lifters, and linen trolleys and even fire extinguishers. These are not things you and I face in our home environments and yet we expect people living with dementia to navigate their presence and purpose.

There is significant research that speaks to the *size and scale* of the home and how this helps to create more supportive environments [69]. Where there are fewer people living in a space then it is more likely that that space will feel homelike. It is unlikely any of us would choose communal, open plan living - smaller spaces offer dignity, control and increased wellbeing for those who live there. However, it is possible to create and curate these spaces within large environments with clever placements of household furniture and rethinking spaces. It is important not to forget that s cale also includes the smaller details, such as light switches which should be familiar and not institutional style banks of switches that confuse the user and add to the stressors within the environment.

Of course, while supporting a dignity of risk and choice, our environments need to be safe places for those who live there as well as those who work in them. *Unobtrusive safety measures* should be passive, sitting in the background doing their job, while those that live in the environment continue to enjoy their day to day lives. What is important here is how we understand different risks and manage them wisely and discreetly. So much focus in care settings remains on eliminating risk. This has the unintended consequence of diminishing personhood and wellbeing for those who live there.

An example of this is making areas safe and secure by blending exit points that are not for resident use into the background. At HammondCare we call these features "Harry Potter" doors – a little like the train station they cannot be seen unless you know and need to use them. This comes with a requirement for staff training but is an effective mechanism, ensuring domestic and familiar environments by keeping back of house areas that store equipment and staff rooms well hidden.

It is also important that fencing, door locks, safety switches and monitoring technology should provide a person with privacy, dignity and freedom and not impinge on their rights as a human being. There has been a lot of debate around the use of murals to disguise exit, entry points and other features and while there are good examples of the positive use of murals, Prof Mary Marshall in her book *Talking Murals* (2019) promotes the ethical and practical use of murals within care home spaces. It is important that they do not add to distress, confusion, or disorientation (i.e. staff members appearing through a seascape mural concealing an exit point) [70].

Agnes Houston, who lives with dementia, in her book *Talking Senses* (2018) highlights the negative impact of overstimulation through unwanted stimuli on wellbeing and quality of life [71]. Not only is it distressing, frightening and/or distracting but the act of working through these unwanted messages can be exhausting. *Reducing unwanted stimuli* caused by noise, staff, and visitor movement through our care settings by creating spaces that are clear, simple and intuitive enables people with dementia to focus more on what they want to do. Removing institutional visual clutter, thinking about reflection (including acoustics) and light, carpet, soft furnishings all reduce the noise in open spaces.

Within our environments, just like we would want in our homes, we need spaces to do the things that "spark joy". This will be different for everyone, so the challenge in communal living is to provide spaces and opportunities for this to occur. For some, it may be group activities but others the ability to connect with their interests individually will be key to their day-to-day wellbeing. This cannot be achieved without knowing the person – more than just their favourite things, but what brings them purpose. It is our purposeful activity that promotes our independence, yet we may be complicit in removing this from people living with dementia in our role to be 'helpful'. For *ordinary activities* to occur, we need to create spaces that are familiar and consider destinations such as small-scale supermarkets within our care settings, hairdresser and barber shops – even include domestic washing machines and clotheslines (or driers in colder climates) for day-to-day clothes washing to enable those that live there to participate in these activities should they choose to. But perhaps of most importance is the kitchen. With access to fresh food, the ability to see and smell the food being prepared and be part of the process if you choose to. Or to be served. But to feel included and purposeful.

It is important to have *different spaces for different uses.* Long gone (we hope) are the institutional settings of beds in wards and one large space for all things dining and entertainment. Rooms and spaces should be instantly recognisable so that those who live there know what is going to happen when they enter. Environments should be consistent – a lounge should stay a lounge, and a dining room a dining room. Changing purpose adds to the mixed messages and confusion. Being able to find your way around and get to where you go is crucial to any of us to help us feel in control.

People living with dementia must feel confident as they move around their home and not overwhelmed with choices or exhausted by distances. This includes *multiple consistent cues*

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to orientate ourselves. Our spaces should support *wayfinding and walking* so short corridors and clear, meaningful destinations give people the best chance of finding their way. More importantly, this level of design means less reliance on signage or memory. We use landmarks in our own homes to navigate our spaces and by using familiar and interesting things to mark the way support wayfinding in our care home spaces. There may be an opportunity here to positively use murals – however these should be weighed against the impacts for the communal group living in the space.

Regardless of where you live in the world, outdoor spaces are important to us all. They can provide essential access to sunshine, an awareness of the changing seasons and weather patterns and opportunities to do meaningful things. *Outdoor spaces* can be thought of as 'another room'. Research has demonstrated that simple exercise increases our appetite, muscle and bone strength and raises mood, including exposing our skin to sunlight for Vitamin D and reduces depression[72]. The ability to engage in familiar and again, purposeful activities in outdoor spaces – be it simply the act of walking along 'no fail' pathways, bird watching, sweeping, or participating in raised garden bed activities can provide enjoyment, fulfilment, and increased quality of life. Passive or active activity – the ability to have *easy access to outdoor spaces* is vital.

Finally, within our care environments we must provide both *scope for personalisation* and *community connection*. Very few people **choose** to go into an aged care setting, and we often hear people who live there plead to 'go home'. This speaks to our home as a place where we feel safe, where our belongings and familiar items are. Even if a care setting is welcoming and engaging it isn't **their** home. Personalised environments reinforce a sense of self and for those who provide care can provide critical insights into a person's life history and what is important to them. There are opportunities for these items to move beyond the bedroom into more communal spaces – such as a piano or a favourite painting or icon. Internationally we have seen creative examples of memory boxes outside resident rooms which act as a familiar landmark for orientation and conversation starters for care staff. Where possible, encourage people to bring familiar furnishings – a favourite chair or dresser, their own lamp or rugs and bedspreads. Look beyond what we see as 'clutter' and think about what you need in your spaces. Within this, maintaining friendships and links outside the care home needs to be supported.

When family and friends visit, they should feel comfortable in the space as well but for the person living with dementia the ability to continue to engage in community living is just as important. This may be in the inclusion of a café or playground on site creating welcoming places that family and friends will want to visit and where the person with dementia can connect outside of the care home. Most importantly though, the appearance of a care home should look as much as it can like a regular house or apartment within the local community it is situated in. Building signage should be discreet which maintains dignity and reinforces the message to staff, visiting contractors and others that this place is somebody's home, not a workplace.

Dementia design is just good design. These design features can work in family homes, they can be integrated into community spaces, acute care, and of course aged and supported care living. Like we did with ensuring disability accessibility decades ago we need to create and curate spaces that are both age and dementia friendly. That maximise independence, not only for the person living with dementia but their families and those that care for them as well. We can design truly enabling environments but unless we empower our care staff to use them appropriately, the outcomes will be less than ideal. Bringing these two elements together will deliver better care and better quality of life for people living with dementia regardless of where they live.

Stephen Judd said in *Design for Dementia* [68] of the 8 case studies from across the world in this book, *"they are separated by distance, by language, by culture, by climate, and by laws. They are different, with distinctive features. And yet their smallness and sensitivity to scale; their focus upon familiarity, as culturally appropriate homes with which the residents can personally identify; their legibility being understandable and orientating; their promotion of self-esteem, autonomy and individuality; and their appreciation of safety, within an environment of manageable risk demonstrate the providing the best physical environment for people with dementia is not a question of money or luck, but of good, thoughtful client-concerned design"*. Almost 30 years later, we should all aspire to this and beyond.

Appendix One

Spirituality, relationships and dementia

By Professor John Swinton and the Health Television Network

Spirituality is a term that holds various meanings for different people. For some, it is closely tied to religion and a connection with God. For others, it is about answering life's big questions: Who am I? Where do I come from? Where am I going, and why? In our capitalist culture that prizes work, productivity, and competitiveness, certain life experiences, such as retirement, can trigger spiritual crises as people struggle to redefine their identity and purpose. What does it mean to go to sleep as a banker, a carpenter or a plumber, and to wake up the next morning with none of these identities? You work all your life with a particular identity, and then you come to that point of retirement, and it's all gone. You wake up the next day and you're not what you've been for the past 40 years, Dementia can create a significant spiritual crisis.

Relationships matter

Spirituality in its broadest sense impacts all our lives. In essence spirituality is a relational concept that has to do with the ways in which we relate to ourselves, others, the world around us and with God. Relationships matter to human beings. To suggest this is quite counter cultural. For those of us who live in the West, we are taught that we are individuals. We're taught that regarding relationships, you can take or leave them because you are an individual, free, autonomous and independent agent. However, as we will see as we move along, we only appear to be individuals. We are in fact deeply interconnected beings who need one another for pretty much everything. There is more to be said, but for now it is vital to notice that this relational dimension to human beings does not change when we encounter dementia. *Dementia may change relationships, but it doesn't end them.* It's very important to hold that in mind, because culturally, some of us think if you have dementia, you don't want to, or can't relate anymore, because you're not the person you were before. We want to say that this is far from the truth. People *always* want to and need to relate.

Dementia changes relationships, it doesn't end them.

We are imitators

One of the aspects of relationships, we sometimes don't give enough thought to, relates to the fact that as humans, we are imitators. We're constantly mirroring and copying one another. It is fair to say that we find and discover who we are as we imitate one another. This becomes important when we think about human relationships and relates closely to our spirituality.

The still face experiment

There's a lovely little clip-on YouTube of a psychological experiment called the Still Face Experiment.

In it we see a baby having a fantastic time with its mother. Its mother is mirroring her expressions, and she is mirroring them back. They're having a whale of a time. Then the mother turns away. When she turns back, she stops moving her face and stops responding to the baby. The child continues to use all its tricks to get her to smile and react, but the mothers face remains still. The child gets gradually more upset as her attempts at getting a response fail. Eventually the mother begins to move her face and she consoles the baby. What we need to notice here is not only how much we need the presence of others, but also that we need *active* presence, that is, a form of presence that we can engage in, in such a way that we feel that we are noticed, loved and welcomed. Physical presence on its own is not enough. We need relationships that offer us a certain form of engagement. It is quite possible for someone to be with another person and to be absent from them at the same time.

In 2019, I was in Australia for a year. It was just before the pandemic. One of the tasks I had in the research work I was doing was to explore the issue of carer presence. People had been noticing that there was a tendency in age care for carers to be absent from the people they were caring for.

They were physically present, but emotionally absent. For example, carers would be with someone, but also on their phone, or they'd be talking across the person as if they weren't there. Carers would be in the room, but not actually engaging with the individual. When that happens, bad practice comes into play. You don't notice it because being with people in a non-responsive way just becomes the norm. When you have such a culture of absence, the possibility for abuse and harmful behaviour becomes very real. The still face experiment shows what happens when you are not with someone in a responsive way.

Appendix One

Dementia and the need for responsive care

Dr Maggie Ellis, a senior lecturer in the School of Psychology and Neuroscience at the University of St Andrews, Scotland, has done some fascinating work on responsiveness and dementia. Dr Ellis took the idea that human beings are from birth, responsive and relational and began to explore how this relates to people with advanced dementia. Her work showed very clearly that if you can find the right type of communication, and create the right form of relational space, the kind of facial recognition that emerges from the still face experiment applies also to begin with people with advanced dementia. Her research once again indicates that intimacy and the desire for responsive relationships is innate to humans and is not changed by dementia.

Mirror neurones

We can begin to get an inclination of why this might be the case by looking at human neurology. Human beings have a cluster of neurons, which are called mirror neurons. Mirror neurons fire when we see another person's expression or see somebody else's emotions. If I look at you and you smile at me, then I'll mirror that smile because my mirror neurons fire in response to your smile. If you frown at me, I'll frown because my mirror neurons fire and I'll mirror your frown. This is important. Think about this in the context of a care situation. If we're not really engaged with somebody and not aware that our facial expressions are firing the mirror neurons of the person in front of you, we will be missing out on a vital dimension of relational care. Our faces are really important.

This idea of responsive relationality relates to spirituality in important ways. Dr. David Hay worked with me at the Centre for Spirituality, Health, and Disability at the University of Aberdeen in Scotland. David was a zoologist. His basic hypothesis was that human beings are not only hardwired for responsive relationships, they are also hardwired for spirituality. The way he chose to test this was by looking at the spirituality of children, if we are hard wired for spirituality, then it is in the lives of children, before they have been exposed to the secularising forces of society, that we might expect to see this.

In his book *The Spirit of the Child* Dr Hay layers out the results of a beautiful piece of qualitative research, within which he spent months with children trying to see whether or not there was a natural spiritual impulse in these youngsters. What he discovered was that children have a natural sense of awe and wonder and a sense of reaching out beyond themselves, a natural sense of desiring to connect.

Relational consciousness

He names this natural impulse to reach out and connect with others, the world and God, *relational consciousness.* This part of our consciousness is always searching for and searching out relationships. It is however quite possible to quash this natural desire, we saw how this might work at a relational level in the still face experience. But there is another dimension. Hay noticed in his research that the way in which children are educated can tend to squash down their relational consciousness. They go into the school system, and they are taught that certain kinds of facts are important, and certain kinds of facts are not important. Mathematics, science, scientific facts are important. Things like ethics and morality and relationships are important, but not as important. They are taught to be individuals.

And so that natural relational consciousness gets suppressed as children are taught to be a rational individual. This can become a real problem for them in their teens when they are wrestling with the tension between their natural desire to relate and the cultural push to be an individual. This may well have important implications for age care. Could it be that sometimes our institutions, our care homes or whatever setting, can be a place where our relational consciousness is suppressed and pushed down. Do we take seriously enough the natural desire of people with dementia to relate with others and with God? Are our organisations structured to enable relational consciousness to flourish? What David Hay has to say about education might well apply to some of the places that we are involved with. It might be worth doing a spiritual audit of your organisation to see whether it is relationship friendly.

The spiritual problem of loneliness

When we begin to recognise the importance of relationality and spirituality, we can begin to realise why loneliness is so devastating. We get our sense of wellbeing as we interact with responsive others. We gain our sense of self-esteem, not from ourselves, but from interacting positively with other people. The same thing goes for value. Where do you get your sense of being valued? We don't just wake up one morning and say, "I am valuable!" Value is a gift that's given to you by others. It's like a wedding ring. A wedding ring may or may not be expensive, but it's invaluable for the people who wear one, because it represents something powerful. Value is a gift that's given to you. Very often we get that gift through friendship. We give one another value as we engage in friendly relationships with one another.

Appendix One

A practical theology of relationship and belonging

To be who you are you need to be recognised and remembered well

What we have discovered thus far is that we need to be responsive to others to help us function well as fulfilled human beings. To be a fulfilled human being we need to be seen, recognised, valued, and loved. That is not something we do alone. It is something we do together in community.

We often think about dementia in terms of individual memory loss. We assume that the most terrifying thing is to forget things, but perhaps a more terrifying thing is if those around you forget about you. It is a noted fact that when people receive a diagnosis of dementia their friends often step back. You can hear that in the language people use: "She is not the person she used to be." "He would never have done that before." And so gradually the community withdraws and begins to assume that you are not there even though you clearly are! But this abandonment by your friends and community has a profound impact on people for the reasons that we have highlighted previously. Sometimes people even assume that because you have forgotten things about God you are no longer a spiritual being. But all these things are false. We are who we are, not because we remember who we are. We are who we are because we are remembered by others, but ultimately by God. Dementia may change us, but who we are is held in place by others and by God.

Beatrice's prayers

One of my colleagues who is a chaplain who works with people who live with dementia, told me this important story about someone she had met named Beatrice. Beatrice had advanced dementia. She was for much of the time withdrawn and uncommunicative. It was very difficult to get any kind of conversation going with her. One day my colleague sat down with her and decided to pray with her. She said, "Beatrice, I'm going to pray with you." My chaplain friend began to pray. She said: "Our Father" and immediately Beatrice began to pray. She prayed and she prayed, and she prayed. My friend listened in to hear what Beatrice was saying, she couldn't understand it, but Beatrice was clear and intentional. She was partaking in words that only the Spirit could understand. When a person prays, God hears. When God hears, something changes in creation, Beatrice's prayers matter. The fact that someone has neurological damage does not mean that their prayers do not matter. We don't often look for the spiritual gifts of people with advanced dementia. Often, we assume that our task is to give things to people with advanced dementia, that is of course important, we give ourselves through our relationships. But perhaps we need to give more thought to what we might receive? Perhaps people with dementia on all the different parts of their journey have things to give to offer to all of us, to society, to church, to the body of Christ. Perhaps we need to consider why it is that we don't spend more time listening, learning, and relating with people on their dementia journeys. Who knows what all of us together could discover if we did?

Our job is to love

There's a lovely book by the theologian Joseph Paper called Faith, Hope and Love. In the chapter that focuses on love, he talks about love and recognises it as a complicated thing.

It's good that you are here and I'm glad that you exist.

We love many things. We love our ice cream, our dogs, our work, our children. He pushes us to think of love in this way; love is saying to the other, it's good that you are here, I'm glad that you exist. Love is welcoming people into relationships of belonging. There's something very beautiful about the simplicity of such a statement, particularly when you're working with elderly people who are often losing the respect of others. This way of framing love - it's good that you're here and I'm glad that you exist - helps us to get into that space, where we are really present with people in a way that taps into their relational consciousness and helps them and you, to be together in responsive relationships. As we love one another, so we discover that dementia may be a difficult journey, but if we walk it together, we can find hope and new possibilities.

Appendix One

Developing and managing ‘A1Snehanjali’ assisted living elder care for dementia as a social enterprise: challenges and impact

By Sailesh Mishra, Founder President of Silver Innings Group and A1Snehanjali assisted living elder care home, Mumbai, India

Silver Innings since 2008 is working towards creating an elder and dementia friendly world where ageing becomes a positive and rewarding experience. Our organisation promotes the concept of age friendly society, which is an inclusive society where all age groups and genders live in harmony.

Our A1Senhanjali – assisted living elder care home, a project of Silver Innings was started in 2013, it is one of its kind a 24 x 7 assisted living elder care home, in the state of Maharashtra, for those who do not need constant medical intervention or nursing home care. It is based near Virar, on the outskirts of Mumbai and is an innovative way of looking at elder care. The home caters to elders who need special care such as those living with dementia, Parkinson’s and those who are very old. 'A1Snehanjali' project offers our residents both personalised and group programmes and services that focus on stimulating mind, body and soul. A therapeutic and secure environment is provided to the residents along with innovative non-pharmacological interventions if required.

While working on A1Snehanjali as a social enterprise, we not only understand an Indian perspective towards dementia and ageing, but also encountered some challenges and tried to resolve it through our passionate team effort. We are happy to share our decade long journey of care, which will not only help society, community and entrepreneurs but also governments to make a policy and plan for dementia as well as aged care.

Mindset:

India as a country is still a society where elders are respected and part of a family. While urban areas are warming up to the idea of retirement homes, from our experience there is still a social stigma attached towards children whose parents are in retirement homes. Older people too feel that it is their children’s responsibility to take care of them in their old age. Initially in 2008, when I started Silver Innings, I myself was against the concept of ‘old age homes’ due to the poor conditions, lack of systems and the way the residents are treated. But working on the ground by 2012, my opinion had changed, and I felt the need for specialised care homes for dementia or retirement homes for older people.

Location

As a developer or a person building an assisted living elder care home, one of the first problems we faced was acquiring land. Land is costly and difficult to find near big cities. The cost of land is so expensive that it takes more than three years to break even while running a home. Hence most retirement homes are built outside cities or on the outskirts of cities. To build ‘A1Snehanjali’ we wanted a peaceful and large plot so we could provide the right surroundings to the residents to lead a peaceful life. We acquired a piece of land on a 10-year lease in the outskirts of Mumbai at a reasonable cost, which meant we could break even faster and in Aug 2013 we started A1Snehanjali.

Finance

It was difficult to get a loan from a bank to build the assisted living home. Banks are not used to being approached by developers for retirement homes and assisted living, they were not confident of this business plan and the demand. The banks we approached, found the terms ‘elder homes’ and ‘assisted living’ new. Banks are wary of individual developers or smaller developers, but funds larger construction of houses for building retirement communities. Fortunately, I received help from friends and family and I started our first home in August 2013.

Human resource

This is the biggest challenge while running a retirement home or any care facility. I found it very difficult to find the right people to work in the elder care industry. Very few people are professionally qualified for geriatric care or dementia care, there is no incentive to work in the elder care industry. Dealing with older people and dementia requires lots of patience and is a demanding job. Sometimes the residents’ needs are physically or mentally challenging and taking care of them is tough. The staff also do not see growth prospects and glamour in this industry, and they exit after some time. There are many opportunities for the youth

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to work in shopping centres, call centres and the delivery industry etc. If you recruit people and train them, then it's difficult to retain them. Also, you might get professionally qualified people, but they are not affordable. I feel that even if you find qualified staff with the right attitude towards older people, you must retain them despite the higher costs, since finding staff with the right attitude is very difficult. What we felt was 'attitude' is the qualification for elder care.

Motive

The classification of retirement homes or care facilities as 'not for profit' NGOs, Trusts or a commercial retirement communities is one of the most crucial aspects. While some 'not for profit' organisations operate retirement homes as a social enterprise or 'no profit no loss' model, builders and construction companies build retirement homes for making a profit. While I built the assisted living elder care home as a social enterprise, I am aware that many builders construct retirement communities as a part of their business to make a profit.

The human touch is a very important aspect of retirement homes. I believe that adding the human touch is what differentiates homes run by NGOs or social enterprise and those run commercially. However, it is important to realise that just because the assisted living elder care home is being run as a social enterprise they do need money for day-to-day operations. Social enterprises are not to be looked upon as charities. It was difficult to convince people that our assisted living care home was a social enterprise and not NGO, as we needed to charge residents.

Taxes

Goods and Services Tax (GST) is an indirect tax which was introduced in India on July 1, 2017. The cost of residential care services as well as non-residential care services have increased after the implementation of the GST. This has increased the economic burden of not only the elder members but their families as well. The increase in taxation has also affected the service providers who, as a result, have increased their charges on the services provided by them.18% GST on residential care services as well as non-residential care services has made things difficult for admission, also due to this we could not raise our charges, but our expenses keep on increasing every year by 10%.

Food

Being a country of many food habits, taste, religion, communities and cuisines; catering to the different dietary preferences of all the residents in an assisted living elder care home is a huge task. Dietary preferences and dietary constraints are innumerable and maintaining the variety and quality requires effort and interest by the developer and management.

Diversity

In India we have a melting pot of cultures and religions. Language, climate, tradition, religion, dressing, greetings; all so different. From diets to traditions, from festivals to social interaction preferences, there is a great range of preferences in the population and at old age people get more selective in their choices. In such circumstances, creating occupational activities, recreational activities, daily food menus, décor and a harmonious environment for all the residents is a consuming task.

Impact

While we were working on our A1Snehanjali 'assisted living elder care home' our focus was to provide the best right and most holistic care for people with dementia. But what we actually managed to do was to provided immediate relief for families, created employment generation for the local tribal community, introduced innovative therapeutic intervention, promotion of non-pharmacuetical approach, financial and social support to staff and their family. We undertook community work with the local population in the form of health camps. We raised awareness of government schemes. In order to reach out to young minds we adopted local government primary ZP School, did advocacy and networking around dementia and also worked on empowerment, internships and hands-on training for college students.

Reward

However, despite all these problems, running an assisted living elder care home is a very rewarding experience personally. Interacting with the satisfied residents and their grateful families is what keeps us going. We have children of the residents of our A1Snehanjali thanking us for the care and love with which we take care of the residents. Over the years we have started making a little profit. With the profits we were able to start other social development work. I believe in my mother's life mantra "forget yourself for others, and others will never forget you". Living by this, I have made my assisted living elder care home an oasis for people with dementia and older people to live their old age with peace and dignity. The problems that we face while running the care home are insignificant when compared to the joy and happiness we bring to the lives of our residents and their families.

Conclusion

Dementia, like elder mental health has long been neglected, but now its status has changed as it has become not only a national, but also a global, public health priority. While we all, as entrepreneurs, businesses house, social activists try our best to make a difference to people with dementia and their families, but equally it is the responsibility of the Government of India to formulate and implement a National Dementia Plan.

As per the paper published online in 2021 'The Implementation of National Dementia Plans: A Multiple-Case Study on Denmark, Germany, and Italy' by Nadia Céline Boeree, Claudia Zoller, and Robbert Huijsman; "to meet the needs of people with dementia and their caregivers, which include older children, spouses, daughters, sons, community; governments the world over face pressure to incorporate dementia into national policy, as well as to develop and implement national dementia plans able to sustain high-quality care and support for people with dementia, and ensure that health and social care systems for them are sufficiently structured and funded."

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Hearing the voices of lived experience in designing for dementia

By William Yeates and Marie Alford
The Dementia Centre, HammondCare

"Being outside in nature is an escape from dementia....it may sound strange, but it feels like it's diluting it (dementia) when I'm out in the open. Because when you're inside, you're closed in, and it feels like dementia is immediately surrounding you".

These words from Wendy Mitchell who was diagnosed with dementia in 2014 at the age of 58 (One last thing: How to live with the end in mind) resoundingly reminded of us of the 'why' we need and must think about design for dementia from the lived experience of people living with dementia. The days of institutional living, long corridors, small windows, locked doors and low light must never return. We dedicate this piece to Wendy who died earlier this year in 2024, and all those living with dementia.

When we listen to the voices of people living with dementia, we have the opportunity to learn so much more than what we can through textbooks or even guidelines. William (Bill) Yeates who was diagnosed with dementia in 2018 also cared for his father with dementia. He told us;

"One of the biggest fears that my father spoke about when I discussed the notion of him moving from his home into residential care, was that he was moving out of his comfort zone into a new place that didn't look like anything like his home where he had been living in for over 30 years. For example, moving into residential care meant that he no longer had a kitchen or a loungeroom to watch TV, an office to do work in and the door to his room would be closed at nighttime. As a result, he felt extremely uncomfortable with the whole notion of moving out of his home."

So often do we forget the importance of designing spaces that are domestic and familiar. But not domestic and familiar to you or me as designers, architects or care providers but what is familiar to the people who will be living in these spaces. No doubt the challenge is as Bill tells us the 'familiarity' his father was searching for in communal spaces. The need for small rooms outside of the busy-ness and over stimulation that can occur in larger rooms in communal living. Bill also reflected on a recent cruise he went on, and that size and scale from 'forward to aft' meant he felt completely lost but whilst in his room, and adjoining living areas he felt totally safe.

Agnes Houston who was diagnosed with dementia in 2006 talked about the impact of dementia being more than just memory which is important when we consider the overwhelm of design features. With more and more care homes requiring features such as elevators to transport across multi-levels, the appearance of these lifts becomes as vitally important as the function they provide. Agnes says;

"...when I walk into the lift, it looks as if there's no bottom to it... "

which is immediately disabling for someone living with dementia. The use of mirrored walls in the lifts – designed to give illusions of space can further overwhelm and confuse a person living with dementia.

Wendy Mitchell said about the use of mirrors:

"Some people come to the house and comment on the fact there aren't mirrors anywhere but more and more these days I find them confusing and disorientating. To me a reflection doesn't signal where the room stops and starts".

In the recent Australian Government Dementia Design Competition **Reimagining where we live**, Gwenda Darling who was diagnosed with frontotemporal dementia in 2013 talked about the impact of light and sound as 'pollution' for experience living with dementia alongside the pattern and designs of floorings and carpet. Gwenda says;

"...if there's a pattern in the carpet, if there's flecks in the flooring, you bend to pick the flecks up, little patterns, you feel like you're falling into a hole, you've got to sidestep the patterns. The visual, spatial, it's really important that it's clearly defined. Make sure that you have nothing that looks like you're walking (into) a hole....it's too confusing".

Dementia Design should maximise independence. When we spoke with Bill Yeates he highlighted the importance of maintaining one's independence as a significant contributing factor to overall mental health and wellbeing. The concept that you are still capable of doing daily activities, regardless of how small or large should never be given up on.

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That independence speaks to the connection with community as much as the build of care home settings. Agnes Houston at the Scottish Dementia Working Group Ageing and Dementia Meeting in 2012 talked about maintaining daily activities and the struggles she faces;

"Even getting into the doctor's room is a challenge. May name is called. Which way do I go grom the waiting room? When I find the door, it's closed. Do I know or wait?"

Wendy Mitchell also talked about her experience of 'closed doors' and then impact on her experience living with dementia.

"...closed doors are just very confusing for people with dementia, as you don't know, you don't remember what's on the other side of the door...and I simply ended up removing the doors. Simple solution but it meant I could see where each door led."

The Australian led HammondCare Dementia Centre delivered the first Design School for People with Lived Experience of Dementia in 2018 which gave voice to those whose experiences continue to challenge and inform our thinking. Professor Mary Marshall, former Director of the Dementia Services Development Centre at University of Stirling and Advisor to the Australian Dementia Centre who led these schools said about these schools;

"I think it's easy to lose sight of the important principle in all of this (design), which is about stepping into the shoes of someone with dementia and imagining what they're experiencing. You can talk highfalutin design terms and design models, but actually empathising with what it must be like to be an older person, with diminishing sigh, diminishing hearing, painful joints, combined with an increasing failure to understand and make sense of what you're living in. It's not that difficult to know what a humane and decent environment for people in that position is."

The words that embodied the change in the disability sector decades ago, nothing about us, without us resonate when we consider design for people living with dementia. As providers of care, at home or in case settings this is the opportunity and challenge for us all.

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Appendix Two

Place based stories from across the Commonwealth

This appendix includes a range of reports demonstrating the range of approaches to dementia with many ideas that can be shared amongst policy makers, health and care professionals and civic society.

Appendix Two

Dementia update – Africa

By Femada Shamam

Introduction

This report provides an analysis of the dementia landscape in Africa, focusing on the unique experiences of **Botswana, South Africa, Kenya, Nigeria,** and **Uganda**. It explores regional frameworks, national policy developments, caregiving dynamics, awareness and support initiatives, and the crucial need for respite care for carers. This update aims to provide insights into the current state of dementia care and highlight the steps being taken to address the growing challenges associated with dementia in Africa.

Understanding the regional frameworks

The African Union (AU) is on the cusp of ratifying the AU Protocol to the African Charter on Human and People's Rights on the Rights of Older Persons (AU Protocol). Once ratified, this document will serve as a legally binding regional instrument, emphasizing the limitations of relying solely on family care for older adults, particularly those living with dementia. The protocol together with the AU Common African Position on Long Term Care for Africa serves as the overarching policy framework relevant to the provision of care and services to older persons in Africa. These policy documents point out several critical issues:

1. Reliance on families cannot ensure quality and integrated care for many older adults who need it, especially the poor and those living with dementia or related conditions.
2. Family care can result in neglect and abuse of older care recipients.
3. Family caregiving can engender substantial direct costs as well as lost opportunities for health, education, employment, or other economic engagement among family carers, the majority of whom are women.

This recognition underscores the inadequacy of family care alone and highlights the need for comprehensive, integrated care systems to support older persons living with dementia.

The role of the African Union

The African Union's commitment to a unified approach towards dementia care is critical. The AU's endorsement of a common position on long-term care reflects an understanding of the broader socio-economic impacts of dementia. By providing a framework for member states, the AU aims to foster regional cooperation, knowledge sharing, and the development of best practices in dementia care. This collaborative approach is essential for addressing the disparities in healthcare infrastructure and resources across different African nations.

Legal and policy implications

Once ratified, the AU Protocol will have significant legal and policy implications. Member states will be required to align their national policies with the regional framework, ensuring that dementia care becomes a priority in national health agendas. This alignment may also facilitate access to international funding and support for dementia-related programs, enhancing the capacity of African countries to manage the growing dementia responsibility.

National policy development

Countries across the African continent are at different stages of developing national dementia strategies. The push for these strategies is driven by community organizations and private bodies advocating for a structured approach to dementia care.

South Africa

In South Africa, organisations and projects such as STRiDE (Strengthening responses to dementia in developing countries), Geratec, Eden Alternative SA, Association for Dementia and Alzheimer's SA (ADASA), and The Association for the Aged (TAFTA) have been at the forefront of advocating for a national dementia strategy. These organisations emphasise the importance of creating inclusive societies where people living with dementia can live with dignity and flourish. They also highlight the need for targeted education and awareness programs to reduce stigma and promote understanding of dementia. The provision of support and care for people living with dementia falls within the mandate of the following national departments: Department of Social Development, Department of Health and the Department of Human Settlement.

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Uganda

In Uganda, community-based organisations like MY GRANDMAA-PAA-UGANDA are leading the call for a national dementia strategy. These organisations focus on raising awareness about dementia and providing support to families and individuals affected by the condition. They emphasise the need for a holistic approach that includes medical care, social support (which recognises the role of spirituality in the lives of the person living with dementia and the larger community), and community education.

Uganda's approach to dementia care includes:

- **Community-Based Care Models:** Leveraging community health workers to provide in-home care and support for people living with dementia.
- **Public Awareness Campaigns:** Conducting nationwide campaigns to educate the public about dementia and reduce stigma.
- **Policy Advocacy:** Working with government officials to incorporate dementia care into national health policies and budgets.

Botswana

Ageless Inspiration, and Dementia Botswana (Pelonomi Foundation) are key players advocating for a national dementia strategy. This organisation works to improve the quality of life for older adults with dementia by providing support and resources to families and carers. They also conduct awareness campaigns to educate the public about dementia and reduce stigma.

Botswana's dementia care strategy focuses on:

- **Capacity Building:** Training healthcare professionals and carers to provide quality dementia care.
- **Rural Outreach Programs:** Extending care and support services to rural and remote areas where healthcare infrastructure is limited.
- **Collaboration with Traditional Healers:** Integrating traditional healers into the formal healthcare system to bridge cultural gaps and improve care acceptance.

Kenya

In Kenya, the Ministry of Health is working on a National Dementia Plan in collaboration with local organisations like Agewatch Africa Foundation and Alzheimer's & Dementia Organisation Kenya (ADOK).

The plan aims to:

- **Enhance Diagnostic Services:** Improve access to diagnostic tools and training for healthcare providers.
- **Develop Dementia-Friendly Communities:** Foster communities that are supportive and accommodating of people living with dementia.
- **Increase Funding for Dementia Research:** Allocate resources for research to understand the specific needs and challenges faced by people living with dementia in **Kenya**.

Nigeria

Nigeria is in the early stages of developing a national dementia strategy. Efforts are being spearheaded by organisations such as Dementia Nigeria and Alzheimer's and Dementia Association of Nigeria (ADAN).

Their approach focuses on:

- **Raising Awareness:** Conducting educational programs to inform the public and healthcare professionals about dementia.
- **Advocacy for Policy Change:** Engaging with policymakers to prioritise dementia care in national health policies.
- **Support Networks:** Establishing support groups for people living with dementia and their carers to share experiences and resources.

The dementia narrative in Africa

Africa is the youngest continent, but with increasing life expectancy, dementia is becoming more visible. Various stakeholders providing community services have reported that understanding of dementia is limited, and this is one of the most concerning factors. In many traditional cultures, there isn't even a word to describe dementia. For instance, in IsiZulu, one of the 12 official languages in South Africa, the closest expression is "isifosokholwa," which refers to losing memory. In Uganda, dementia is referred to as an older person's illness, "Obu lwadde bwabakadde."

Cultural perceptions

The lack of awareness about dementia is evident in the local explanations for its occurrence. In some communities, dementia is attributed to witchcraft or punishment from God. These beliefs reflect the significant cultural barriers to understanding and addressing dementia. Community

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workers in South Africa, Kenya, and Uganda also highlight the intersection of a lifetime of alcohol abuse and the prevalence of HIV/AIDS with the increasing numbers of people living with dementia.

Case study: South Africa

In South Africa, the narrative around dementia is slowly changing thanks to the efforts of organisations like ADASA. They are working to shift the perception of dementia from a mysterious, shameful condition to a recognized medical issue that requires care and support. ADASA's education programs target various community groups, including traditional healers and pastors, who are often the first point of contact for families dealing with dementia. Their targeted groups for education and awareness also extend to public combi taxi operators and the youth.

Case study: Uganda

In Uganda, MY GRANDMAA-PAA-UGANDA is addressing the cultural stigma surrounding dementia by engaging with local leaders and communities. They conduct workshops and training sessions to educate people about the signs and symptoms of dementia and to dispel myths about its causes. This grassroots approach is crucial in a country where traditional beliefs still hold significant sway.

Case study: Kenya

In Kenya, Agewatch Africa Foundation has partnered with an organisation in the neighbouring Democratic Republic of Congo and is working to change the dementia narrative by partnering with local media and influencers to spread accurate information about dementia. They also collaborate with schools to educate young people about brain health and dementia, aiming to create a more informed future generation.

The impact of traditional beliefs

Traditional beliefs and practices play a significant role in shaping the dementia narrative in Africa. Many communities rely on traditional healers for health advice and treatment. Integrating traditional healers into the formal healthcare system can help bridge the gap between modern medicine and traditional practices, improving acceptance and understanding of dementia care.

The role of religion

Religion also influences perceptions of dementia. In some communities, dementia is seen as a spiritual issue rather than a medical one. Engaging religious leaders in awareness campaigns can help address these misconceptions and promote a more scientific understanding of dementia. Increasingly service providers are including religious and spiritual leaders in their programmes as these are the first point of intervention sought when a community member starts presenting with behaviours consistent with dementia.

Family caregiving

For many countries in the region, the provision of support and care remains the primary responsibility of family members. This is acknowledged in macro policy frameworks at both regional and national levels. Regional dynamics also play a role in the availability of families to provide the care and support needed.

Migration and conflict

Migration from urban to rural areas is common across many countries, impacting the availability of family carers. In Kenya and the neighbouring Democratic Republic of the Congo, the ongoing conflict has severely affected social care networks. Many widows living with dementia are unsupported, as their partners or husbands have lost their lives during the conflict. This situation underscores the vulnerability of older adults in conflict zones and the need for robust social support systems.

Economic impact

The economic burden on family carers is another significant issue. Caring for a family member with dementia often means reduced income due to the need to cut back on work hours or leave employment altogether. This financial strain is compounded by the direct costs of care, such as medical expenses, which many families struggle to afford. In South Africa, the loss of income and increased care costs can push families into poverty, highlighting the urgent need for financial support and respite care options.

Emotional and physical strain

Family carers often experience high levels of stress and burnout due to the demanding nature of dementia care. The lack of formal support services exacerbates this strain. In Uganda, carers report feelings of isolation and helplessness, as they are left to manage the complex needs of their loved ones with little external assistance. This emotional and physical toll underscores the importance of providing comprehensive support for carers.

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Case study: Nigeria

In Nigeria, the reliance on family caregiving is particularly pronounced. Dementia Nigeria has highlighted the challenges faced by carers, including the lack of formal support services and the cultural expectation that families should care for their elderly relatives. To address these issues, Dementia Nigeria advocates for policy changes to provide financial support and respite care for carers.

Regional dynamics

The availability of family carers is influenced by regional dynamics, including migration and conflict. In Kenya and the Democratic Republic of the Congo, ongoing conflict has disrupted social care networks, leaving many older adults with dementia unsupported. These dynamics highlight the need for coordinated regional responses to dementia care.

Awareness and support initiatives

Service providers in different countries have noted the importance of education and awareness of the disease and the response thereof. Awareness and education programs are conducted at various levels, targeting different audiences.

Community-based initiatives

Community-based organisations play a crucial role in raising awareness about dementia. In Kenya, Agewatch Africa Foundation has partnered with ATRASID in the Democratic Republic of the Congo to provide care and support to individuals experiencing brain health conditions. This partnership involves practical assistance with domestic chores, such as laundry, cooking, fetching water, washing dishes, and providing food. These initiatives highlight the importance of community-based support in the absence of formal care services.

Case study: Kenya and the Democratic Republic of the Congo

Agewatch Africa Foundation and ATRASID's collaboration demonstrates the power of grassroots initiatives in addressing dementia care. By focusing on practical support, these organisations help improve the quality of life for people living with dementia and their families. Their work also underscores the importance of cross-border partnerships in tackling shared challenges.

Public awareness campaigns – using multiple platforms for dissemination

Public awareness campaigns are essential for changing perceptions and reducing the stigma associated with dementia. In South Africa, ADASA approaches education and awareness programs from a human rights perspective. They advocate for inclusive societies that help people living with dementia to live with dignity and flourish. Awareness programs target specific groups, including youth, traditional healers, pastors, prison staff, prisoners, and taxi associations.

It has been noted that a myriad of approaches to education and awareness is evident from formal webinars (eg Eden Alternative SA; Bessie Makhatini Foundation) to community-based programmes (Ageless inspirations, MY GRANMAA GRANPAA, Tafta, ADASA) and engaging local media platforms, especially the radio stations which has a wider reach into the rural areas.

Youth engagement

Engaging youth in dementia awareness is crucial for creating a more informed future generation. By educating young people about brain health and the risks of dementia, organisations like ADASA hope to reduce the future prevalence of the disease and promote healthier lifestyles.

Traditional healers and pastors

Traditional healers and pastors are key community leaders who often serve as the first point of contact for families concerned about cognitive decline. By educating these leaders about dementia, ADASA aims to improve early diagnosis and support for people living with dementia in their communities.

Public transport sector

Involving the public transport sector, such as taxi associations, in dementia awareness campaigns helps ensure that individuals in the formal and informal public transport sector are knowledgeable about the disease and can play a role in dementia care and support.

Private sector initiatives

The private sector also plays a significant role in dementia care and awareness. In Cape Town, Geratec and the Eden Alternative SA provide services and training to the long-term care sector. These organisations conduct formal training workshops to create awareness and reduce the stigma attached to neurocognitive impairment. Their initiatives include the STRiDE (strengthening responses to dementia) project mentioned earlier in this report.

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Case study: South Africa

Geratec and the Eden Alternative SA's initiatives highlight the importance of private sector involvement in dementia care. Their training programs not only improve the quality of care but also contribute to changing societal attitudes towards dementia. By fostering partnerships with other stakeholders, these organisations help create a more supportive environment for people living with dementia.

Innovative approaches

Innovative approaches to dementia care are emerging across Africa. In Uganda, the focus on the spiritual dimension of dementia work recognizes the centrality of spirituality in everyday life. This holistic approach acknowledges the cultural context and seeks to provide care that respects the spiritual beliefs of individuals and their families.

Art and cultural practices

There is growing interest in understanding the role of traditional practices in promoting health, neuroaesthetics, and perceptions of memory. Research into African cultural and art practices and their impact on brain health offers new insights into dementia care. These practices can provide therapeutic benefits and enhance the quality of life for people living with dementia.

The need for respite care

A common theme emerging in terms of care and support is the need for respite for the carers of people living with dementia. This is not a uniquely African theme, but the nuances of care in Africa must be taken into account regarding what respite means, how affordable and accessible the solutions for respite care are.

Case study: Botswana

In Botswana, Ageless Inspiration advocates for the development of respite care services to alleviate the burden on family carers. Their approach includes training volunteers to provide short-term relief for carers, allowing them time to rest and attend to their own needs. This initiative highlights the importance of community involvement in providing respite care.

Financial support for respite care

Providing financial support for respite care is crucial in making these services accessible to low-income families. In South Africa, advocacy efforts focus on securing government funding for respite care programs. By alleviating the financial burden on families, these programs can help ensure that carers receive the support they need.

Community-based respite services

Community-based respite services offer a practical solution for providing relief to carers. In Uganda, MY GRANDMAA-PAA-UGANDA is exploring community-based respite care models that leverage local resources and volunteer networks. These services provide a cost-effective way to support carers and improve the overall quality of care for people living with dementia.

Policy advocacy for respite care

Advocacy for policy changes to include respite care in national health agendas is essential. Organisations across Africa are working to raise awareness among policymakers about the importance of respite care. By incorporating respite care into national dementia strategies, governments can ensure that carers receive the support they need to continue providing quality care.

Conclusion

The dementia landscape in Africa is characterised by diverse challenges and initiatives. Understanding regional frameworks, national policy developments, caregiving dynamics, awareness and support efforts, and the critical need for caregiver respite are essential for creating an enabling environment for people living with dementia and their carers. Continued advocacy, education, and innovative approaches are crucial to developing comprehensive dementia strategies across the continent.

The efforts of community organisations, private sector initiatives, and regional frameworks demonstrate a growing commitment to addressing the complex needs of people living with dementia and their families. By fostering collaboration and leveraging cultural strengths, Africa can build a robust support system that ensures dignity, quality care, and improved quality of life for those affected by dementia.

By expanding and deepening our understanding of dementia in Africa, we can develop effective strategies to address the growing challenges associated with this condition. Through concerted efforts and a commitment to inclusive, culturally sensitive care, we can create a future where individuals with dementia and their families receive the support they need to live well.

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Dementia and cognitive impairment among Indigenous and Aboriginal populations: a comprehensive review

By Dr Philip Ventry

Acknowledgement: Mr David Stevens, Standards Wise International, for support and encouragement to write this review

Introduction

Dementia and cognitive impairment are significant public health issues that affect populations worldwide. Indigenous and Aboriginal communities face unique challenges regarding these conditions due to cultural, social, and systemic factors within health systems. This paper synthesises current knowledge on the prevalence, diagnosis, care, and risk factors of dementia among Indigenous and Aboriginal populations, drawing from a comprehensive review of recent studies. Understanding these challenges and identifying effective interventions is essential to improve dementia care and outcomes for these communities.

Prevalence and incidence

Cognitive impairment and dementia in Aboriginal Australians

Lo Giudice et al. (2015) conducted a longitudinal study investigating the incidence and predictors of cognitive impairment and dementia in Aboriginal Australians. Their findings revealed that Aboriginal Australians experience higher rates of dementia compared to their non-Indigenous counterparts. This disparity is attributed to a range of factors, including lower educational attainment, higher prevalence of chronic diseases such as diabetes and hypertension, and socio-economic disadvantages. The study emphasised the importance of early detection and culturally sensitive interventions to mitigate these disparities. Moreover, the findings highlighted the need for targeted health policies and programs that address the specific needs of Aboriginal populations[1].

Childhood Stress and Adversity: Radford et al, (2017) linked childhood stress and adversity to late-life dementia in Aboriginal Australians. The study underscored the long-term impact of early-life experiences on cognitive health. Childhood adversity, including trauma, neglect, and socio-economic disadvantage, was found to be significantly associated with an increased risk of dementia later in life[2]

APOE Genotype: Lavrencic et al. (2022) examined the role of the APOE genotype in dementia incidence among Aboriginal Australians. The study identified the APOE ε4 allele as a significant risk factor for cognitive decline, alongside other lifestyle and genetic factors[3].

Urban vs. regional prevalence

Radford et al. (2015) explored the prevalence of dementia in urban and regional Aboriginal Australians, revealing significant regional disparities[4]. Urban populations had better access to healthcare services, contributing to earlier diagnosis and better management of dementia. In contrast, regional and remote areas face challenges such as limited healthcare infrastructure, lower health literacy, and cultural barriers that hinder access to care. The study highlighted the need for tailored health services and outreach programs to address the unique needs of Aboriginal Australians in different regions. Additionally, it underscored the importance of investing in healthcare infrastructure and workforce development in remote areas to improve dementia care outcomes.

Torres Strait Islands study

Russell et al. (2020) provided insights into the prevalence of dementia in the Torres Strait, showing a substantial burden of dementia among the Torres Strait Islanders[5]. This population faces additional challenges due to geographical isolation and limited healthcare access. The study underscored the necessity of developing culturally appropriate healthcare services and policies that consider the unique cultural and social contexts of the Torres Strait Islanders. Furthermore, the research emphasised the importance of community engagement and the integration of traditional knowledge and practices in health interventions to enhance their effectiveness and acceptability.

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Diagnostic challenges and approaches

Cognitive assessments

Hindman et al. (2023) explored clinicians' views on cognitive assessments with Aboriginal Australians[6]. The study identified several barriers, including language differences, cultural perceptions of health, and limited access to diagnostic tools. Aboriginal Australians often have different cultural understandings of health and illness, which can affect their responses to standard cognitive assessments. The study advocated for the development of culturally tailored assessment tools and training for clinicians to improve diagnostic accuracy and cultural sensitivity. This approach includes incorporating Indigenous languages and culturally relevant examples in assessment tools, as well as enhancing clinicians' cultural competence through targeted education and training programs.

The KICA screen

LoGiudice et al. (2010) introduced the Kimberley Indigenous Cognitive Assessment (KICA), a culturally appropriate tool for dementia screening among Aboriginal Australians[7]. The shortened version, KICA Screen, demonstrated strong psychometric properties, making it a reliable tool for early diagnosis. The KICA Screen considers cultural differences in communication styles and health beliefs, providing a more accurate assessment of cognitive function in Aboriginal populations. The study highlighted the importance of using culturally validated tools in clinical practice to ensure accurate and meaningful assessments of cognitive health. Moreover, the research suggested that regular screening using the KICA could facilitate early intervention and improve long-term outcomes for Aboriginal Australians with dementia.

Risk factors and protective factors

Childhood stress and adversity

Radford et al. (2017) linked childhood stress and adversity to late-life dementia in Aboriginal Australians[2]. The study underscored the long-term impact of early-life experiences on cognitive health. Childhood adversity, including trauma, neglect, and socio-economic disadvantage, was found to be significantly associated with an increased risk of dementia later in life. The study called for interventions addressing childhood adversity and promoting resilience to improve cognitive health outcomes in Aboriginal communities. These interventions might include trauma-informed care, mental health support, and programs aimed at reducing socio-economic inequalities. Additionally, the research highlighted the potential benefits of community-based initiatives that foster social support and cultural identity, which can serve as protective factors against cognitive decline.

APOE genotype and cognitive decline

Lavrencic et al. (2022) examined the role of the APOE genotype in dementia incidence among Aboriginal Australians[3]. The study identified the APOE ε4 allele as a significant risk factor for cognitive decline, alongside other lifestyle and genetic factors. The findings suggested that genetic predisposition, combined with environmental and lifestyle factors, contributes to the higher prevalence of dementia in Aboriginal populations. The study highlighted the need for targeted interventions that address both genetic and modifiable risk factors. These could include lifestyle modifications such as promoting physical activity, healthy eating, and smoking cessation, as well as regular health screenings and management of chronic conditions like hypertension and diabetes.

Dementia prevention and intervention

Dementia prevention program

Mateo-Arriero et al. (2023) described the co-design of a dementia prevention program tailored for Aboriginal Australians (DAMPAA)[8]. The program focused on culturally relevant activities and education to reduce dementia risk, emphasising community involvement and empowerment. The co-design approach ensured that the program was culturally appropriate and aligned with the values and needs of Aboriginal communities. The study demonstrated the effectiveness of community-driven health interventions in reducing dementia risk and improving health outcomes. Moreover, the research highlighted the importance of ongoing community engagement and collaboration to ensure the sustainability and success of such programs.

Healthcare provider perspectives

Improving dementia diagnosis and care

Bryant et al. (2021) gathered perspectives from healthcare providers on improving dementia diagnosis and care for Aboriginal and Torres Strait Islander people[9]. Key

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recommendations included enhanced cultural competency training for healthcare workers, increased community engagement, and the integration of traditional knowledge with biomedical approaches. The study emphasised the importance of building trust and collaboration between healthcare providers and Indigenous communities to improve dementia care. Additionally, the research suggested that involving Indigenous health workers and community leaders in the design and delivery of dementia care services could enhance their effectiveness and cultural appropriateness.

Telementoring programs

Haydon et al. (2022) evaluated the Dementia ECHO telementoring program aimed at increasing dementia knowledge and skills in First Nations-led health services [10]. The program used a hub-and-spoke model to connect primary care providers in remote areas with dementia specialists. The study found that the program significantly improved healthcare providers' confidence and competence in managing dementia, demonstrating the potential of telehealth initiatives in addressing healthcare disparities. Moreover, the research highlighted the benefits of telementoring in fostering professional development and knowledge exchange among healthcare providers, ultimately leading to improved patient care.

Lived experiences and cultural understandings

Australian Aboriginal perspectives

Gubhaju et al. (2022) explored the lived experiences and understandings of dementia among Australian Aboriginal people in Western Australia [11]. The study revealed that cultural beliefs and practices significantly influence the perception and management of dementia. Aboriginal people often view dementia through a holistic lens, considering the spiritual and social dimensions of health. The study highlighted the need for healthcare services to respect and integrate these cultural perspectives in dementia care. Additionally, the research emphasized the importance of involving Aboriginal elders and community members in the development and implementation of dementia care programs to ensure their cultural relevance and acceptance.

Cognitive test norms

Lavrencic et al. (2019) established cognitive test norms for healthy ageing, mild cognitive impairment, and dementia in older Aboriginal Australians [12]. This population-based study provided essential data for accurate diagnosis and monitoring of cognitive health in this demographic. The study emphasized the importance of using culturally appropriate normative data to improve the accuracy of cognitive assessments and ensure equitable healthcare for Aboriginal populations. Furthermore, the research suggested that incorporating these norms into clinical practice could enhance the early detection and management of cognitive impairment and dementia among Aboriginal Australians.

Ethical considerations and research scope

Ethical issues in Indigenous research

Bryan et al. (2022) conducted a systematic scoping review of ethical issues in Indigenous cognitive impairment and dementia research [13]. The review highlighted the importance of ethical considerations, including community consent, cultural sensitivity, and the inclusion of Indigenous researchers in study designs. Ethical research practices are crucial for building trust with Indigenous communities and ensuring that research benefits the participants and respects their cultural values. The study also emphasized the need for ongoing dialogue and collaboration with Indigenous communities throughout the research process to address ethical concerns and ensure the relevance and appropriateness of the research. Longitudinal Cohort Studies.

Radford et al. (2006) conducted a longitudinal, population-based study on resilience, cognitive decline, and dementia in older Aboriginal Australians [14]. The study provided valuable insights into the progression of dementia and identified potential protective factors unique to this population. Longitudinal studies are essential for understanding the long-term effects of various risk and protective factors on cognitive health and for developing effective interventions. Additionally, the research highlighted the importance of considering cultural and social factors in the design and implementation of longitudinal studies to ensure their relevance and acceptability to Indigenous populations.

Intervention and care strategies

Online education and training

Poulos et al. (2021) developed the Caring for Spirit program, an online dementia education and training initiative for Aboriginal and Torres Strait Islander Australians [15]. The program aimed to enhance carers' knowledge

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and skills, promoting better dementia care practices. The study demonstrated the effectiveness of online education in reaching remote communities and providing accessible training for carers. It also emphasized the importance of culturally appropriate educational content that reflects the values, beliefs, and experiences of Aboriginal and Torres Strait Islander communities. The research suggested that integrating online education with community-based support and resources could further enhance the effectiveness and impact of the program.

Active and healthy ageing program

Radford et al. (2020) collaborated on the co-design of an active and healthy ageing program using mobile technology to reduce dementia risk [16]. This program highlighted the potential of technology in delivering health interventions to remote Indigenous communities. The study showed that engaging older adults in physical and cognitive activities through mobile platforms can promote healthy ageing and reduce the risk of dementia. The program's success underscores the importance of innovative and culturally tailored health interventions. Additionally, the research emphasized the role of community involvement and ownership in the design and implementation of such programs to ensure their sustainability and relevance.

Culturally appropriate care models

Integration of traditional knowledge

Integrating traditional knowledge and practices into dementia care for Indigenous populations can improve acceptance and effectiveness. Aboriginal and Torres Strait Islander peoples have rich traditions of healing and community care that can complement biomedical approaches. Incorporating traditional practices, such as storytelling, art therapy, and communal activities, into dementia care plans can help bridge cultural gaps and provide a more holistic approach to care. This integration requires collaboration with Indigenous elders and community leaders to ensure authenticity and respect for cultural traditions.

Community-controlled health services

Community-controlled health services (CCHS) play a crucial role in providing culturally appropriate care to Aboriginal and Torres Strait Islander communities. These services are governed and operated by Indigenous people, ensuring that healthcare delivery aligns with community values and needs. CCHS can offer tailored dementia care programs that incorporate cultural practices, provide education and support for carers, and facilitate early diagnosis and intervention. Strengthening CCHS and increasing their capacity to deliver dementia care can improve health outcomes and empower Indigenous communities.

Future directions and research needs

Addressing social determinants of health

Future research and interventions should focus on addressing the social determinants of health that contribute to the higher prevalence of dementia among Indigenous populations. Factors such as poverty, education, housing, and access to healthcare significantly impact cognitive health. Comprehensive strategies that address these underlying determinants can reduce health disparities and improve dementia outcomes. Policies aimed at reducing socio-economic inequalities, improving educational opportunities, and enhancing access to quality healthcare are essential components of this approach.

Culturally adapted interventions

Developing and evaluating culturally adapted interventions for dementia prevention and care is a critical area for future research. These interventions should be co-designed with Indigenous communities to ensure cultural relevance and effectiveness. Examples include culturally tailored health promotion campaigns, community-based support programs, and culturally specific cognitive training exercises. Pilot studies and community trials can help assess the feasibility and impact of these interventions, providing valuable insights for scaling up successful models.

Longitudinal and multigenerational studies

Longitudinal and multigenerational studies are needed to understand the long-term effects of risk and protective factors on cognitive health in Indigenous populations. These studies can provide insights into the progression of dementia, the impact of early-life experiences, and the role of genetic and environmental factors. Additionally, they can help identify critical periods for intervention and the long-term benefits of preventive measures. Collaborations with Indigenous researchers and communities are essential to ensure the relevance and ethical conduct of these studies.

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Enhancing cultural competency in healthcare

Improving cultural competency among healthcare providers is essential for delivering effective dementia care to Indigenous populations. This includes training on cultural awareness, communication skills, and understanding the social and historical contexts of Indigenous health. Healthcare institutions should integrate cultural competency training into their curricula and professional development programs. Additionally, employing more Indigenous healthcare workers and fostering inclusive and respectful healthcare environments can enhance the quality of care for Indigenous patients.

Technology and innovation in dementia care

Leveraging technology and innovation can improve dementia care delivery and accessibility for Indigenous populations. Telehealth, mobile health applications, and remote monitoring systems can overcome geographical barriers and provide timely support and interventions. These technologies can facilitate early diagnosis, continuous monitoring, and personalized care plans. Ensuring that these innovations are culturally appropriate and accessible to Indigenous communities is crucial for their successful implementation.

Policy and advocacy

Advocacy for policies that support dementia care and research for Indigenous populations is vital. This includes increased funding for Indigenous health services, support for community-controlled health organizations, and policies that address the social determinants of health. Engaging policymakers, healthcare leaders, and Indigenous communities in advocacy efforts can drive systemic changes that improve dementia care and health outcomes. Collaborative advocacy initiatives can raise awareness, influence policy decisions, and secure resources for Indigenous health programs.

Further research suggestions

1. Rural and remote vs. urban comparisons:

Investigate the differences in dementia prevalence and care between rural/remote and urban Indigenous populations. This research could focus on identifying specific challenges faced by those in remote areas, such as limited access to healthcare services, cultural barriers, and geographic isolation. Additionally, it could explore how these factors contribute to disparities in diagnosis, treatment, and outcomes. Studies could also examine the effectiveness of different models of care, including community-based programs and telehealth services, in addressing these challenges[17].

2. Rates of depression and anxiety

Examine how rates of depression and anxiety in later life may compound the impact of dementia on Indigenous populations. Understanding the co-occurrence of these conditions is critical, as they can exacerbate cognitive decline and complicate care. Research should investigate the prevalence of these mental health issues among older Indigenous adults, the factors contributing to their higher rates, and the best practices for integrated care. Studies could also explore how cultural factors influence the experience and reporting of mental health symptoms [18].

3. Early-life interventions

Research interventions targeting childhood adversity to assess their long-term impact on reducing dementia risk. Given the established link between early-life stress and later-life cognitive decline, it is essential to identify and implement strategies that can mitigate these effects. Interventions might include programs aimed at reducing childhood trauma, improving socio-economic conditions, and enhancing educational opportunities. Longitudinal studies could track the effectiveness of these interventions over time and their potential to reduce dementia prevalence in future generations [19].

4. Community-based resilience programs

Develop and evaluate community-based programs aimed at fostering resilience and social support as protective factors against cognitive decline. These programs could incorporate traditional practices, community activities, and social support networks to strengthen community bonds and promote mental wellbeing. Research should focus on the design, implementation, and outcomes of such programs, considering the unique cultural contexts of Indigenous communities. Pilot programs could provide valuable insights into the best practices for fostering resilience and preventing cognitive decline.

5. Genetic and environmental interactions

Explore the interactions between genetic predispositions and environmental factors in the development of dementia. This research could examine how genetic factors, such as the presence of the APOE ε4 allele, interact with lifestyle factors like diet, physical activity, and exposure to toxins. Studies should aim to identify high-risk groups and develop targeted

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prevention strategies. Additionally, research could explore the potential for personalized interventions based on genetic and environmental profiles[3].

6. Technological innovations

Assess the effectiveness of innovative technological solutions, such as mobile health applications and telehealth, in improving dementia care for Indigenous communities. This research should evaluate the feasibility, acceptability, and impact of these technologies in remote and underserved areas. Studies could explore how technology can enhance early diagnosis, provide ongoing support and monitoring, and deliver culturally tailored health education. The integration of traditional knowledge and practices into these technological solutions should also be considered to ensure cultural relevance and acceptance[20].

7. Policy and advocacy

Examine the role of policy and advocacy in supporting dementia care and research for Indigenous populations. This research could analyse the effectiveness of existing policies and identify gaps that need to be addressed. It should explore how advocacy efforts can influence policy changes, secure funding, and raise awareness about the unique challenges faced by Indigenous communities. Collaboration with Indigenous leaders, healthcare providers, and policymakers is essential to develop comprehensive strategies that address the social determinants of health and improve dementia care outcomes [21].

8. Culturally adapted interventions

Develop and evaluate culturally adapted interventions for dementia prevention and care. These interventions should be co-designed with Indigenous communities to ensure cultural relevance and effectiveness. Research should focus on the feasibility and impact of interventions such as culturally tailored health promotion campaigns, community-based support programs, and cognitive training exercises. Pilot studies and community trials can provide valuable insights into the best practices for scaling up successful models[15].

9. Longitudinal and multigenerational studies

Conduct longitudinal and multigenerational studies to understand the long-term effects of risk and protective factors on cognitive health in Indigenous populations. These studies can provide insights into the progression of dementia, the impact of early-life experiences, and the role of genetic and environmental factors. Research should also explore the critical periods for intervention and the long-term benefits of preventive measures. Collaborations with Indigenous researchers and communities are essential to ensure the relevance and ethical conduct of these studies[19].

10. Enhancing cultural competency in healthcare

Investigate methods to improve cultural competency among healthcare providers. This includes training on cultural awareness, communication skills, and understanding the social and historical contexts of Indigenous health. Research should evaluate the effectiveness of cultural competency training programs and identify best practices for their implementation. Additionally, studies could explore the impact of employing more Indigenous healthcare workers and fostering inclusive and respectful healthcare environments on the quality of care for Indigenous patients[22].

Conclusion

The reviewed studies underscore the significant burden of dementia and cognitive impairment among Indigenous and Aboriginal populations. Key challenges include diagnostic barriers, cultural differences, and limited access to healthcare services. A lack of health infrastructure (centres and accommodation) in rural and remote areas also significantly impacts the capacity for change. However, innovative approaches such as culturally tailored diagnostic tools, community-based prevention programs, and telementoring initiatives show promise in addressing these challenges. Future research should continue to focus on ethical considerations, community engagement, and the development of culturally appropriate interventions to improve the cognitive health and overall wellbeing of Indigenous and Aboriginal peoples. Collaborative efforts between researchers, healthcare providers, and Indigenous communities are essential to address the complex and multifaceted nature of dementia and cognitive impairment in these populations.

Appendix Two

A multi-institutional interdisciplinary collaboration in Malaysia using innovative diagnostic and management solutions for dementia prevention

By Maw Pin TAN[1], Rahimah IBRAHIM[2], Abu Bakar ABDUL MAJEED[3], Suzana SHAHAR[4], Pei Lee TEH[5] on behalf of the AGELESS[1] investigators

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Introduction

In 2018, the Institute of Public Health of Malaysia conducted the first national survey dedicated to older adults, which established the prevalence of dementia in Malaysian residents aged 60 years and older as 8.5%. As the Department of Statistics of Malaysian estimated that 3.7 million Malaysians were aged 60 years and over in 2023, the total estimated number of persons aged 60 years and over living with dementia in Malaysia would have totalled 320,000. Considering Malaysia is a rapidly ageing nation, without any risk reduction efforts, with the population aged 60 years and over projected to rise to 6.3 million in 2040, this total number will increase to over 535,000 by 2040.

Ageing has been identified as a priority research area by the Ministry of Higher Education for the past decade, resulting in an increasing number of published studies in Malaysia on cognitive capacity and dementia. However, published dementia related research has seen limited translation into practice, in the absence of any dementia specific or related policies. In fact, specialist dementia clinics remain limited to a few urban centres, with a dozen more towns having access to dementia services integrated into geriatrics or geriatric psychiatry clinics. The delivery of clinical services remains diagnostic and drug centric since the first memory clinic was founded two decades ago. The person with dementia and caregiver education and non-pharmacological management aspects of dementia care remains largely neglected.

In 2019, the Minister of Health of Malaysia at that time had agreed to the development of a National Dementia Action Plan (NDAP) just two years after the launch of the Global Dementia Action Plan by the World Health Organization. Work began in earnest and a draft soon emerged, which sadly then became the victim of a political coup and the COVID-19 pandemic. The development of the plan stalled and was subsequently shelved until the third Health Minister for that parliamentary term announced that his father-in-law, the fourth Prime Minister of Malaysia is living with dementia. With cohesive lobbying from non-governmental and academic groups, the plan was revived and is now about to be launched. The focus has now shifted to securing the date of the launch and addressing effective funding and implementation of the NDAP.

The Transforming Cognitive Frailty into Later-Life Self-Sufficiency (AGELESS) research project has held together a multi-institutional collaboration which began in 2012 when researchers from four public universities combined efforts to successfully bid for a multimillion-ringgit grant from the Ministry of Higher Education to fund the Towards Unusual Ageing (TUA) project (RM 5 million). Following a three-year funding gap during which the dedicated team continued to maintain the cohort through smaller grants, the project team regrouped and expanded to successfully bid for a further RM6.05 million to fund the AGELESS programme.

This collective effort now holds together 50 investigators from seven private and public institutions of higher learning, at various stages of their careers from the disciplines of geriatric medicine, neurology, neurogenetics, pharmacy, nutrition and dietetics, psychology, physiotherapy, audiology, biomedical sciences, medical imaging, microbiology, human ecology, biomedical engineering, health economics and business studies.

In addition to generating research output in cognitive capacity and other age-related issues for the past decade, the collaboration has also led to capacity building in the form of dozens of postgraduate students, with a further 26 PhD students currently registered under the programme. The rest of this article will describe the ongoing work on five of the areas addressed by the AGELESS programme[23].

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[1] The Transforming Cognitive Frailty into Later-Life Self-Sufficiency (AGELESS) project, 2019-2025 is a Malaysian Ministry of Higher Education Long Term Research Grant Scheme funded study.

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Early detection

Outcomes of research studies on curative treatment for dementia for the last two decades have been disappointing. Scientists now agree that the best chance for a cure, hangs on the ability to detect dementia early before symptoms emerge. However, like many low- to middle-income countries, the development of accurate and culturally relevant tools for diagnosis at any stage let alone pre-dementia, remains challenging[24]. Having follow up data that spans a decade on this population which spans the breadth of demographic, lifestyle, socioeconomic, medical, psychological, physical, physiological and laboratory information on individuals, our data scientists are now hot on the case of artificial intelligence to develop prediction tools for cognitive decline. By predicting whether an individual is likely to experience deterioration in their cognitive capacity, the individual is then able to evaluate and identify modifiable lifestyle factors that could then be effectively altered to reduce their risk of subsequently developing dementia.

Societal burden

Population ageing and the increasing prevalence of dementia in Malaysia[25] underscores the need for more studies into the burden and impact of functional limitations among older individuals. Cognitively fragile older persons often have various chronic medical illnesses that impair their self-care and quality of life. The societal costs of physical and cognitive frailty must be understood to guide policy and financial decisions. Addressing this challenge involves a whole-of-society approach that includes healthcare practitioners, policymakers, carers, and the community, as well as lobbying for evidence-based upstream policy measures.

Studies on the costs of managing functional impairment in older adults, affecting individuals, the healthcare system, and society, including families and carers has, therefore, been conducted.

Research to prevent "social admissions" to hospitals highlights the importance of adequate home care. A psychoeducational intervention for carers to address the complex healthcare needs of persons living with dementia, comprising five-point care, ADL support, fall prevention and emotional resilience for the caregiving journey is developed through this. Additionally, qualitative investigations were carried out to explore the unmet needs in dementia care partnerships, negotiated care agreements among siblings, and the pathways taken to seek assistance within the community.

Gut-brain axis

The limitations of current treatments against dementia call for cost-effective and non-invasive biomarkers that can facilitate early diagnosis, classification and prognosis. To this end, we have uncovered potential blood-based Alzheimer's disease (AD) biomarkers using the OMICs approach. Part of our data that was deposited at the National Centre for Biotechnology (NCBI) public domain has been used by other researchers for neuroscience research.

Our findings warrant longitudinal investigation of these biomarkers in people with well-characterised mild cognitive impairment (MCI), and other dementias as well as asymptomatic people with preclinical disease. In parallel with gut dysbiosis and gut microbiota-host interactions that are increasingly recognized for their vital roles in neurodegeneration, our recent data found faecal markers to complement the blood-based AD biomarkers with new perspectives from the gut microbiota and the gut-brain axis. It appears that gut dysbiosis (i.e. imbalanced gut microbiota) could compromise the intestinal barrier, leading to an altered plasma proteome.

Our sequencing of stool samples revealed opportunistic pathobionts that are associated with cognitive impairment and frailty markers in older adults. We are currently assessing the impact of multi-domain interventions (i.e. exercise and diet) in shaping gut microbiota towards reversing cognitive frailty.

Multi-modal lifestyle interventions

One third of dementia cases can be prevented in the next 25 years by tackling its modifiable risk factors including hearing impairment, head injury, excessive alcohol, air pollution, psychosocial risk factors- depression, low social contact, and less education; and cardiovascular-related risk factors- hypertension, diabetes, smoking, obesity, and physical inactivity [26]. Since the risk factors of dementia are multifactorial, various review and experimental studies emphasise the effectiveness and the need for a multi-domain intervention in dementia prevention or reversing the predementia stage, such as cognitive frailty (CF). Thus, we are conducting a multidomain intervention trial to reverse CF among a multi-ethnic older adult in Malaysia[27].

This study is part of the World-Wide FINGERS (Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability), which is forefront in international collaboration of dementia prevention. The study protocol of the study has been published earlier. The outcomes of this trial could be upscaled as a cost-effective strategy to reduce the risk of dementia.

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Mobility

Mobility is important for healthy ageing, impacting older adults' health, independence, social participation, and wellbeing. It involves the ability to navigate one's environment independently or with the aid of devices or transportation.

However, not all older adults experience seamless mobility; many face significant challenges, particularly those with cognitive frailty a condition increasingly prevalent in ageing populations.

Our study aimed to explore these challenges through detailed narratives from older adults about their daily mobility experiences, encompassing activities inside and outside their homes, and transportation usage. Participants from diverse backgrounds in urban and rural settings, with varying levels of frailty and cognitive abilities, were included to provide a broad spectrum of perspectives. This approach enabled a comparative analysis of mobility issues across different environments. In addition, our research team developed and tested a smartphone app to assist older individuals by leveraging volunteer support.

This innovative solution is designed to cater to a broad demographic, including those low-income older adults who often face greater mobility challenges. Our findings aim to direct future research and inform interventions that improve mobility and quality of life for older adults through technology-mediated mobility solutions.

Research that matters – making it count

Having cashed in heavily on public-funding for research in terms of scientific publications, infrastructure and human capacity development, what would really matter to the people now is that the research positively changes the course of their lives by reducing the chance of them ever developing dementia, but also to see a positively altered journey if dementia does emerge. The research programme has worked hard at public and stakeholder engagement from its inception. Stakeholders were involved through focus group discussions right from the beginning, while recruitment was only possible by engaging community groups. Findings of our studies are shared through public talks organized by non-governmental organizations, and more recently, industry sponsors with the blossoming of our silver industry.

With our published findings, our reputation has also grown internationally with enduring collaborations now in existence with the World-wide FINGERS, COSMIC studies, DAVOS Alzheimer's Collaborative and the Alzheimer's Disease Data Initiative to name a few. This allows us to work with other international centres, combining efforts with the hope of coming up with answers quicker.

What remains seemingly elusive, is for us to work with government agencies to utilize the resources that we have developed to ensure effective adoption and implementation through policy change. The ongoing systemic issues that have become increasingly problematic but appear impossible to change is frustrating, leading one to conclude that change we must, no matter how difficult and painful it is. We remain hopeful, that with the Health White paper that was passed by parliament last year, and the National Ageing Blueprint that will be published this year, the implementation of the NDAP will be facilitated by a revised and renewed government structure which embraces the multiagency and societal approach it very much needs.

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Malta's contribution to dementia policy

By Prof. Marvin Formosa B.Psy., P.G.C.E., M.A., Ph.D., F.G.S.A., C.P.G.

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Studies indicate that by the year 2050, 3% of the population of Malta will be living with a form of dementia. It is evident that this condition is emotionally and financially taxing for those who have it, as well as their family members and carers[28].

In response, the Maltese government, specifically Malta's Ministry for Health and Ageing, in January 2024 launched a second dementia strategy that builds upon the previous national strategy - namely, Empowering Change (2015-2023).

The 2015 strategy set a solid framework for care and support including the establishment of a dementia helpline and the formation of the Dementia Intervention Team. There was also an increase in dementia activity centres. A review of the objectives implemented from Empowering Change was carried out and new evidence-based practices were sought, so that novel objectives were brought forward. The second strategy is entitled Reaching New Heights since it aims to significantly improve the quality of services and the quality of life of persons living with the condition in Malta [28].

This strategy aims to achieve this by working on seven action areas which are summarised below: -

Awareness and understanding of dementia

A dementia-friendly society is ideal for creating inclusivity and accessibility in community settings that maximise the opportunities for health, involvement, and security for everyone. This will safeguard the quality of life and dignity for people living with dementia, their carers, and families. The actions in the plan for Malta include organising national awareness events that are culturally specific to Malta and Gozo in partnership with people living with dementia, providing up to date public information, collaborating to improve the social and built environment, promoting dementia friendly areas and behaviours that are culturally relevant for Malta.

Reducing the risk

The action plan for Malta is to ensure that public information and training for health and care professionals includes aspects relating to risk reduction such as guidance around increasing physical activity, preventing and reducing obesity, promoting balanced and healthy diets, quitting smoking and alcohol use, encouraging social engagement, promoting cognitively stimulating activities, preventing and managing diabetes, hypertension, and depression. Initiatives highlighting these new developments, throughout the life course will help the population reduce the risk of developing the condition.

Timely diagnosis

In Malta and Gozo, it is the primary care physician that acts as the first point of contact for individuals suspecting memory loss, however early diagnosis is often missed due to a lack of training. The action plans in Reaching New Heights make many recommendations about improving collaboration and training to ensure more timely diagnosis, use of best practice tools and appropriate support. Utilising cutting-edge diagnostic methods will enable individuals to obtain pertinent information, advice, and guidance as soon as possible. It is also recognised that making advance care planning, while an individual is still able to make important decisions about care and support requirements, as well as decisions about money and legal matters, is extremely advantageous.

Living well with dementia

The new strategy builds on the provision implemented as part of Empowering Change. Ensuring that everyone has access to person centred, coordinated care by the Dementia Intervention Team. As the condition progresses, there are several different ways to promote wellness and coping strategies that can be helpful so that the person adapts to the changes that are happening. Throughout this journey, there are opportunities to find services that best suit the person's requirements and plan support so that the family can live well with the condition. The strategy puts forward an approach that is positive and empowering, focused on helping persons living with dementia and their families to live well with the condition. The strategy also covers the transition to residential settings and the potential for the use of digital solutions.

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Workforce development

The development and training of a workforce with the capacity and competencies to provide high-quality services and support to the growing population of people living with dementia, as well as to successfully address the complex and progressive effects of dementia at all levels of society, are issues of growing public health importance. Reaching New Heights highlights the difficulties in expanding the dementia workforce and the fact that dementia training is lacking and uneven. Being able to address the workforce challenge is essential to providing equitable and non-discriminatory health services to underserved populations [28]. The strategy puts forward initiatives and objectives on how the nation can develop a workforce which can provide quality services for persons living with dementia.

Dementia management & care

Throughout the dementia journey, integrated, culturally appropriate, person-centred care can ensure that the preferences of persons living with dementia are met, and their autonomy is respected. Seamless integrated care across settings is the main goal in management and care, and this will significantly improve the quality of life of individuals affected by the condition. The strategy in Malta that there needs to be collaboration to provide a continuum of care across all settings including hospices. The strategy details actions to review integrated care pathways, increase the number of beds for people living with dementia and recognise and implement appropriate palliative care.

Research & information systems

Data from systematic, routine population level monitoring of a core set of dementia indicators is needed to support evidence-based choices to improve services and evaluate progress in the implementation of the national dementia strategy. This national strategy on dementia will be implemented in the next seven years and the government will be creating an Inter-Ministerial Committee, led by the Ministry for Health and Active Ageing, that will coordinate and oversee its implementation. This will ensure that the actions outlined in the seven sections of the policy are implemented in an effective and efficient manner. It will also ensure that people living with dementia, carers, and family members are included in the implementation process by evaluating priorities and establishing a plan of action, timeframes, and key players.

This strategy is thereby a comprehensive plan which continues to build upon the previous strategy to address the challenges of dementia in Malta. It also provides the framework for the delivery of quality improvements in local dementia services and addresses health inequalities in this field. This strategy brings about more than a crucial and gradual quality upgrade in the continuously expanding healthcare system of our country. Above all, it is another step forward in supporting the wellbeing of our nation. This document is a clear example of how all our policy and collective decisions are to be based on a person-centred approach, as we aim at improving the quality of life of persons living with these conditions, and their families. Indeed, a striking element of this strategy is that it is built on empathy. The medical sector often places huge emphasis on medicine, technology, research and infrastructure, all elements which are critical and which we will continue investing in, and yet at times these render the services provided less personalised, less understanding and even unwelcoming.

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Dementia Policy in Australia

By Dr Stephen Judd

Like most health policies, Australian dementia policy has moved through cycles of advocacy, practice, research and improving services. And, in doing so, it has sometimes neglected measures that are low cost, and highly effective but which take time to yield substantial results.

Advocacy

In the 1980s dementia policy was influenced by the experience of carers and the need to provide empathetic support and advice to the carers of those living with dementia. From 2000 rejuvenated Alzheimer's Australia (AA) raised awareness and advocated priority areas for governmental action. AA's successful influence is evident in the National Framework for Action on Dementia (2006 – 2010 and its successor 2015-2019).

Unlike the advocates for other health conditions, the vast majority of those with moderate or severe dementia are less able to be the 'voice' of dementia. In more recent years, spokespersons have therefore been drawn from those with Early Onset Dementia whose retained abilities make them effective voices. This has shaped policy and, while a crucial and welcome voice, it is important to remember that the face of dementia is overwhelmingly older. Additionally, as more is heard from Younger Dementia it is important that 'carer burden' is not neglected.

Research

Funding research is an important policy response. Sadly, Australia's Royal Commission into Aged Care Quality and Safety (RC) observed that there have been many missed opportunities in research and innovation" and that "the field of aged care research struggles to compete for research funding grants" [29]. The Australian experience has been that research findings were rarely translated into practice.

The exception was the Cognitive Decline Partnership Centre, which in 2014-2019 brought researchers and industry together and whose practical projects focused on best practice evidence, resources and tools. Inspired by the Canadian Collaboration Centres for Public Health, its work was driven by the industry, not academics. It is an approach which should be replicated [30].

The project that most shaped dementia policy was the CDPC's INSPIRED research project. It found small domestic models of care resulted in better quality of life, fewer hospitalisations/A&E presentations, fewer inappropriately administered medications and saved $A12,000 per person compared to traditional aged care homes [31].

Such research influenced the RC's recommendations and the resulting Australian Government's accommodation design guidelines [32]. While a few innovative providers have been providing such 'domestic' care homes for decades they have been the exception to the rule and there has been no financial incentive to provide such services. There are indications that this may soon change [33].

At home care

Most Australians living with dementia understandably want to receive support in their own home and there has been an increase in government financial support for that purpose. One unhappy by-product of increased support for home care has been a demonstrable increase in 'carer burden'. One highly effective policy response to such family carer burden over the past decade has been the 'dementia respite cottages' that allows family carers to 'have time off' [34].

Residential care

Residential care policy for people living with dementia has historically experienced a tension between 'mainstreaming' people living with dementia on the one hand and, on the other, providing special and specific services. The RC concluded that the care of people living with dementia was 'at times, abysmal' and that staff in all 'mainstream' services should have mandatory dementia training [29].

There have only been a few providers who, in the belief that the key to quality is focus, have focused on dementia-specific services with staff trained for that purpose.

The tension remains: should limited public funding be spread across the many like 'fairy dust', probably with limited impact? Or rather, should resources be concentrated where they are most needed?

While it is true that as many as half of those who require residential care have a dementia diagnosis, it is only the very few whose behaviours are challenging to support and make 'mainstreaming' in itself a challenge. To that end, two innovative programs have been transformative:

The creation of Dementia Support Australia in 2016 meant that "Flying Squads" were able to provide rapid response assistance – response within 4 hours and on-site anywhere in Australia within 48 hours - to other carers and providers around the country who were struggling with people who were exhibiting BPSD. This has been a highly effective service which has reduced hospitalisations and improved on-site care.

The Specialist Dementia Care Program (SDCP) has supported a network of small units within care homes for people with very severe BPSD. To date, there are about 16 such units with the objective that 35 will be established nationwide.

A belated focus on measurement and prevention

Successive Action Plans have been comprehensive and given priority to issues such as timely diagnosis, carer support, education and awareness. But what has been missing to date has been measured by the number of Australians who have dementia. Any stated estimates have been little more than extrapolations from outdated international studies. Fortunately, in September 2021 the Australian government announced a long overdue development: the establishment of the Australian Institute of Health and Welfare's National Centre for Monitoring Dementia which will use existing datasets to calculate more accurately the number of Australians living with dementia and make more accurate projections into the future[35]. This is a welcome and cost-effective initiative: an evidence-based approach demands that you cannot manage what you cannot measure.

This is even more critical because there is consistent international evidence that the incidence of dementia is going down not up [36]. The missing – or at least muted – link in Australia's dementia policy is prevention. This is curious because a concerted, long-term focus on brain health at all ages; while not showing attractive 'quick fixes' is a low-cost policy approach. It promises to reap public health benefits in the decades to come in much the same way as "Quit Smoking" campaigns have halved the rates of Australian smokers in two decades with consequential public health benefits. Further, by giving agency to all Australians to do something about their risk of developing dementia it challenges the fatalistic perspective that dementia is a normal, inevitable part of ageing[36, 26, 37, 38]

After all, while much 'policy is political', it is certainly true that 'all health is personal'.

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Dementia Initiatives and Innovative Practices from the Asia-Pacific Region

By Muhammad Hanif Ahmad, Shyh Poh Teo

Introduction

Dementia is a significant concern in the Asia-Pacific region. The Asia-Pacific region will experience a significant increase in the number of people living with dementia, with estimates projecting an increase from 23 million in 2015 to almost 71 million by 2050[39]. A recent shift towards Western lifestyles resulted in increased risk factors for dementia such as midlife obesity and physical inactivity[40]. When Asians are compared with Caucasians, Asians have a higher proportion of vascular dementia [41] and are three times more likely to have cerebral small vessel disease, which increases the risk of rapid cognitive decline, brain atrophy and dementia. Carriers of the APOE4 gene have slower brain shrinkage with small vessel disease, but this protective gene is lower in Asians. One in three Asians also have increased tau protein in the brain, which is associated with dementia[42]. There is also limited awareness and understanding of dementia in the region. Cultural beliefs and practices contribute to the stigma surrounding dementia, affecting access to diagnosis and care for people living with dementia. Dementia is a leading cause of disability in older people, a carer burden and a financial burden for individuals, families and societies. In 2015, the estimated cost of dementia in the Asia-Pacific region was USD$185 billion [40]. Thus, there is an urgent need for policy interventions to address the growing impact of dementia in the region.

While there are many challenges in the Asia-Pacific to tackle dementia, such as the geographical and cultural diversity, there are several strengths including tailoring interventions to meet the specific needs of individuals with dementia, and regional collaboration and networking to share useful knowledge and strategies. The region is rich in innovation and examples of best practices; of which several are shortlisted for this article. These examples are a culmination of inspirational ideas gleaned from regional meetings organized by Alzheimer's Disease International (Asia-Pacific Regional Office), the Association of the Southeast Asian Nations (ASEAN), and World Health Organization (Western Pacific Regional Office).

Awareness and inclusion: community outreach programme (COP) on dementia with Universiti Brunei Darussalam (UBD) – Brunei Darussalam

Demensia Brunei (DB), a non-governmental organization (NGO) affiliated with Alzheimer's Disease International collaborates with Universiti Brunei Darussalam (UBD) in various projects to raise awareness about dementia. At the PAPRSB Institute of Health Sciences in UBD, medical and nursing students are provided teaching sessions about dementia and dementia care skills. These students have been involved in and contributed to DB initiatives on raising public awareness through roadshows, community screening for dementia initiatives and dementia-related research.

The Discovery Year in UBD provides students an opportunity to gain experiences outside the university, which can be through studying abroad, internships, community outreach programs (COP) or incubation to apply business skills. Students from the Faculty of Arts and Social Sciences (FASS) have selected demensia Brunei for their COP for the past 5 years. While students are from different majors (Malay and Linguistics; Design and Creative Industries; English Studies; Geography, Environment and Development; History and International Studies, Malay Literature; Sociology and Anthropology), they are given educational information and hands-on experience with people living with dementia before running community projects on dementia awareness activities. The different backgrounds and skills are tailored to projects, ranging from dementia-friendly environments, reminiscence therapy and planning activities in dementia support groups.

The COP is a mutually beneficial experience for DB and the students: while they gain knowledge about dementia, they also contribute creativity and enthusiasm and share what they learnt through social media, writing articles and giving media interviews. Notable achievements during the COP include running an online 'dialogue' which was broadcasted with on-site support to all four Senior Citizen Activity Centres, recruiting more than 1000 participants for a community screening for dementia project [43] sharing their experiences at an international forum [44] and Alzheimer's Disease International Asia-Pacific Regional Conference, and designing mascots and comics to tell stories about dementia.

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Risk reduction: AGELESS (transforming cognitive frailty into later-life self-sufficiency) - Malaysia

The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER)[45] was a multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring to prevent cognitive decline in at-risk older people. After 2 years, the intervention group had improvements of 25% for cognition, 40% for performing complex tasks, 83% for executive function and 150% for processing speed compared to the control group[46]. As the Asia-Pacific region has a high incidence of vascular risk factors, these interventions show significant promise in reducing dementia risk. However, the region has significant cultural diversity, such as dietary and lifestyle practices, health awareness and engagement, digital literacy and health infrastructure, thus the feasibility of implementation may be difficult.

Cognitive frailty (CF) is the simultaneous presence of physical frailty and mild cognitive impairment and is a precursor to developing dementia. While the prevalence of cognitive frailty ranged between 1-12% globally[47] a study in Malaysia found that 37% of community-dwelling older adults were cognitively pre-frail, while 2.2% had CF[48]. Thus, the Transforming Cognitive Frailty into Later-Life Self-Sufficiency' (AGELESS) study[27], a multidomain intervention applying the FINGER model as part of the World-Wide FINGERS network of multidomain trials for dementia risk reduction and prevention was started in December 2019.

The AGELESS project is a comprehensive initiative combining two Malaysian longitudinal cohort studies that aim to address early detection, the gut-brain axis, mobility difficulties and digital phenotyping in cognitive frailty. For the multidomain interventions to reduce cognitive frailty, the effectiveness of interventions, cost, adherence and feasibility of implementation using online and face-to-face sessions were evaluated. Preliminary results suggest that cognitive frailty may be reversed through multimodal interventions. While more results are expected, the lessons from AGELESS on how to roll-out such programmes are also valuable for the Asia-Pacific region[49].

Dementia diagnosis, care & support: – CARA (community, assurance, rewards, acceptance) - Singapore

Dementia Singapore supported by the National Council of Social Services (NCSS) and the Agency of Integrated Care (AIC) launched an innovative dementia membership programme through a mobile application called CARA (Community, Assurance, Rewards, Acceptance) on 23 November 2021[50]. The app offers features such as safety assurance, rewards and benefits to improve social acceptance for people living with dementia and carers and develop an ecosystem of support. Singapore residents living with dementia, carers of a person living with dementia, and members of the public who want to support the dementia community are eligible to sign up. The app is available for download on the Apple App Store and Google Play Store.

There are several key features. The 'Safe Return' function is a unique identifier for people living with dementia, providing assurance to carers when they move freely and independently within a safe community. If they wander or get lost, they can show the app to members of the public, who can scan the QR code and notify the carers that they have been found. A call function is available to contact the caregiver directly to facilitate a safe return home. Family members and carers can link their CARA accounts to their loved ones with dementia through the 'Connected Care Circle' feature to receive safe return notices and updates. CARA members can enjoy lifestyle benefits throughout their dementia or care journey, such as access to vintage music, discounts and priority privileges from carefully selected partners. There are also recommendations for mind-stimulating wellness programmes, activities, dementia-friendly activities, a catalogued list of solution providers and a community platform for extra support and resources, incorporating the Dementia Singapore one-stop resource portal (dementiahub.sg).

The CARA initiative strives to improve the quality of life for individuals with dementia and their carers, and promote community understanding, engagement and support to build an inclusive and supportive environment for those affected by dementia.

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Caregiver support: Atria – ADFM community corner (AACC) – Malaysia

In 2017, the Alzheimer's Disease Foundation Malaysia (ADFM) collaborated with the Atria Shopping Mall, Petaling Jaya to set up the Atria – ADFM Community Corner (AACC)[51]. This was a dementia friendly and inclusive space to have conversations about dementia and share ideas, information and resources. Regular programmes include talks on health and wellbeing (Saturday afternoon), yoga for older people (Sunday morning), caregiver sessions (monthly) and arts, crafts and puzzles (weekdays, 4-6pm). These activities are provided with voluntary support from doctors, specialists, practitioners and facilitators. Every month, around 163 people living with dementia and 152 carers attend the programme. Since then, the Atria Shopping Mall has earned the title of being the first dementia-friendly mall in the world.

Conclusion

Dementia is a concern in the Asia-Pacific, with an expected increased prevalence and profound impact on individuals, families, healthcare systems and societies. It is hoped that these examples from the region will stimulate further discussions and motivate stakeholder actions to manage dementia as one of the urgent priorities in the region.

Appendix Two

Making meaning to lives: Alzheimer's and Related Disorders Society of India (ARDSI), Calcutta Chapter

By Nishi Pulugurtha

In 1999, an octogenarian Mrs. Shefali Chaudhuri formed the Calcutta Chapter of Alzheimer's and Related Disorders Society of India (ARDSI) to reach out to several families who had a loved one with dementia.

Mrs Chaudhuri's daughter, Deepika who was in her fifties, had been diagnosed with Alzheimer's Disease and following the diagnosis Mrs. Chowdhuri met Dr Jacob Roy Kuriakose who had set up ARDSI Cochin Chapter in Kerala. On her return to Kolkata, Mrs. Chowdhuri began to care for her daughter, ARDSI was located at her home.

What Mrs. Chaudhuri began in 1999 continues to function in the city of Kolkata. The ARDSI, Calcutta Chapter is under the ARDSI National Office which is the only non-government and non-profit social organization that works in the area of dementia in India. ARDSI, Calcutta Chapter, works to spread awareness of dementia and create an acceptance of the condition through education, advocacy and services. It hopes to make life a little better for those living with dementia and their carers and families. The organization has been adjudged the "Best Chapter" in India twice. The members of ARDSI Calcutta Chapter consist of family carers of persons living with dementia, professional carers, specialized dementia care experts, doctors, including neurologists, psychiatrists, neuropsychologists and geriatricians, professionals from different fields, eminent personalities from various walks of society, social workers and people who are interested in working for elders and those inflicted by Dementia.

2024 is a landmark year for ARDSI Calcutta Chapter as it completes 25 years of service. For the last two decades, ARDSI Calcutta Chapter has been working throughout West Bengal by organizing a memory screening clinic, offering counselling services whenever required, and organizing dementia training and awareness workshops. The organization has a daycare centre in Kolkata and offers a home companionship service for families. Regular carer support meetings are organized both online and offline. ARDSI Kolkata, thus, is endowed with a rich multi-directional expertise and experience devoted to its mission.

During the financial year 2022 - 2023, ARDSI Calcutta Chapter continued to provide the kind of services that it always had been providing. Several awareness campaigns, training workshops, carer support meets, office and home counselling –have been organized both in the physical mode as well in the online mode. Utilizing the virtual platforms, that started to be used during the pandemic, has made it possible to reach out to a much larger number of people, of just in and outside the city of Kolkata but also people located in other districts of West Bengal, in other parts of India and abroad as well.

In the 2022-2023 financial year, about 25 awareness programmes were conducted in clubs, schools, colleges, in government offices, consulates, hospitals and social organizations. Some of these awareness programmes were held in various institutions and organizations. ARDSI Calcutta Chapter has been looking to reach out to the younger members of the society so that they would be tuned sensitively to the cause and spread the word around. ARDSI Calcutta Chapter has a social media presence and posts details of its events and various activities and some of its awareness sessions now take place online.

"As a caregiver myself, one of my takes from the first carer support meet that I attended at ARDSI was that I was not alone. Being together in a room with other carers, listening to their stories, seeing them share their pain and tears and yet holding on with some smiles on this journey was something that gave me much hope".

Carer support meets are a regular feature at ARDSI Calcutta Chapter. In the 2022-2023 financial year, ARDSI conducted 12 such carer support meets where family carers spoke out and shared their caregiving journey. Several counselling sessions were organized with home and office visits. A few were done online as well. Around 57 home visits and 24 office visits were conducted in the 2022-2023 financial year.

One of the biggest problems that family carers face is the availability of trained help. The help/ayahs that one gets from centres in Kolkata and elsewhere in the state are all untrained and have no clue about the condition. And carers, many of them are illiterate and learn while they are on the job. Keeping this in mind ARDSI Calcutta Chapter has been organizing home training workshops for both family and professional carers. Several training programmes were conducted for family carers, helps/ayahs at home and from several organizations working in the area not just in Kolkata but in Siliguri in the northern part of West Bengal and Bangladesh as well.

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An interesting workshop was organized at the ARDSI Calcutta Chapter dementia day care centre. This workshop was conducted by Oran Aviv on "Hands on Dementia" which spoke on the use of reflexology to help persons living with dementia. A Problem-Solving workshop was conducted by Somnath Gupta for the staff and volunteers of ARDSI Calcutta Chapter. A workshop on the modalities of how to conduct brain health for diagnosing dementia was organized for the staff of ARDSI Calcutta Chapter as well. A dance movement therapy session was also done by Kolkata Sanved. Each of these interactive workshops enables our staff and volunteers to upgrade and learn new ways of caregiving that could be used in their daily work schedules.

Organizing memory clinics has been an important part of the work that the ARDSI Calcutta Chapter does. In the 2022-2023 financial year 15 such memory clinics were conducted that treated 99 people in our Chandannagore campus. Several more were conducted in Kolkata and its vicinity. On the 15th of May 2022 ARDSI Calcutta Chapter decided to spread out a bit and extend care and support to people living in North Bengal. A Dementia Care Centre in Siliguri was inaugurated under the aegis of the ARDSI Calcutta Chapter. Depend Ablez, an organization working in elderly care approached the ARDSI for guidance and help. They wanted support to extend care to their clients living with dementia. ARDSI has been extending its home companionship programme to some of their clients as well.

Screenings of our documentary film "Muhurto" were organized in Kolkata and as part of the Kolkata Film Festival in December 2022. The documentary is now uploaded online and is available on YouTube. Made in Bengali the short documentary speaks of dementia and how it affects people. It also features ARDSI as an organization working in the area.

Sriti Sudhay, the daycare centre of ARDSI Calcutta Chapter, is a warm space that offers so much cheer and solace to those who spend time here. In the financial year 2022-2023, 18 people regularly attended the daycare centre. All major events and festivals are celebrated at the daycare centre – Holi, the Bengali New Year, Christmas and so on. Family members often join us in these celebrations. An annual picnic is organized each year with staff, volunteers, people living with dementia and their family members joining in.

ARDSI Calcutta Chapter has bought some and in the southwestern part of Kolkata and plans to set up a residential care home specifically for people living with dementia, a research hub for studying dementia related topics, a state-of-the-art training centre for care skill development. The team at ARDSI Calcutta Chapter hopes that the support that received till now increases by leaps and bounds. The dream that we share needs to see a fruition. Care in dementia is of utmost importance and the hope is that this new project brings more hope and smiles to several people. ARDSI Kolkata is resolved to work in the area, to raise awareness and train more people to enrich the quality of life for those living with dementia.

There is so much more to do and hope to do in the years to come. ARDSI Calcutta Chapter want to work more in raising awareness all over Bengal and in all communities and social groups, to increase knowledge centring around prevention and early detection of the condition, to improve further the quality-of-care training and investment in non-clinical research on dementia and related conditions. The immense amount of support and encouragement from people from all walks of life has stood ARDSI Calcutta Chapter in its stead as it moves ahead in our journey.

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Examples of dementia services in England

by National Care Forum

The National Care Forum (NCF) is a membership organisation for not-for-profit organisations in the care and support sector. As a lead voice for not-for-profit care NCF is involved in encouraging and supporting the development of a range of care models to enable every not-for-profit provider to provide specialist dementia care. NCF members meet at regular forums to learn from each other and collaborate in a trusted, supportive and open environment.

The UK regulator, the Care Quality Commission, is currently building its strategy to improve dementia care across the health and care system. This, combined with its NCF's focus on its membership, demonstrates the work continues in pursuit of the discovery of what really good dementia care looks like.

UK care providers place a strong focus on specialist, person-centred dementia care. However, there is certainly scope for this specialist care development to spread further and wider, incorporating the advancements that technology can deliver, particularly at the earlier stages of the condition where prompts and sensors can help. The resulting ripple effect could hopefully reach the whole of the care sector, ensuring that every person with dementia and their loved ones have access to the highest possible quality care for their needs. Unpaid family carers can be essential to the wellbeing of people living with dementia, but all too often they feel overwhelmed as they cope with unimagined changes to their relationships alongside managing their caring responsibilities. There is growing awareness of the need to support family carers alongside the person living with dementia.

Among NCF members there is great tailored practice being developed, some of which are included in the two examples below.

Music therapy at MHA

MHA, one of the UK's largest charity care providers, runs a Music Therapy service employing more than 30 highly skilled, registered Music Therapists, delivering free of charge individual and group Music Therapy sessions across our care homes.

Music Therapy is an established psychological, clinical intervention that can engage people living with dementia through live music, singing, percussion, musical cues, and expressive communication. It can help people living with dementia to relieve stress, encourage self-expression, share experiences, and connect with others, evoking many different emotions and memories. Through collaboration with care colleagues, we can understand and respond to an individual's evolving needs, developing strategies to support positive and person-centred relationships and care planning. We also recognise the important role music plays for family members, colleagues, and engagement with the wider community.

The way cultural and personal identity manifests in sessions can vary from a resident sharing information of their own volition to families sharing information with the therapist. This information can then be introduced within the sessions, to support engagement, and promote a positive sense of identity. An example of this is a therapist reaching out to the son of a resident of Chinese descent for more information about their culture. The therapist was then able to introduce the Chinese instruments Guzheng and Erhu sounds, using a music application on a tablet.

When supporting any referral to Music Therapy, the therapist will always liaise and collaborate with the individual's wider circle of care, as identified in their care plan. This could be close family and friends and care colleagues.

To ensure that their needs are met, the therapist gets to know everyone on a deeply personal level. By knowing about their life, choices and preferences, it is possible to understand who they are, their background, personal history and life experience. These are all vital in enabling therapists to provide the best possible care. An individual living with dementia may be unable to share this information directly, so building a relationship with family and friends is essential when developing care plans. This engagement with loved ones not only supports the individuals with dementia but also maintains a link between the individual and their families. The process of moving into a care home can be extremely difficult not only for the individual concerned but also for their families and loved ones.

Acknowledging and celebrating cultural background can have a profound impact on the individual within sessions, from supporting reminiscence to activating long-term memory. Culturally significant songs or pieces of music can encourage interaction and the sharing of individual experiences. Residents recall more detailed reminiscence and memory recall, with this type of engagement than had previously been observed.

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Musical interactions have enabled residents living with dementia to engage and interact with the therapist and beyond the session itself. Musical interactions enable individuals to confidently engage in two-way dialogue, whether that is musical or conversational, sharing that experience with another.

This sharing and celebration of cultural identity and personal history can positively enhance the sense of personhood for the individual, at a time when, through the experience of dementia, some sense of self may be lost. Music Therapy can be a form of interaction and communication to enhance wellbeing and quality of life, supporting individuals in later life.

Producing better dementia outcomes through the household model at Belong

Belong Villages provides micro-communities with a mix of housing options, care services and facilities that are open to the public, as well as residents. While this may sound like an ambitious project, small households at the heart of the villages were initially piloted within traditional care homes. Their success showed the importance of the environment in promoting better outcomes for people living with dementia and a number of key elements that are transferable to a range of settings.

Promoting independence through open plan layouts

A 'household' in Belong is home to 10-12 residents, each of whom has their own private room with an ensuite bathroom arranged around a shared open-plan space with a living room, dining room and kitchen.

This layout is designed to maximise independence for people living with dementia by ensuring that they have a line of sight to all the main areas of their home and, crucially, that they can easily navigate without relying on memory. It also makes it easier for Belong colleagues to observe residents unobtrusively so they can pick up on signals that they may become anxious or distressed more discreetly and create distractions or other interventions when needed.

Easy adaptations

One of the advantages of this model is that it doesn't need a large space. Indeed, this configuration was originally trialled by Belong by converting areas within the traditional care homes previously operated by the organisation. The décor of the households was influenced by the latest research into dementia-friendly environments with modern, simple colour palettes helping to eliminate confusion potentially resulting from busy patterns.

Colleagues noted that residents were less prone to feeling distressed and displayed greater well-being because of the change in environment, and the success of these early pilots spurred the organisation to design its villages around the household model.

Influencing wellbeing through a homely environment

The smaller size and open plan layouts of the household also contribute to creating a more homely setting that is far removed from the institutional feel of long corridors and canteen style eating spaces. Lounges have a fireplace, providing a homely focal point, and there are picture frames and noticeboards filled with shared events from household family life. Books, jigsaw puzzles and other prompts to help stimulate conversation and activities.

Belong stopped asking staff to wear uniforms, again contributing to a more homely and less clinical feel. Sometimes the décor in a person's house is replicated in their accommodation.

Encouraging appetite through home cooking

To recreate family mealtimes, staff cook and eat together with residents in the households.

The kitchen and dining area is at the centre of this environment which means that the smell of freshly cooked food travels through the households, indicating that mealtimes are approaching. As a result, we see that people living with dementia have greater appetites, where it might have once been more difficult to encourage them to eat. Snacks, such as fresh fruit, and drinks can also be left out on the kitchen side as they might be at home.

Wider community

Beyond the household, the village hub being open to the public and has the effect of creating vibrant communities, providing the opportunity for residents to maintain relationships, as well as make new ones, promoting a sense of belonging and reducing feelings of isolation.

Activities and events are designed to encourage and bring the community into Belong villages, in partnership with local organisations, as well as artists, musicians and other performers.

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This includes engaging with local schools to coordinate intergenerational activities, from reading and singing to art and science experiments.

Specialist input of Admiral Nurses

While all Belong team members are trained to support people living with dementia, Belong's Admiral Nurses provide free, specialist input for the carers of people living with dementia, mainly supporting family members, but also adding another level of expertise that Belong colleagues can draw upon.

Provided in partnership with Dementia UK, Admiral Nurses are registered nurses specialising in dementia care. This ranges from advice on how dementia might affect a person and their family to expertly assessing care requirements and securing financial support.

The service is provided in partnership with Dementia UK, making dementia specialist mental health nurses, who work alongside the Belong team available to provide advice and support across a range of services, including the recently launched B's dementia cafés for members of the wider community.

It is notable how this integrates with the care village model. Often a person's first interaction with Belong is through the Admiral Nurse service upon receiving a dementia diagnosis while living independently.

Above and beyond

Transforming the care environment is just the start of revolutionising dementia care – it needs to be supplemented by an approach to supporting people that enables them to lead active and fulfilling lifestyles, according to their own choices. Examples of this include a varied schedule of activities and events, as well as personalised exercise programmes, provided by our exercise specialists.

Appendix Two

National plan for dementia in New Zealand: an overview

By John Collyns

Executive summary

This report provides an in-depth analysis of the National Plan for Dementia in New Zealand, examining its existence, status, date of publication, and the review mechanism in place. Drawing upon information from reputable sources such as Alzheimer's NZ and Te Whatu Ora, the report explores the current state of dementia care, support, and research within the country. The findings aim to inform an international audience about New Zealand's efforts in addressing the challenges posed by dementia and ensuring the wellbeing of those affected.

1. Introduction

Dementia is a global health concern with far-reaching social and economic implications. As populations age, the prevalence of dementia is expected to rise, necessitating strategic national plans to address this challenge. This report focuses on New Zealand's response to dementia through its National Plan, examining key aspects such as publication date, current status, and the mechanism for regular review.

2. Background

Dementia refers to a range of cognitive impairments that interfere with daily life activities, with Alzheimer's disease being the most common form. In New Zealand, the ageing population is a significant factor contributing to the increasing prevalence of dementia. Recognizing the need for a coordinated and comprehensive approach, the New Zealand government has developed a National Plan for Dementia.

3. National plan for dementia: existence and overview

In 2013 the (then) Ministry of Health developed a Framework for Dementia Care, with the assistance of a range of stakeholders and providers. The framework provides someone with dementia with the services they need, from diagnosis to the end-of-life stage. It encouraged different health and social services to work together to provide people with integrated care. It emphasises services that consider a person's wishes, cultural preferences and lifestyle. It also encouraged health professionals to diagnose dementia earlier to ensure people can get the help they need as soon as possible.

Alzheimer's NZ plays a pivotal role in advocating for those affected by dementia, and it actively engages with the government to shape policies and strategies. The National Plan for Dementia in New Zealand is a critical document that outlines the government's commitment to addressing the challenges associated with dementia.

In 2019, New Zealand's National Plan for Dementia was developed by stakeholder organisations for the three-year period to 2023. This document represents a collaborative effort involving government agencies, healthcare professionals, advocacy groups, and other stakeholders. The plan is designed to provide a roadmap for enhancing dementia care, support, and research across the country.

3.2 Key components

The plan encompasses a range of key components, including:

Early Diagnosis and Intervention: Emphasizing the importance of early detection and intervention to improve outcomes for individuals living with dementia.

Caregiver Support: Recognizing the essential role of carers and outlining strategies to provide them with the necessary support and resources.

Research and Innovation: Promoting research initiatives aimed at better understanding dementia, improving treatment options, and ultimately finding a cure.

Public Awareness and Education: Focusing on raising awareness about dementia within the community and educating the public to reduce stigma and promote understanding.

3.3 Collaborative approach

The National Plan for Dementia reflects a collaborative approach, involving various sectors such as health, social services, and research. This multi-faceted strategy aims to address the complex challenges associated with dementia comprehensively.

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4. Insights from Alzheimer's NZ

Alzheimer's NZ, as a leading advocacy organization, provides valuable insights into the challenges and successes of dementia care in New Zealand. Through its collaboration with the government and active involvement in policy discussions, Alzheimer's NZ contributes significantly to shaping the landscape of dementia support.

4.1 Caregiver support

Alzheimer's NZ actively advocates for increased support for carers, recognizing the vital role they play in the lives of individuals with dementia. This includes access to respite care, educational resources, and financial assistance to alleviate the burden on carers.

4.2 Public awareness initiatives

Alzheimer's NZ spearheads public awareness initiatives to destigmatize dementia and promote understanding within the wider community. These initiatives aim to reduce discrimination and create a more inclusive environment for individuals living with dementia.

4.3 Research collaboration

Collaboration between Alzheimer's NZ and research institutions contributes to advancing knowledge about dementia. By supporting research initiatives, the organization plays a crucial role in driving innovation in diagnostics, treatment, and ultimately, finding a cure for dementia.

5. Te Whatu Ora and Indigenous perspectives

Te Whatu Ora, with a focus on Māori health and wellbeing, provides a unique perspective on dementia care, considering the cultural and indigenous context. Understanding the specific needs of Māori individuals with dementia is essential for developing inclusive and culturally sensitive policies.

5.1 Cultural competence in dementia care

Te Whatu Ora emphasizes the importance of cultural competence in dementia care. Recognizing and respecting cultural differences ensures that individuals from diverse backgrounds receive care that aligns with their values, beliefs, and traditions.

5.2 Community engagement

Te Whatu Ora actively engages with Māori communities to understand their unique challenges and needs regarding dementia. This community-driven approach facilitates the development of targeted interventions and support systems.

5.3 Inclusivity in policy development

Te Whatu Ora advocates for the inclusion of indigenous perspectives in the development and review of the National Plan for Dementia. This ensures that policies are not only culturally sensitive but also address the specific challenges faced by Māori individuals living with dementia.

6. Challenges and future directions

Despite the progress made in dementia care in New Zealand, several challenges persist. These challenges include:

6.1 Equity in access

Ensuring equitable access to dementia care and support remains a priority. Disparities in access based on geographic location, socio-economic status, or cultural background need to be addressed to provide fair and comprehensive care to all individuals.

6.2 Workforce capacity

The demand for dementia care services necessitates a well-trained and adequately resourced workforce. Investments in training programs, recruitment, and retention strategies are essential to meet the growing needs of the ageing population.

6.3 Integration of technology

Exploring innovative solutions, such as the integration of technology in dementia care, can enhance support systems and improve the quality of life for individuals with dementia. This includes telehealth services, assistive technologies, and digital platforms for information and resource sharing.

6.4 International collaboration

Given the global nature of dementia, fostering international collaboration in research and best practices can accelerate progress. New Zealand can benefit from sharing experiences and learning from successful approaches implemented in other countries.

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7. Conclusion

In conclusion, the National Plan for Dementia in New Zealand represents a significant step forward in addressing the complex challenges associated with dementia care and support. With a focus on early diagnosis, caregiver support, research, and public awareness, the plan demonstrates a comprehensive and collaborative approach.

However, we are not aware of any regular reviews and the active involvement of stakeholders, to ensure the plan remains adaptive and responsive to the evolving needs of the community. As New Zealand continues to navigate the complexities of dementia care, international collaboration and the integration of diverse perspectives will play a crucial role in shaping the future of dementia support in the country.

Appendix Two

UK Research and Innovation (UKRI), healthy ageing challenge

By Dr Cynthia Bullock

A pivotal UK Government investment to support the ageing society called the Healthy Ageing Challenge was delivered by UK Research and Innovation (UKRI). Launched in April 2018, UKRI is a non-departmental public body sponsored by the Department for Science, Innovation and Technology (DSIT). UKRI brings together the seven disciplinary research councils, Research England, which is responsible for supporting research and knowledge exchange at higher education institutions in England, and the UK's innovation agency, Innovate UK.

The Healthy Ageing Challenge was delivered by Innovate UK and the Economic and Social Research Council. The aim was to help businesses, including social ventures, to develop and deliver services and products which support people as they age, along with the innovative business models that will help them be adopted at scale.

The projects supported with funding, research and knowledge exchange opportunities, will enable people to remain active, productive, independent and socially connected across generations for as long as possible. The investments aligned to seven themes of healthy ageing. These paint a holistic picture of what makes a healthy later life, and provide a framework for tackling market failures, stimulating innovation, and narrowing inequalities in healthy life expectancy. Living well with cognitive impairment is one of the themes. The theme supported innovations and tailored care that can improve the quality of life for people with cognitive impairment and their carers, extending independent living.

Several impact reports covering both the research and innovation activity undertaken as part of the Healthy Ageing Challenge were recently published, links below.

- Healthy Ageing Challenge: https://www.ukri.org/publications/adding-life-to-years-healthy-ageing-challenge-impact-report/
- SBDRP: https://www.ageing-sbdrp.co.uk/impact-report/

Below are several case studies and video case studies with specific relevance to dementia.

Care

Reading Clear: https://youtu.be/4O4hWqt8evs

Stroke survivors and those living with neurodegenerative conditions experience persistent visual impairment. Being deprived of reading may lead to poorer mental and cognitive health and social isolation.

Read Clear is an evidence-based assistive reading aid developed by scientists at the University College London. Read Clear can improve reading in people with brain-related visual difficulties resulting from neurological conditions, such as stroke or dementia. Coproduced with people living with Posterior Cortical Atrophy and successfully tested in a randomised clinical trial, the Read Clear app can bring reading back into the lives of people with brain injury by offering customised settings that the user can control and adjust to their specific reading needs.

The ambition is to make the app universally available, free of charge, across all operating systems and web browsers so no one with access to the internet will face barriers to using it.

Ear Gym: Around 40% of people over 50 in the UK have some form of hearing loss, with 1 in 6 people of working age affected by hearing loss. Hearing loss is usually gradual. One of the first signs of hearing loss is difficulty understanding what is being said. We can still hear the conversations around us, but it becomes harder to apply meaning to what we hear. This is even more of a challenge in busy places when there is often a lot of background noise competing for our attention.

Ear Gym produces gamified experiences where we can test our hearing so that we can understand baseline hearing levels and achieve improvement through exercises. Ear Gym has extensively researched the link between poor hearing and earlier onset of dementia, to provide a set of self-care hearing programmes, designed to delay this risk.

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With increased interest in audiological self-care and clear evidence of improvements in individuals' hearing capacity, people can look forward to ageing healthily, maintaining social connections and staying in work for longer.

Music in Mind: https://www.musicinmind.org/

Music in Mind Remote (MIMR) is a company co-founded by the University of Manchester and Manchester Camerata. MIMR was founded to scale the delivery of music therapy-based activity to help improve health outcomes and quality of life for people living with dementia in care home settings.

For the last 12 years, Manchester Camerata has delivered music therapy-based activity to people living with dementia. Their unique approach uses improvisation to help people living with dementia express themselves and communicate with others. These sessions help reduce frustration, enable new connections to be made, and have a profound effect on daily life.

Work

Tribe: https://youtu.be/9cTndrrqIEU?si=Gaw438KE9EzwlNTL.

Access to later-life care is significantly affected by where we live. Bronze Software Labs spotted an opportunity to address the problem after the company's CEO experienced the disparity first-hand through a family member. The project aims to eliminate care inequalities in later life care. An artificial intelligence engine builds a picture of regional care landscapes using multiple data sources – including local authorities and the NHS.

Local councils can then map present and future care needs against available services, identifying gaps and then training new carers – including volunteers. The Tribe Project is also enabling the upskilling and accreditation of new paid and voluntary carers with the aim of creating up to 750 micro-enterprises and stimulating local, flexible care markets. People can commission exactly the services they need with a council-run personal budget, reducing council costs, streamlining personalised care services, levelling up regional inequalities in care options, and creating new, better paid care jobs. The model is currently being tested in multiple areas of England.

Bellevie: https://youtu.be/T97_qoOfh_I?si=41aLvD38kVAaLZXb.

Most older people want to remain in their own homes for as long as possible. Many require some degree of care to do so. But the 'time and task' model of home care is broken. Older people feel they are a 'tick box'. Staff are demotivated. Even prior to the pandemic, 38% of care workers were leaving the profession annually[26].

BelleVie Care is pioneering an alternative solution, enabling older people to thrive while creating attractive, meaningful careers. Self-managing teams of Wellbeing Support Workers have the autonomy and knowledge to personalise and optimise care strategies.

BelleVie has so far built eight teams, been rated 9.6/10 by clients and has achieved an impressive employee Net Promoter Score (eNPS) of 62%. This two-year investment programme scales up the concept. It will build a whole operating system to underpin a network of these teams, support them with digital tools, and research how best to measure outcomes relevant to each client.

Housing

Senior Co-Housing in Torfaen: The environment we live in has a significant impact on our health. Working alongside The Wales Cooperative Centre, Bron Afon community housing is exploring the introduction of a senior cohousing model to ensure that older people are given more choice in their accommodation options, allowing them to age well.

Allowing people to 'live together, apart'. People can enjoy the benefits of eating together and socialising, using shared facilities such as washing machines, tools and vehicles; and take advantage of the reduced cost of living and environmental impact by limiting resource consumption through the shared use of resources.

Reducing or delaying the need for access to costly health and social care interventions, living in cohousing has had a positive impact on residents by enhancing their sense of wellbeing, reducing loneliness and isolation, and providing continued activity, engagement, personal autonomy and independence.

DesHCA: https://youtu.be/QNRx9QrHsEs?si=iT7BjQXuVhabH8IM

The multidisciplinary DesHCA team involves stakeholders from all areas of housing provision, including people experiencing ageing and cognitive change, architects and designers, housing experts, planners, builders and housing providers. Designed and built virtual and real designs that act as demonstrators and testbeds for innovations to support healthy cognitive ageing. These designs were evaluated from stakeholder points of view, then considered at a larger scale to examine their real-world feasibility.

DesHCA fed into the UK and Scottish Government City Region Deal for Central Scotland (Stirling and

Clackmannanshire), providing groundwork for local housing developments. The focus of this is sustainable, lifetime health, community and economic development addressing deprivation and inequality. The findings have been used to generate legacy tools which the project has started to use in various contexts. DesHCA's book for people thinking about ensuring their home can support them as they age ("Designing for Lifetime: Tips and Tricks for Creating a Home that Supports You") has reached hundreds of people who have attended events, has been used by the University of Stirling Dementia Services Development Centre's (DSDC) professional clients to use in their practice, and has been circulated by the Royal College of Occupational Therapists (RCOP) to 36,000 Occupational Therapists across the UK, following feedback that it was 'just what we need' to advise OT clients. DesHCA has developed teaching materials for use in professional postgraduate training and these have been used in courses including Occupational Therapy, Dementia Studies and Housing Studies.

Physical activity

ENLIVEN: Staying physically active can help you remain independent by preventing loss of physical mobility and slow age-related cognitive decline. But for people ageing with dementia, there are many barriers to accessing nature outdoors. The research informed the co-design and evaluation of sustainable business initiatives. The work enhances the outdoor visitor economy's capacity to ensure accessibility for people with cognitive impairment.

People living with dementia, especially those living in deprived areas and from ethnic minorities, informed the research, which used creative, arts-based approaches to ensure meaningful engagement. ENLIVEN supported a wide network of stakeholders in helping create more accessible, enjoyable and stimulating experiences. The strategy includes Knowledge Exchange Forums and small grants to support the development and implementation of innovations.

Through a Community of Practice, a growing network of nearly 50 businesses are connecting and sharing experiences about becoming dementia friendly. 25% of people aged 50 to 70 are physically inactive.

Beamish Museum

This project involved a 10-week photography course celebrating the connection between nature and art, culminating in an exhibition of participants' work which is now permanently on display at the museum.

Kew Gardens

The project used reminiscence as a tool to engage people living with dementia from diverse backgrounds with plants and nature, connecting people with experiences from their past through international plant collections. The project was co-developed with an African-Caribbean community group of people living with dementia through an initial series of consultations and art workshops Healthy Ageing Challenge.

Connecting through culture

https://youtu.be/YN1bkhVonjA?si=rDoAl4dkfN3vh0LQ.

The pandemic exacerbated loneliness in later life, increasing reliance on digital services. COVID-19 restrictions have also profoundly affected the arts and culture sector. This project tackled these issues simultaneously – meeting the demand for digital innovations in the creative sector, whilst building audiences for the arts and increasing social connections as people age.

The project forged partnerships with people in later life, community organisations working with older disabled, socioeconomically and racially minoritised people, and the creative industries. Tabletop Travel emerged from the Connecting Through Culture as We Age project through a process of co-design with older adults. A prototype has been built that pairs a meal kit with food stories from India through a technology-enhanced meal box containing visual, audio, and tactile interactions.

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Multi-sector collaboration – spotlight on Essex, Coventry and Birmingham in England

By Maria Blanche, Dementia Partnership Delivery Lead – Essex County Council, April Ross, Service Manager, Coventry County Council and Edward Roberts, Compassionate Birmingham

Essex County Council governs the non-metropolitan county of Essex and is one of the largest local authorities in England. As part of 'Everyone's Essex' the Council is focused on four key areas where outcomes really matter for the quality of life of our residents. These are the economy, the environment, children, and families and promoting health, care, and wellbeing for all the parts of our population who need support, alongside twenty commitments across these key areas that remain mindful of addressing both the challenges of today and tomorrow.

'As this report sets out, this is about developing strong partnerships, throughout the public and voluntary sector, and beyond. It is about always wanting to listen and learn from those with lived experience – to hear what we are doing well and, especially, where we need to do more – and not be too concerned with who gets the credit, but to have a collective focus on clear outcomes.

'Our Dementia Strategy was launched two years ago. In commending the examples of our work set out below, I recognise our need constantly to be looking to build on this and, as demographic pressures continue to grow, never lose that vital focus on those we all wish to support – ensuring they have the care they need.'

'So many of us have been affected by dementia in some way, shape or form. And many will know the real devastating impact it can have. We are on the side of all those living with dementia; committed to making sure that they, together with the family and friends that support them, have the best possible support services to lean on.'

Councillor John Spence, Cabinet Member for Health, Social Care and Integration – Essex County Council

Essex intergenerational age-friendly programme

This intergenerational programme of work is led by Adult Social Care, working alongside Education, Libraries, Public Health, Care settings, and the wider Voluntary, Community, Faith, and Social Enterprise (VCFSE) sector. To build a range of age-friendly activities to engage with both young and older people, a model goes beyond just connecting older people with services but connecting older people within the centre of community life, with people of all ages and interests with the centrality of focus and importance on interventions aligned to social determinants of health. This programme supports creating Age-Friendly generations, developing spaces for enabling environments that draw on strengths and all-age assets, reducing perceptions of ageism bringing young and older together increasing social connections to promote positive health and wellbeing outcomes from the early years to further years. Within an increased awareness of ageing and dementia, and opportunities to develop and harness children and young people's attributes and skills in citizenship, kindness and compassion for future social and health impact and lasting legacies in our communities.

Key principles include:

- Promoting an Essex Age-Friendly community footprint to all-age approaches.
- Focusing on All-Age Asset Based Community Development (ABCD).
- Creating age-friendly spaces as a catalyst to live and age well.
- Supporting social participation and connectivity around care and kindness.
- Unlocking social community capital to harness the benefits of all-age contributors.
- Driving social change to promote age-friendly communities.

As part of this programme of work Adult Social Care has published an Essex Age-Friendly Collaborative Toolkit created as a user-friendly resource to inspire, showcase, and encourage more ideas to make a difference, which can be found here. One in three children and young people will know someone with Dementia, with Essex creating a dementia friendly generation through engaging with children and young people to increase their awareness of

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dementia and the impact on the person living with dementia, their carers, and families. This work shares the multiple benefits of reducing social isolation through enabling and empowering environments that promote social mobility and levelling up in the capacity for skills, community and education that draws on the strengths and assets within proactive age-friendly environments in Essex. Furthermore, how inclusive communities can be seen to promote social cohesion, reduce social isolation and increase awareness and understanding through action resulting in social change in active citizenship with a longer-term focus on reducing health inequalities.

Essex inclusive dementia communities programme

In Essex, Dementia Friendly Community Networks aim to increase dementia awareness in local areas, through place-based approaches to enable communities to be accessible and support people living with dementia, including Carers and Families. The locality approach with a focus on 'let's talk about dementia' raises awareness including changing people's perceptions of dementia and the way they think, act, and talk about dementia, creating communities that are inclusive and part of enabling environments. Alongside the wider benefits of raising awareness, this supports the promotion of earlier conversations and timelier diagnosis, alongside the wider aspects of earlier intervention and prevention within the community.

To help build these communities, this includes work across both public and private sectors such as:

- local community organisations
- businesses
- organisations
- schools
- places of worship

This work also includes working with District Councils as part of planned communities such as new housing and care developments. We know people living with dementia feel safer in a community that is understanding and supportive of their needs, with feelings of safety increasing a sense of maintaining independence and empowerment to be able to continue to take part in activities that are meaningful to the person, within dementia-aware, caring, and compassionate communities.

Essex dementia hour – Community360

The 'Dementia Hour' is a pilot education and awareness dementia design concept that has been developed by Community 360 (C360) who are part of our Voluntary Community, Faith, and Social Enterprise Sector (VCFSE) working in Essex which builds on previous place-based social action around Dementia. The organisation has developed training and video materials that focus on the modifiable risk factors to Dementia, one of these videos can be found here and draws on the Dementia prevention, intervention, and care: 2020 report of the Lancet Commission (2020). This innovative 'Dementia Hour' has been developed to provide a wider and deeper understanding of dementia, both in how we can help make the world a more dementia-friendly place and learn things people can do to reduce their own risk of developing Dementia. Following community co-production, the sessions are being extended to focus on aspects including care, communication, environmental factors, and practical ways to reduce the potential risks. There is current activity to scale-up this work in Essex and current thinking to explore a focus on targeted activity linked to areas of deprivation, particular groups, and minorities.

Coventry

The Coventry Dementia Partnership Hub was co-produced with people living with dementia and their carers (via Alzheimer's Society Focus groups). Two engagement workshops were held, one for people living with dementia and their carers and one for stakeholders that was led by people with dementia. The discussions were captured as visual image based on the vision of people living with dementia and their carers.

The Coventry Dementia Partnership Hub includes a wide range of partners including The Alzheimer's Society, Age UK, Carer's Trust, Arden Memory, Sky Blues in the Community, Coventry Lions, Tamarind Centre, Hope in Unity, Coventry Muslim Forum, GGPN, Emergency Services, the NHS, the local authority, assistive technology solutions, benefits advice, Admiral nurses, veteran services etc. However, the key partners and members of the Board are people living with dementia and carers.

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The three components are –

At the heart of the hub is a dementia friendly social space and cafe, within this, various partners run drop-in sessions for information and advice, scheduled every month. There are sessions called "Chat with Dave" which is peer support provided by someone who was diagnosed with young onset dementia. He encourages discussions around death.

Coventry City Council provide day services from the hub which is the only dementia outreach service and the only young onset dementia service in Coventry including memory courses, coffee mornings, walk and talk and drop-in sessions.

A community resource: partners deliver sessions from the hub based on feedback from people living with dementia and their carers. For example, funding has been secured for 50 iPads and a six-week computer course is being offered including internet safety, social media, online banking/shopping, GP portal for online prescriptions request and dementia friendly interactive apps. The iPad becomes the property of the person with dementia at the end of the course, set up for their purposes. The aim of this programme is to prevent social isolation and promote health and wellbeing.

In Coventry, England as part of the Dementia Partnership Hub, there is a Culturally Inclusive subgroup led by local people including the Coventry Muslim Forum, Lions Club of Coventry Godiva and the Tamarind Centre. The subgroup work is primarily focused on addressing the barriers preventing people from diverse communities from accessing support and services at the Dementia hub.

The subgroup raises awareness and works with communities on obstacles to dementia care in those diagnosed with dementia from a diverse community or for care providers in this section of the population. These obstacles include:

- Social stigma.
- Provision of culturally sensitive care.
- Unmet needs resulting from the adverse impact of sensory deprivation, lack of social interactions and meaningful activities, maintaining previous roles and support for grief and loss.
- Significantly less effective dementia care from statutory services compared to their counterparts from White British communities despite these communities being at much greater risk of developing dementia, and therefore are more likely to present in crisis and/or at a later stage.

The subgroup highlights that people from diverse communities are more likely to face barriers, including late or missed diagnosis, reduced access to treatments, and inappropriate or inadequate support coupled with problems caused by language barriers. These barriers mean that local people are relying on non-specialist local, community-led organisations for support.

The subgroup aims to:

- Raise the awareness and understanding of dementia among ethnic minorities.
- Promote equality/equity, diversity, and inclusion to enable fair opportunity to be involved, and have access to resources and treatment.
- Remove barriers to dementia care via a person-centred approach.
- Collaboratively work with the Steering group of the Coventry Dementia Hub Partnership.
- Set up an economically viable model for sustainable care.

Birmingham

The Birmingham Dementia Strategy was launched in March 2023 and will run until March 2028. It was co-produced involving people living with dementia, their carers, and people from across health, care and community organisations.

The city has a Steering Group that covers Birmingham and Solihull. It includes over 30 organisations, such as statutory organisations, charities, carers groups and hospices. Furthermore, there are internal council steering groups that direct the efforts of Adult Social Care (ASC) and Public Health (PH).

Birmingham is one of the most diverse cities in the UK and has identified the following groups as demonstrating greater differences with regard to accessing dementia support.

- Asylum seekers and migrant communities
- Ethnic minority communities
- Gypsy, Roma and Traveller communities
- Homeless communities
- Learning disability communities
- LGBTQIA+ communities
- Prison communities

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Below are the six key areas which form the framework around which the strategy sits. Created from the multi-sector collaboration and life-course approach, it provides a focus for action, evaluation, and ongoing engagement with citizens about what they have said is important to them.

Birmingham is now looking to fold dementia under the compassionate cities umbrella. The city was awarded compassionate city status in February of 2022 by Compassionate Communities UK. It has been broadly agreed that dementia would fit well under the compassionate cities umbrella and allow for more resources to be mobilised to help people in need. In effect, this will extend the range of organisations and allow for greater collaboration.

The goal is to create dementia friendly communities and dementia friendly venues. To do this, there needs to be greater awareness of what dementia is and is not in communities to allow for greater support for people living with dementia. This links to the dementia friendly venue work, which seeks to improve public spaces for people living with dementia. These spaces will be pubs, shops, public transport, as well as libraries, museums, and other cultural spaces.

As part of the city's compassionate status, there are a wide range of events to engage citizens. Each year, during Dying Matters Week, Brum YODO (a Birmingham based CIC) organises A Matter of Life and Death festival in the city. This festival has focused on events around death, dying, bereavement, and loss, but as we go forward, we hope to include dementia within the events held to continue the normalisation. This is also well timed as Dying Matters Week and Dementia Awareness Week are both in May each year.

The compassionate cities and dementia steering groups feel that there are natural cross-overs in their work. It is hoped that there will be great benefit from bringing these two networks closer together.

Appendix Two

Overview of Dementia in Jamaica

By Denise Eldemire-Shearer

Jamaica is a Caribbean island of 2.9 million people and 15% of the population is ageing, over sixty so it faces many challenges associated with ageing populations including increasing cases of dementia and providing necessary long-term care.

There is a National Council for Senior Citizens to advise the Government and a National Policy on Seniors but little legislation to enforce. The prevalence of dementia in the Caribbean was reported by Alzheimer's International as 6.5% and is projected to increase by 60% by 2030. A National study in 2016 found the Jamaica prevalence was 6% and increasing with age to 30.9% in persons over eighty. The prevalence was higher in females 36.8% than in males 17.6%[53].

A significant finding was that vascular dementia was found in 32.4% of cases. Given the high levels of chronic disease including hypertension 61.7% (72% in females) and diabetes 26% in the over sixty population in Jamaica the finding has significant implications for reducing the prevalence of dementia. In addition, 45% of cases of Alzheimer's also had vascular disease.

The common deficits in affected persons included poor executive function and aphasia in addition to memory loss. This information is important in designing family and caregiving support as being unable to communicate is frustrating to both the person and the caregiver, while not being able to perform activities of daily living indicates the level of care and support needed. Parallel studies on caregiving had similar findings.

Dementia is not well understood in society. Ageism plays a role in a person not accessing care as many of the early symptoms are thought to be due to old age and both persons and families do not visit their healthcare provider for an assessment and early intervention. Families are embarrassed by some of the behaviours of affected family members and do not accept dementia as being an illness. Education about the disease is an identified need.

Care for persons living with dementia is usually provided by family and the informal system, there are very few paid services[47]. Many families are multi-generational despite the declining family size and depend on each other for support[54]. However social dynamics have changed over time with improved education, especially of females and their increased labour force participation means they are not home during the day to provide care. Culturally families believe the care of older persons is a duty and the families' responsibility and there is reluctance to put older persons in residential long-term care additionally it is not widely available and when it is costly which many cannot afford. Also, very few community-based support such as home help is available.

Formal Health Promotion initiatives focus on current disease and little information is provided on dementia. Carers often express frustration about not understanding the disease and being unable to cope. Caregiver burnout is not recognized and is a concern to dementia practitioners. Furthermore, there are a few dementia support organizations and joining support groups is not part of the culture. Caregiver support is a well-documented need that is not being met[55].

Health Care in Jamaica

The Health Care system in Jamaica is a combination of the public in which health care is free at the point of service and the private system which is not. Unfortunately, insurance coverage is low (20%) and does not cover long-term care. Universal health care coverage (UHC), one of the targets of the Sustainable Development Goal 3 (SDG 3) is estimated at 65% and is lower than the mean for the Region 75.4%[56]. While health care in the public health system is free, out-of-pocket expenses can be costly.

Jamaica emphasizes primary health care which is offered at three hundred and forty-two clinics island-wide and is where persons living with dementia access 90% of their care. The clinic system is supported by the National Health Fund which provides subsidized medications for chronic diseases and specifically targets older persons. It does include some dementia-related medications. In 2020 government of Jamaica recognized that with the demographic and epidemiological transition, there was a need for a reorganization and expanded scope for services and introduced primary care reform. In 2023 the reform stated that care of older persons would be part of the package of services[57].

Care of persons living with dementia is included in the package being offered beginning with mental status screening at the point of entry. The need for support of families and carers is included. The importance of community support is recognised, and the job description of community health aides expanded to include specific items on the care of older persons.

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There is some integration of services for older persons and while none are specific for persons living with dementia, they can access the services. The Ministry of Social Security has programmes to reduce poverty. The Ministry of Local Government provides two thousand public long-term residential beds as part of its poverty alleviation efforts. Govia in 2021 reported this meets less than 0.005% of the population[58].

Training

Adequate training of human resources both formal and informal (the families) is essential to improving the care of persons living with dementia and their quality of life. The University of the West Indies (UWI), Mona through the Mona Ageing and Wellness Centre (MAWC) initiated programs to increase training in geriatric and gerontology offering a Diploma in gerontology and a diploma in Clinal Geriatrics.

Following the initial Inter-American Development Bank (IDB) project on long-term care, a manual on community caregiving has been developed and a training programme for community carers from the informal system and Community Health Aides (CHA).

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This section provides a small sample of solutions from across the Commonwealth. It should be noted that inclusion of solutions in this report does not mean that these examples are endorsed by CommonAge, although several are with our many partners in the field of dementia.

CommonAge aims to create an accessible directory of solutions and approaches supporting people living with dementia as part of a Commonwealth wide network. If you have a product that you would like to make us aware of please make contact via the website at www.commage.org or by email to secretariat@commage.org

Appendix Three

What relevance, if any, does an intergenerational programme have for older people?

By Trish Amichi

Overview

From the outset it must be made clear that the aim here is not to present a scientific or academic piece of work. That is best left to experts in those areas. Rather, the intention is to provide a description of the Australian-based international visual art and literacy programme, BIG ONES LITTLE ONES© (BOLO), noting outcomes and the relevance of this intergenerational programme, currently and into the future. Primarily, BIG ONES LITTLE ONES© works to 'give children a voice and let them shine,' but it also allows for positive interactions and exchanges between adults (BIG ONES) and children (LITTLE ONES). While art and storytelling – twin arms and critical elements of the programme – provide channels for communication and engagement, they also help bridge the gaps arising from cultural and language differences. The value placed on these factors is significant because of the direct link between art and culture and the principles on which BOLO is based.

In terms of positive outcomes from the programme, it is important to understand that these are not determined by, or limited to any age group, culture, education or ability level. Finally, considering significant demographic changes taking place on a global scale, the question of whether BIG ONES LITTLE ONES© and/or other intergenerational programmes are actually useful or relevant is raised but left for readers to contemplate and determine the answer for themselves.

PART 1 – THE BIG ONES LITTLE ONES© STORY.

In 2004, a small art exhibition was held in Sydney. It featured pictures and drawings created by LITTLE ONES – primary school children, aged 6 and over. Significantly (and quite unusually) these works were hung alongside paintings by some of Australia's most renowned (as well as emerging) Aboriginal and Torres Strait Islander artists. These BIG ONES, personal friends of the curator, had chosen to support the event by making their prestigious works available for the exhibition.

Referring to both groups of artists and to the various sizes of work on display, this event was given the title "BIG ONES LITTLE ONES." Although considered a great success by participants, schools, artists, and audiences, it was never intended that this be anything other than a 'one-off.' However, interest in and community demand for 'more of the same' was so great that the original concept rapidly evolved. Over the next few years, this Sydney-based production grew to include more BIG ONES as well as more LITTLE ONES. It became recognised as an international visual art and literacy programme that provided access and opportunities for children and young people to express their thoughts and feelings and share these with others.

The process involved is as follows: A particular 'theme' is presented to the young ones. They are asked to interpret it and are given the freedom to do so by using images and words that they themselves choose. Such activities encourage creativity and use of imagination and support development of literacy skills. In turn, this helps underpin education, which lies at the heart of BOLO and provides an anchor point for every BOLO endeavour. Education is the focus because of the power it has to bring about positive change. When completed, several works are selected for inclusion on the next BOLO exhibition and/or are included as visuals for BOLO educational and cross-cultural workshops. Every participant receives a specially designed BOLO certificate, in recognition of their creative efforts. They are also sent a personal letter thanking them for their participation in and contribution to the programme.

By showcasing their work in the same events, the older artists provide LITTLE ONES with guidance, inspiration, encouragement, motivation, and role models. Furthermore, by working side-by-side with the children (regardless of that being in the classroom or in the community) BIG ONES can pass on cultural information, skills and knowledge to the next generation – benefiting the children and the community alike. In addition, including BIG ONES' work in BOLO's exhibitions, provides artists with new sales opportunities and gives audiences the chance to see new works created by some of Australia's most famous artists and on public display for the very first time.

BOLO operates with integrity and regardless of boundaries or borders – ***real or perceived.*** While the focus is on young ones who are disadvantaged (for whatever reason) ***all*** children are welcome to participate in the programme. These factors reflect BOLO's values of respect, social inclusion and cultural awareness. BOLO's outcomes are

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assessed following delivery of events and prior to making any adjustments to the programme. Both quantitative and qualitative data is considered relevant as BOLO remains a social venture – not a scientific one. A small sample of the information available is presented below *(Figures 1-4)*. Collectively, it provides an overview of the growth, expansion and outcomes of the programme and demonstrates how far BOLO has come since that 'one-off' event.

Figure 1

A comparison of BOLO numbers: the number of original participants (2004) listed against those to date (2024).

Participants	Original numbers (2004)	To date (2024)
Artists – BIG	6	122
Artists – LITTLE	80	8000
From Schools/communities	5	92
Countries represented	3	30
Events held	1	40
Host countries	1	8

Figure 2

Feedback/comments reflecting ideas about BOLO, as seen from different perspectives.

Teachers	The students that take part in the project are growing as learners and as individuals. They are proud of their work and, as a result of their being part of the BOLO programme, they become more confident and more independent learners and individuals.
	I hope that the pictures (for BOLO) that our children have drawn give an insight into this beautiful land in which they call home.
	The children enjoy new things; they love listening to stories about the artwork too.
Community members	This project helps reduce isolation...It's a source of motivation and inspiration for children...it also contributes to more understanding and friendship between young people from different backgrounds and cultures.
	Remarkable 'gathering-in' of nations through the eyes of Big Ones/Little Ones
Audience	These children's paintings are very imaginative. It reminds me of my childhood.
	It's fantastic to see work by children (from so many different communities and countries) all in the one place.

Figure 3

A list of BOLO countries (including host countries) demonstrating the programme's reach.

Afghanistan, **Australia, Bahrain, Brunei, China**, Egypt, Greece, **Iceland**, Indonesia, India, Iraq, Israel, Jordan, Kingdom of Saudi Arabia (KSA), Kuwait, Lebanon, **Malay-sia**, Mongolia, New Zealand, Oman, Palestine, Papua New Guinea, the Philippines, **Russia, Sharjah (UAE)**, South Africa, the Solomon Islands, Syria, **Thailand**, Timor Leste, Tunisia, Trinidad & Tobago, Türkiye, the USA, Western Sahara.

BOLO's guiding principles are based on statements in two key documents. The first is the UN Declaration of Human Rights (1948) where, according to Article 27: *"Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts..."*. The second is the UN Convention on the Rights of the Child (1989) where Article 31 confirms *"the right of the child to...participate freely in cultural life and the arts."*

It seems obvious that intergenerational activities, such as those intrinsic to the BOLO programme, are a plus. For example, when BIG ONES share their stories with, and pass on history, skills and knowledge (including about culture) to LITTLE ONES, there is an opportunity for reciprocal teaching and learning. Furthermore, interactions between the generations can help build connections, confidence and resilience, improve feelings of "well-being" and promote "openness to others and respect for diversity within society at large" (as noted in UNESCO's new Global Framework referred to above). The following quotes (in Figure 7) are from BIG ONES and LITTLE ONES who have participated in the programme. Their words reflect some of the benefits of intergenerational interactions.

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Figure 7

Comments from BIG ONES and LITTLE ONES about benefits of participation in BOLO

BIG ONES	(BOLO) is a quality learning experience that gives our children the opportunity to work with elders as they did traditionally – taking time to sit and talk together and receive guidance from the older artists – this has been a valuable experience for our students.
	Working with the children...was a good experience. I believe there should be more elders...working with our children. It was great to see how the children drew different symbols and added their own stories.
LITTLE ONES	(BOLO) is fun, it's interesting...I love drawing and I feel excited (about being in BOLO).
	It was a bit hard (drawing a turtle), but it was good when they (Elders) helped us.
	(Today I learnt) I can draw, I can do art, I can do anything; I can be a hero
	The best bit was drawing and planning my ideas with the Elders. It was good when Elders showed us the symbols (for camp, tracks, footprints).
	Even if you have a problem – you can still do things; even if you can't talk (or have no hands)
	(Doing this is good) because people can find their inner self' ...we loved working together.

When BIG ONES LITTLE ONES© was invited to Malaysia to mark the country's International Children's Day celebrations, it bought Elders and children from Australia together with Malaysian audiences in the Atria Shopping Gallery: the very first dementia-friendly shopping mall in the country; one which included a 'Community Corner' for people living with dementia and their loved ones. Following the delivery of several dance performances, cross-cultural interactive, intergenerational workshops (including art and storytelling), the BOLO programme culminated in the production of new community artwork. This was led by renowned Aboriginal artist, Uncle Bruce Shillingsworth, assisted by the other Australian Elders and 12 children (students of Yurungai Learning Centre in Sydney). All local LITTLE ONES and their family members, including those visiting the Community Corner were invited to help create this painting.

Concluding statement:

The author wishes to thank everyone who has participated in the BIG ONES LITTLE ONES© programme. The support of all the people in Australia and in all other BOLO-linked communities and countries, who have ensured BOLO's continuity since that first small exhibition in 2004, is greatly appreciated.

Respectfully acknowledging traditional owners and custodians of this land and Elders – past, present and emerging – including those with disabilities.

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The Archie Project – Intergenerational Awareness

By Fiona Mahoney the Founder and Chief Executive of a charity called Reminiscence Learning based in Somerset, England, United Kingdom.

Overview

The charity writes and produces its own bespoke training courses, covering topics such as reminiscence, creative activities, dementia awareness, and the importance of life-story work in an accurate, respectful, inclusive, empowering and non-stigmatising manner. These are delivered by an extensively trained team to healthcare professionals, care staff, volunteers and family carers alongside businesses, organisations, and the general public.

The charity has created a unique, universally accessible training course for primary school children which will permeate their newfound knowledge through their families, friendship groups and support networks.

The Archie Project is an exciting intergenerational dementia awareness project that links primary schools, care homes, sheltered housing schemes, businesses, services and community members, to ultimately dispel the fear and stigma often associated with dementia and create more dementia friendly communities.

Why Archie?

A brightly coloured knitted scarecrow was adopted as a mascot for Reminiscence Learning, many people living with dementia will use mascots or dolls as a source of comfort and attachment.

Archie was first introduced to the health care industry in 1999 when he was included as part of a European research project called "Remembering Yesterday Caring Today", [1] whereby individuals living with dementia and their carers joined together in reminiscence sessions, sharing memories and life stories in group settings. This was a research project carried out across 10 countries with the UK being represented by Fiona Mahoney, Occupational Therapist from NHS Stratfield House, Somerset Partnership Trust. Research Group Leads were tasked with sourcing a mascot for the group and both observing and recording the impact its ongoing presence in sessions may or may not have.

Archie was named by an attendee of the sessions, a gentleman named 'Bill'. Each session Bill would greet 'Mr Scarecrow,' as he was previously known, using the greeting "Good morning, Archie", before he settled down within the group setting. He appeared to sense an ongoing familiarity with the mascot, and it appeared to create a sense of continuity due to its ongoing presence and visibility. This in turn offered Bill a feeling of safety and security, providing him with a sense of self-confidence in his continued ability to follow created routine and social engagements. His long-term memory prompted him to remember that he had been in a state of well-being for his last session, adding further stability to his ongoing levels of contentment within the situation.

In 2011 Reminiscence Learning were invited to stand as the regional Charity of the Year for a leading supermarket chain. As part of their working relationship with the store, the charity delivered dementia awareness training sessions to all team members. The wide demographic of ethnicities, preferred language bases, educational and linguistic variances presented by a store-wide demographic highlighted a need for a concise, user-friendly, non-patronising and respectful method of communication to highlight the signs and symptoms of dementia, alongside ways in which individuals can interact confidently both in their professional roles and within the wider community. Thus, the charity wrote 'Archie's Story [2] which is a large-print, illustrated paperback book using simple ideology and concise terminology to outline and emphasise the various points raised throughout dementia awareness training sessions.

Why write a story?

Dementia is a complex subject that can easily become too technical. It can become medically confusing and overwhelming to those living with the changed behaviours and both the clinical, behavioural and psychological symptoms, as well as the potential for life changing, stressful challenges that may occur for those living in caregiving roles. The decision to write a book that would clearly and simply outline the many types of dementia and Alzheimer's disease and the fact that there is no cure, stems from it being a user-friendly method of transferring information to large groups of learners, who may then take on the information at their own pace and in their own learning style.

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When creating 'Archie's Story', Mahoney and Holmes employed the idea of colour being drained from Archie when he felt in a state of ill-being and was experiencing the feeling of being unloved. The story progresses to portray how colour and vibrancy returned to his clothes when he was in a state of well-being, feeling loved and being treated in a manner consistent to that of his friends – a very simple concept but one that both adults and children can relate to on a very personal level.

Although the book was originally written for adults, it was a natural evolution that both the literature and the concept of 'Archie's Story' had transferable use within children's education and could help enable them to understand the basic facts about dementia. This would provide a satisfactory intergenerational base, and dispel the fear and stigma that is often present in younger people and those with little prior knowledge of behavioural changes that may come with the progression of the disease.

Archie goes into Primary Schools

The first Archie Project was established in 2012, with the purpose of linking primary schools and care homes together over the course of an academic year.

550 children between the ages of 5 and 13 took part in the initial project and all participants received an Archie story book, workbook and stickers as physical memorabilia.

Once children had learned about dementia through taught workshops and bookwork, they started to visit their local care home, engaging with older people who had memory loss or dementia and began sharing activities together on a regular basis. A research project led by Exeter University [3] had exciting results that showed a significant shift in the children's stereotypical views of older people, (becoming more positive after the intervention) and their attitudes and intentions on how to treat older people living with dementia (becoming more inclusive and helpful after the intervention than before) – children 7-9 years old showing the best response.

The Archie Project now reaches across the UK and is honoured to have Angela Rippon CBE as its Patron. In 2013, Archie made his way to Australia, further reinforcing a global need for these sorts of approaches to be accessible with content digital and adaptable with location and language differences. The Project is now fully accessible online and can be taught both online or via teacher-led training, as well as via in-person workshops and school events as led by a team of specially trained Archie Leads across the country.

The Archie Project is for children aged 7-9 years. There are Teacher guidelines and a selection of Archie Merchandise for the children, designed to ensure the Project is memorable and has sustainability within the local community. Archie plaques, window stickers, mascots and Archie images become an easily recognisable symbol for a dementia friendly community. With a comprehensive guideline package, this Project can easily be introduced to schools, care homes and sheltered housing schemes. There is an assembly, scarecrow parade, song, drama, Archie mascot, quizzes/ activities and an educational board game to enhance their learning. Children visit care homes on a regular basis and interact confidently using their new dementia awareness knowledge, enjoying intergenerational activities such as shared lunches, storytelling sessions, dancing, snooker, baking, gardening and crochet clubs.

Overall aims of the Project are:

- To deliver an easy to understand, fun and interactive training session that teaches young people basic dementia awareness, signs and symptoms alongside the three main types.
- To provide tips on how to communicate with someone living with dementia and to use these newfound skills and knowledge to engage with individuals in the community in a more confident and positive way.
- Teacher training workshops to support their knowledge.

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The Spark of Life Model of Care

By Jane Verity, Founder, Dementia Care International[1]*, Hilary Lee, President, Dementia Care International, Mischeal McCormick, Richard Semanda, Jesca Nakiribango, Elizabeth Aina-Scott, James Mbatia Kinuthia, Nilanjana Maulik, Clara D'Souza, Nur Sahara Binte Kamsani, Nang Soe Mon Oo, Tania Hammond, Anthony Ryan, Trudy Wadsworth and Anderson Simfukwe*

Introduction and background

The *Spark of Life* Model of Care (*Spark of Life*), currently implemented on 5 continents, offers governments and international healthcare providers in the Commonwealth countries, a cost-effective best practice resource to address the challenges in dementia care and solve the key issues. In particular, the model equips leaders in diverse dementia services and cultures with 'evidence based, culturally appropriate and human rights-orientated' [4] education that they can deliver to their teams so they can provide integrated person-centred care.

The model is sustained through having healthcare leaders in each service educated and certified as Master Practitioners. These leaders are provided with specialised dementia education that can not only be used to educate their staff but also the wider community.

Founded in 1993, Dementia Care International is the independent organisation behind the *Spark of Life* Model of Care. This model has the strength of both scientific and humanistic theoretical foundations and is grounded in clinical practice.

The focus is on the quality of the connection between the carer and the person with dementia, building competencies in the psychological and emotional aspects of care. The model facilitates a fundamental shift from being emotionally disengaged to being emotionally engaged, creating the foundation for an equal and respectful relationship that humanises the experience of dementia.

In 2007 detailed research insights [5 6] were incorporated into Spark of Life and a quality management system was specifically designed for dementia care leaders. Over the next 14 years the model was field tested in 12 countries and further developed.

As part of the consultation for the development there was a clear directive from the OECD to overcome the workforce challenge of staff recruitment and retention. This recommendation now forms a cornerstone of the model, ensuring a strong focus on nurturing staff and improving their emotional health.

Transforming lives Supporting Healthcare Leaders across the Commonwealth

Dementia Care International currently supports healthcare leaders in eight Commonwealth countries who are implementing *Spark of Life*. Through the Dementia Foundation for *Spark of Life*, (Dementia Care International's charity arm), scholarships have been provided for CommonAge Ambassadors to attend the certified three-week Master Leadership Programme. This certifies them to implement *Spark of Life* in their individual services and regions. Furthermore, ongoing leadership support, education and mentoring has been provided on a personal basis to each Master Practitioner.

Spark of Life Model of Care creating an exceptional culture & care delivery

By Mischeal McCormick, Master Practitioner, Owner of Adriel House & Adriel Rest Home, Amberley, South Island, New Zealand

Adriel House and Rest Home are two dementia specific homes, situated in a rural farming community, 40 kilometres north of Christchurch, New Zealand, each with 21 residents. *Spark of Life* was chosen as it includes specialised education, with tools that enable this information to be passed on to every staff member in the facility, as well as a self-evaluation guide that supports continuous improvement as best practice. Education resources provided as part of the model are well presented, researched, easy to follow and of high quality. From a leadership perspective, the ongoing support, mentoring and two monthly professional development teleconferences are valued.

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This approach has enabled Adriel to have a point of difference, to think outside the box and move away from the boundaries of convention. *"We have learned to discover new possibilities and solutions to challenging issues facing people living with dementia. This has led to innovation and new ideas in the team. These ideas don't need to be expensive or grand, but they have a huge positive impact on staff, residents and families."*

Adriel's culture and care delivery has been enhanced, providing genuine person-centred care. Each resident is appreciated as an individual person and supported on their own journey. All staff at Adriel work as a team, supporting people living with dementia. Families are also included, invited and encouraged to share in the care of their loved ones. Everyone communicates and works together to ensure the residents remain as individual and independent for as long as possible. This focus is integrated into their daily support, written care plans, and it is now the norm.

Meaningful activities based on the *Spark of Life* philosophy are provided for residents which give them purpose, motivation, opportunity for reminiscing and boost their self-esteem. Residents now have a reason to get out of bed in the morning. Because of this, for the last 10 years, we have not required the use of personal or physical restraint. In addition, fall rates have decreased. Due to the welcoming, inclusive and understanding atmosphere created by all staff, new residents feel at home and settle in quickly.

Staff have shifted to a rehabilitation mindset and residents remain independent for longer with their quality of life improved. The doors to the garden are open for residents to walk freely in and out and they are encouraged to collect the paper from the mailbox, pick flowers from the garden, feed the numerous animals, weed and water plants and vegetables. Staff are empowered and their self-esteem and confidence in their job has improved. Their communication with residents is enhanced and they experience immediate positive results from the residents. Witnessing these outcomes is profoundly rewarding and is at the core of why staff now love to work with people who have dementia.

In April 2014, Adriel received its first Continuous Improvement (a New Zealand standard that represents exceptional outcomes) by independent auditors for using Spark of Life and for being able to evidence a reduction in behaviours of concern and depression, this has been repeated in 2017 and 2021.

Transforming the lives of people with dementia – providing life-changing education and outreach support in Uganda

By Richard Semanda, Spark of Life Master Practitioner and Geriatrician, Founder of Geriatric Respite Care Foundation and CommonAge Ambassador and Jesca Nakiribango, Founder of the Dyslexic Rise and Shine Association, Kampala, Uganda

Introduction

Geriatric Respite Care Foundation and Dyslexic Rise and Shine Association are the first organisations in Africa to pioneer the Spark of Life, educating families, communities and health professionals on how to support people living with dementia.

The organisations have observed unpredictable health challenges in people in Uganda, and especially when it comes to older persons living with dementia. The situation is worse as there remains an outdated, negative common perceptions and assumptions about the condition. There is a rapidly accelerating ageing population in Africa, and the problem has been compounded by the fact that there were no training opportunities for dementia care.

Pioneering Africa's first rehabilitative *Spark of Life* Day Centre has transformed many lives of people living with dementia in Kampala and the surrounding region in Uganda. Through educating the local and wider community, the team now provides vital support and information, as dementia in Uganda is often misunderstood and even feared.

The two organisations support each other. Ms. Nakiribango implements *Spark of Life* with her teachers at the Rise and Shine Dyslexic Association. The *Spark of Life* skills we use empower the students to walk tall with confidence and to also have meaningful roles as volunteers for Mr. Semanda's Geriatric Respite Foundation. The students form a special relationship with the older people living with dementia, as the centres share the same building.

Working in a pro bono capacity, the organisations provide a *Spark of Life* Community Outreach programme educating families in smaller towns and villages and rural/remote organisations throughout in Uganda. This outreach service provides, 24-hour care for the 300 nuns at Nkokonjeru Convent. The organisations oversee the programme and provide monthly educational support and mentoring for the nuns, so they can care for their elders with dementia. The result is that the nuns in their community with dementia who had formerly been locked in rooms are now involved in their community with compassionate care, and meaningful connections with the other nuns.

The model is transforming the lives of clients and families, and the wider community, with life-changing and lasting results. The impact of this education helps restore relationships broken through dementia, facilitates inclusion, and empathy both for people living with dementia and their families.

The teaching inspires the community to understand dementia through this model, and staff now have new skills. By reducing the stigma and misunderstandings about dementia, abuse towards people living with dementia in Uganda is being prevented.

A multi-dimensional impact in dementia care in Nigeria

By Elizabeth Aina-Scott, Founder HebronLove and Care Centres and HebronLove Elders Home, Lagos and Ibadan, Nigeria

Established in 2003, HebronLove and Care Centres began as a response to the unmet psychological and emotional needs of the elderly in Lagos. What started as two monthly meeting outlets has since burgeoned into a network of six branches across two cities by 2024, with an annual attendance of over eight hundred individuals including people living with dementia.

Since adopting *Spark of Life*, HebronLove has evolved into a multi-dimensional organization, offering a range of services aimed at holistic well-being. Initiatives include emotional support, psychological counselling sessions, and medical assistance via regular medical outreaches. Emotional well-being through daily interactions and the implementation of *Spark of Life* principles is prioritised, while also providing training to carers to ensure excellence in care delivery.

In line with the commitment to meeting the changing needs of older pople, HebronLove expanded its services in September 2022 with the establishment of HebronLove Elders Home. This transition reflects a dedication to providing comprehensive care solutions, from community-based support to residential care, ensuring that every elderly individual receives the attention and care they deserve. As a result of this model, the team are now driven by a passion for improving the lives of the elderly and remain steadfast in the mission to provide compassionate care and support to this cherished demographic.

"Undertaking the Spark of Life Master Leadership Program to learn how to implement the model not only enabled me to enhance the care for my service, but it helped me understand on a personal level how to support a close family member with dementia. The knowledge I acquired during the program gave me a profound insight into what the issues are for those with dementia, and their personal needs. I learned to step into the shoes of the person with dementia with empathy and compassion and provide the skilled care that enabled them to re-engage with life again". (Elizabeth Aina-Scott)

HebronLove Elders Home offers aged care solutions for the elderly, with specialised care support for residents through the implementation of *Spark of Life*. Services available are Assisted Living, Dementia Care, Home Health Care, Respite Care, and Social Care Services. Staff are trained to look without judgement at each resident, ensuring they are treated with dignity and respect. There is open interaction now between staff and management, fostering a collaborative and supportive environment.

The team has learned to recognise the inherent core emotional needs of each individual. By fostering empathetic interactions between carers and residents, the staff create a nurturing environment where residents feel loved, valued, and empowered.

Providing Dementia Awareness and Innovative Education in Kenya

By James Mbatia Kinuthia Spark of Life Master Practitioner, CommonAge Ambassador
Founder of Sir James Care Homes Africa, Kenya

Sir James Care Homes provides care to older people and is the first in Kenya supporting locals at the grassroots level in remote villages. The mandate of the service is diverse, from taking care of people living with dementia, to those who need palliative care, filling up the gap which existed for many years. The facility and homecare programme consists of Asians, Caucasians, and Africans of different cultures.

"I was awarded a scholarship from Dementia Foundation for Spark of Life and became certified as a Spark of Life Master Practitioner in 2021. This leadership support, along with the personal mentoring I receive regularly from Dementia Care International, is enabling me to achieve my vision of positively transforming the lives of people living with dementia in Nairobi and to enable my service to become a role model of best practice for others in Kenya".

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The *Spark of Life* Model of Care has been in place since 2021, as a best practice model that facilitates dementia rehabilitation and quality care based on empathy, kindness and compassion. The service has been providing dementia education through this model to improve the skills of personnel, and the quality of life for people living with dementia.

Spark of Life is key to supporting our vision to elevate the quality of residential and community care services, including their families. Implementing the model has demonstrated outcomes, via a comprehensive self-evaluation process in the following areas:

1. **Enhanced staff skills –** as a Learning centre, volunteers, managers, supportive partners, interns, and staff remain unique carers in the communities having learnt dementia rehabilitation. The education makes it easier for the staff to connect and communicate meaningfully with the residents and has boosted their confidence and enjoyment at working in dementia care.

2. **Benefits to residents –** long term stay residents are more comfortable and rejuvenated and are sustaining and improving their physical and mental health. This is confirmed with testimonials from family members who visit. In addition, since introducing the model there has been reduced levels of depression in residents. Residents are much happier, and their 'settling in' time span to the home is reduced due to the dementia education, friendly environment and proper leadership.

3. **Enhanced reputation of the service –** more organisations, especially hospitals, have shown interest in establishing strong partnerships over time, due to word-of-mouth recommendations in the community. In addition, there are more enquiries from the community about the services provided. It has become easier to attract and retain staff in a time when many African care workers are seeking overseas employment for higher wages.

4. **Benefits to the community –** women living with dementia remain more vulnerable and their prevalence is higher than men in Kenya. Dementia rescue and care is a life-saving part of the service for some of these most vulnerable people in our community.

Spark of Life education provided through the service has reduced cases of labelling, abuse and neglect and gives rehabilitation opportunities by creating much needed awareness, and a consultation platform such that more people can now call and talk freely about the challenges that they are facing.

Outreach support is enabling the communities to realise that having dementia is not witchcraft, but instead it is a medical condition that can have many causes and needs proper care. This knowledge and awareness is preventing people living with dementia being put to death in rural communities in Kenya.

Community education provided with the model has also enlightened other sectors about dementia care and is helping to reduce for instance, financial abuse and other forms of abuse.

Spark of Life Model of Care – Transforming the lives of people living with dementia in Kolkata, India

By Nilanjana Maulik, Spark of Life Master Practitioner, Kolkata, India Secretary, ARDSI Kolkata, Fellow, Commonwealth Association for the Ageing

The team at ARDSI Kolkata been implementing the *Spark of Life* Model of Care in the services for people living with dementia since 2017, across the eastern region of the country covering the major cities to grassroot villages.

From discussing *Spark of Life* education during awareness building campaigns and with the practical guidance and support of Dementia Care International to train families and professional carers, the impact in terms of deeply connecting with the cause and the journey of the person with dementia is significant.

The most effective aspect of the model is that it has an essential focus on humanising dementia care. This very fact touches people across the highly populated region and hence the impact is profound. In addition, during training sessions with carers the promise that the knowledge and skills are not just for people in the early to moderate stage of dementia, but also for the advanced stage, gives immense hope to those who are in caring roles.

Simple lessons have been learned from the model, for example that to support the person with dementia to be set up for success instead of failure, to help change the perceptions of the community in a positive way towards the condition and address their lack of understanding of the needs of the person with dementia and older people in general.

Staff members and volunteers can relate to *Spark of Life* and are enriched and encouraged to validate the awareness and lucidity of the person by accepting their ways. A client at the Sriti Sudhay daycare centre who thought the space was a temple was not corrected, if he appeared to feel good.

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The focus of the staff was to initiate a conversation and lead it to a positive connection. Another person who found it meaningful to help in the kitchen activities was allowed to do that if her safety was not compromised, or no one else was disturbed. By practicing the *Spark of Life* Model of Care, we guarantee that every member spends their day with lots of smiles, laughter and joy.

The other aspect is that the model helps staff morale, energy and attitude in a valuable way. The staff learn to question themselves and the care environment with insight and their new knowledge consistently. Their positive comfort and heightened confidence level when they are with their clients speaks volumes about this best practice model.

Spark of Life has helped deliver the desired quality of service, promoting experiences of dignity, respect and unconditional love to help people living with dementia experience themselves as valuable persons.

Giving Hope and Saving Lives in Zambia

By Anderson Simfukwe, Founder Alzheimer's and Related Dementias in Zambia (ADDIZ)

Alzheimer's Disease and Related Dementias in Zambia (ADDIZ) is a registered not-for-profit organisation operating in Zambia with the mandate to look into the plight and welfare of older people living with dementia. The organisation is a one-stop shop for all the needs of older people living with the condition.

Using the *Spark of Life* Model of Care we offer the following services to the public:

1. **Dementia Friends Sessions**
2. **Rehabilitative Programme**
3. **Outreach Programmes**

The organisation is currently lobbying the government to promulgate laws, policies, plans and strategies on dementia. We are in serious talks with the government on the formulation and implementation of a National Dementia Plan that will effectively address the needs of people living with dementia and their care partners in both formal and informal carer roles. As at present there is no policy direction for people living with dementia. It is our clarion call to the government to speed up the enactment of various legislations on ageing and dementia in Zambia.

The philosophical ingredients of the *Spark of Life* align well with our jurisdiction and cultural background that enhance caring for our loved ones within our families. The model transcends disease, disability, changed behaviours and differences, to connect with the other person with compassion. ADDIZ utilises the model in the communities and many family members of our clients have confessed the effectiveness of this therapeutical approach and its transformative efficacy.

The model has elevated the wellbeing of our entire target group visiting our centre and those in our support groups. There is positive attestation from our clients, patients, staff and families, who report that this model is a true testament of therapeutical healing. There has been a beneficial impact in our district hospital, schools, and prisons as well as at the centre through the smiles we are putting on the faces of our clients.

Solving the challenges of dementia care in India

By Clara D'Souza, Operations Manager, Spark of Life Master Practitioner, Adharta Trust, Mumbai, India

Adhata Trust is a private social enterprise which is funded by the Trustees and there are no contributions from the members (clients with dementia). The members registered at the 14 centres are from different class. Irrespective of their cultural background, they come together to participate as a group of individuals with the need for care and compassion. Majorly, an after effect of the pandemic is the growing need to address their mental health due to loneliness.

It was an empowering experience to introduce the *Spark of Life* at Adharta Trust, to practice this ideology for moving from the society's perception of disability to ability. Every member of this service is now working towards adding quality of life to older people.

The model enables staff to practice humanised connections with clients who have dementia. This helps to build a strong bond of togetherness which motivates the staff to be more creative and in turn remain attached to the service. Each member with dementia coming to all 14 centres are welcomed with smiles and a personal greeting. The trained Coordinators experience the joy of having the elderly with them and for the members it is an unconditional bond of love and belongingness. *Spark of Life* Education has had a great impact on the approach of the staff as well as their understanding of clients who are living with dementia.

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As a Master Practitioner, learning continues through their various modules designed by Dementia Care International to enhance our skills further. At the beginning of the year, the first module was on an innovative method of goal setting, a valuable tool to segregate goals for long and short term. It highlighted how to remain focused on goals and to prioritise work. A strong and encouraging line taught is that the Master Practitioner is a catalyst of inspiration for the team to go beyond the status quo, and awaken a desire to bring positive change, , and with an optimistic perspective.

Spark of Life Model of Care: a Neuro-Rehabilitative focus in Singapore

By: Nur Sahara Binte Kamsani – Spark of Life Master Practitioner, Medical Social Worker, RenCi Nursing Home, Nang Soe Mon Oo, Spark of Life Master Practitioner and a Nurse Clinician (formerly RenCi Nursing Home, now residing in Finland)

The *Spark of Life* Model of Care is an approach to enriching another person's life, based on love, empathy, and respect. The *Spark of Life* Rehabilitative Programme (one aspect of the model) educates facilitators in the skills for neurorehabilitation to provide the opportunity for people living with dementia to experience improvements in their cognitive and social skills.

The *Spark of Life* Rehabilitative Programme was piloted for five weeks with six residents with dementia. The Bradford Wellbeing profile was used to evaluate the wellbeing of the club members before and after this programme. Wellbeing profile scores of all club members were increased. The indicators show that the higher the score, the better the wellbeing of the individual.

Positive feedback was received from residents and their families as well as care staff from the nursing home. The team strongly believe that the *Spark of Life* Rehabilitative Programme enables care staff to shift their mindset from impossible to possible. With the positive and encouraging outcomes from the pilot programme, the team has decided to continue with the *Spark of Life* Rehabilitative Programme.

Spark of Life Communication Skills is incorporated into daily interactions with other residents, colleagues and community partners at work. This interaction of love and genuine desire to bring the best out of people changes my work attitude and improves work relationships.

Dementia care in South Australia

By Tania Hammond – EFNLHN Aged Care Nurse Practitioner, Anthony Ryan – EFNLHN Nursing Divisional Director Older Persons and Trudy Wadsworth – Nurse Unit Manager, Elliston Hospital

The Eyre and Far North Local Health Network provides residential aged care services at 10 sites across a geographical region of over 330,000 square kilometres that includes regional, rural and remote locations in South Australia. Approximately 60% of the older people who choose to live in our care homes have dementia. Expert services for people living with dementia frequently reside in metropolitan or larger regional centres, and for many of our community members this means travelling long distances to access specialist services and support.

It has been necessary to develop innovative ways of providing dementia specific support and services that are close to people's homes, and still reflect best practice in care. To support every older person to live their best life possible through tailoring services to meet their psychosocial and health needs, we chose Dementia Care International's *Spark of Life* Model of Care. The model safeguards and enhances the human rights of people living with dementia, promoting self-determination and facilitating emotional and psychological wellbeing through human-to-human connection in its purest form.

The education provided assists staff to look past the diagnosis of dementia and see the real person. This enables carers to assist in meeting individual's needs, reducing stressful unwanted situations and setting individuals up daily for success. It enables true person-centred care, creating meaningful and long-lasting relationships between clients, their families, and our staff.

Spark of Life was introduced to the service in 2011, and by 2019 there were four Master Practitioners in the Local Health Network. Master Practitioners are essential as they are drivers of the model, demonstrating effective communication techniques, delivering cost-effective education to staff and families, and implementing the quality management system. A key component of the education is providing skills to facilitate neurorehabilitation in people living with dementia, thereby also reducing behaviours of concern. The healthcare services that have implemented the model experience genuine wellbeing among the people who live there. There are many joyous moments, and both patients and staff have renewed hope.

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This culture shift promotes a supportive environment, and care staff are empowered to provide best practice care to their clients, residents, and patients. With the model, people can successfully shift from caring with their minds to also caring with their hearts (which is required in dementia care), moving from a task orientated organisation to a person orientated organisation, and being able to shift their focus to the perspective and emotional needs of the individuals they are caring for.

Spark of Life Model of Care: Outcomes

Below is a summary of the collective outcomes based on using self-evaluation tools designed as part of *Spark of Life* across the diverse services that have implemented this approach:

For Residents, Clients, and Patients

- Specific improvements in mental abilities, language, self-esteem, social interactions, and emotional well-being.
- Elevated ability to participate in daily activities in ways that were thought to be lost due to dementia.
- Prevention of behaviours of concern, eliminating the need for psychotropic medications.
- Reduction in depression and falls.

For Staff

Enhanced teamwork leading to elevated job satisfaction where staff are empowered, and their self-esteem and confidence improved.

- New skills to facilitate effective communication with residents, clients and patients preventing the mental stress of potentially angry and aggressive responses from those in their care.
- Profound attitudinal shift regarding dementia from being task-oriented to being person-oriented leading to enriched care experiences.
- Uplifting impact with happier workplaces and staff looking forward to coming to work.

For the Healthcare Services

- The development of vibrant and values-based places to work and learn.
- Increased retention and recruitment of staff who genuinely care.
- Becoming preferred employers and providers resulting in operation at full capacity with no vacancies.
- Excellence in audits, in countries where accreditation is in place.

For the Community

- Reduced stigma and fear around dementia through community education that creates awareness and new understanding about dementia.
- Families having improved relationships and gained skills to care longer for people living with dementia at home.
- A broader application for people living with dementia in mental health services, prisons and for those suffering trauma.
- In Africa, witchcraft accusations of people living with dementia are diminishing,lives being saved, and elder abuse is being prevented.

The *Spark of Life* Model of Care provides a cost-effective transferable framework of education and humanising care practices that are meaningful and having a life changing impact in diverse cultures and in all areas of care provision.

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Train the trainer programme: a practical solution using a strength-based collaborative partnership model

By Femada Shamam

Africa is witnessing the fastest-growing population of older people globally. The demographic shift necessitates preparedness to harness opportunities and address challenges, particularly concerning the increasing prevalence of dementia. With the anticipated rise in the number of people living with dementia, society faces significant impacts on healthcare, social services, and caregiving capacities. This underscores the urgent need for education and training on dementia and evidence-based intervention strategies tailored to the diverse needs across the continent.

Genesis of the train the trainer programme

The Train the Trainer programme emerged from the fertile ground of aligned visions for enhanced practices in supporting older persons, with a special focus on dementia care. This practical solution resulted from a collaborative effort, exemplifying how like-minded organisations can amplify their impact through partnership.

The collaborative partnership model

The success of the Train the Trainer programme hinged on three essential components: the network, the host, and the expert.

The network: Commonwealth Association for the Ageing (CommonAge): CommonAge is the only accredited organisation within the Commonwealth structure that focuses on inclusive ageing, with a specific emphasis on older people. The organisation operates on two fronts: advocacy and lobbying and supporting best practice models at the local level. Since 2018, the Africa chapter of CommonAge has been building solidarity and encouraging sharing and learning amongst its members. The idea of a training programme in South Africa was first discussed in February 2023 by the then Vice-Chair of CommonAge.

The host: The Association for the Aged (Tafta): Tafta, a non-profit organisation based in Durban, South Africa, has been providing care and services to older people for the past 66 years. Driven by the purpose of making dignity, growth, and a meaningful life a realistic prospect for all elders, Tafta was approached to host the programme. They completed the application to the Fulbright Programme and were responsible for identifying potential participants, logistical arrangements, and contributing to the training content.

The expert: Dr. Varughese: Dr. Varughese, a distinguished gerontologist, passionate about building the capacity of individuals to support older people through evidence-based practice, played a crucial role. Drawing on her extensive experience in tertiary education and philanthropic work in India, she ensured the content was relevant and relatable to the participants.

The training programme

The intervention was designed as an intensive Train the Trainer programme for individuals across disciplines working in the sector. The twenty-eight participants included social workers, nurses, administrators, policymakers, researchers, entrepreneurs, and social justice advocates. The training combined lectures and group work, expertly designed to support adult learning by drawing on the unique experiences of the participants.

The training impressively brought together individuals from government and civil society, working harmoniously to create solutions centred around supporting older people, especially those living with neurocognitive impairments like dementia. Participants from three different countries added to the richness of experiences shared, reflecting the need for diverse solutions to address the needs in their respective sectors.

Outcomes of the training programme

The programme yielded significant outcomes:

1. **Improved understanding:** Participants from various disciplines, including social work, nursing, research, policy development, business development, management, psychology, and caregiving, reported a significant improvement in their understanding of neurology, sensory systems, dementia, mental health disorders, and care plans. One participant stated, "It was what I needed to enable best practices and service excellence."

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2. **Comprehensive assessment tool:** Participants were introduced to a Comprehensive Assessment Tool for Older Persons.
3. **Effective group activities:** The group activities were intense, insightful, and effective for learning, enhancing the participants skills and knowledge.

Knowledge cascade: Participants committed to cascading the knowledge gained to other role players, including social service practitioners, traditional healers, health ministry departments, students, carers, social workers, and nurses.

Policy influence: The training could potentially inform policies on elder care in developing countries like Kenya through advocacy by local organisations, for example Age Watch Africa.

Knowledge sharing network: A network of knowledge sharing and support was developed between Tafta, the Fulbright Specialist, and the 28 participants, ensuring the training's impact extended into their cities and communities.

Reflections and future directions

The training programme was more than the sum of its parts, rooted in deep sharing and solidarity among the participants. Over 12 days, information was disseminated, friendships were forged, and possibilities for partnerships were broached. Group dynamics played a key role in the learning process, fostering a collaborative environment.

Inspiring words from participants:

- *"We found a way to build a team."*
- *"I have received so much information."*
- *"We will reciprocate; we will be as kind as you were to us."*
- *"The lessons were quite extensive, but you also made them very practical for all of us to understand."*
- *"The group sessions were extraordinarily informative. People shared their views and experiences unreservedly, growing one's thinking and perceptions about many things happening in the sector."*
- *"The plan of action we shared yesterday is to ensure we don't only train six people per person but triple or quadruple that and reach every space within the sector that we can with the resources we have."*
- *"This is the start of a lifelong collaboration."*

Reflecting on the Train the Trainer programme, the African proverb aptly captures its essence: "Gather at the old watering holes for more than water; friends and dreams are there to welcome you." The increasing number of people living with dementia and the caregiving responsibilities require everyone in society to play their role, whether in education, training, advocacy, direct service delivery, or informal caregiving. The Train the Trainer programme stands as a testament to the power of collaborative partnerships in addressing the needs of an aging population and ensuring a dignified and meaningful life for older people.

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Technology/AI and Reminiscence therapy – ELD-AR™

By Mansur Dalal

According to WHO, currently more than 55 million people have dementia worldwide, over 60% of whom live in low and middle-income countries. Every year, there are nearly 10 million new cases. This number will almost double every year, reaching 139 million in 2025[7].

Key findings from the Longitudinal Ageing Study of India (LASI) and Senior Care Reforms in India 2 – Reimagining the Senior Care Paradigm: A Position Paper, Publisher, NITI Aayog Government of India, suggests that around 20% of the elderly in India have mental health issues[8]. The prevalence of probable depression among the elderly is ten times higher than the self-reported prevalence of diagnosed depression, implying a greater burden of undiagnosed depression.

Almost a third of the elderly population exhibits depressive symptoms. In India, an estimated 4 million people are living with dementia, and this number is projected to increase to 14.32 million by 2050.

Digitalisation & Consumption Patterns:

An expected rise is visible in digitally driven care and support services, across the globe. In 2022, the digital healthcare market in India recorded a revenue of INR 440.49 billion (US$5.30 billion), and is projected to achieve INR 1.16 trillion (14 billion US$) by 2028, with a CAGR (compound annual growth rate) of 15.76% during 2023-2028[9].

The market's robust growth is attributed to widespread smartphone and internet adoption, complemented by favourable government policies.

As service delivery is going increasingly online, digitalisation presents significant opportunities for societies with ageing populations. The market for digital technologies, especially those suited to the needs of the elderly, like therapeutic, assistive & health monitoring devices, smart home technologies, and telemedicine services, is expanding in response to the rising market for tech-based elderly solutions in India. Indian elderly, especially those aged 60-70, are embracing digital technology through various means like online transactions, online shopping, social networking, etc. As more senior consumers become aware of the advantages and convenience of digital technologies, this trend is anticipated to accelerate.

It is in this digital space that technology and AI is moving at a fast rate for care of people living with dementia. The aim and objective are towards occupational therapies and activities geared at maintaining the quality of life of a person with dementia. Since memory loss is the main symptom, no cure exists, but medication and management strategies may temporarily improve symptoms.

Reminiscence Therapy:

Reminiscence Therapy (RT) is a therapeutic modality for cognitive stimulation therapy [10] and is taking on a more and more important role, side by side with Information and Communication Technology (ICT). This has the potential to improve and to enhance RT by facilitating access to and selection of biographical information and related content or by providing novel multimodal interaction forms to trigger memories.

Reminiscence Therapy (RT) is an evidence-based behavioural intervention that involves the introduction of familiar pictures, music, or other materials to help individuals reminisce about their past experiences. RT is the most used nonclinical/ pharmacological therapy in Alzheimer's and other types of dementia and has been used since the 1960s in home care, nursing homes and hospital settings. Published reviews of randomised, controlled trials using RT have suggested that RT can significantly reduce behavioural symptoms in individuals with dementia and in seniors with social isolation

A major limitation of RT to date, was that it must be provided physically by a human carer. For this reason, it is highly labour-intensive, repetitive, and time-consuming, and therefore, challenging to deliver at scale. It is simply not practical for a family carer to sit with a person with dementia to go over the same photo scrapbook, home videos, or music daily, and using a therapist or professional therapist for frequent RT is cost prohibitive. Furthermore, RT is given when it is convenient to the carer, not at the convenience of the person with dementia, further limiting the consistency of its use.

There is a need for digital RT technologies that are scalable and that can be provided frequently, consistently, and without the need to depend on family members or healthcare providers.

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Designing effective ICT-RT systems means providing reminiscence moments that effectively add value to the daily lives of people living with dementia, as well as their environment. More so if the system's interaction as well as audio-visual output modalities take the individual person with dementia's sensorimotor skills into account, and – most importantly – if the content and/or game nature of the multimedia intervention is interesting and thus elevates the mood of the participant.

Through various research and case studies conducted on this subject and lessons learned through hypotheses and interpretations, the findings are promising to pave the way to memory-activating – and at the same time fun – through multimedia ICT RTs as the way of the future [11].

The difficulty employing this therapy is gathering personal and family memories to engage the person with dementia in life-review. Digital RT bypasses these difficulties, allowing family to engage in the creation of digital content designed to highlight person-specific memories administered via internet and communication technology.

The focus is how Digital RT (a non-pharmacological intervention) reduces dementia related behaviour.

With the advent of more economical and ergonomic designed AR/ VR headsets, streaming of digital content is on its way to become more immersive and inclusive, much like the "Van Gogh museum".

Mr. Mansur Dalal, who lived alongside his mother who had Alzheimer's, stumbled upon the fact, that his mother would occasionally hum a particular song of the 50's and when the same was shown or played, she surprisingly sang along and almost lip synced. When devotional hymns were played on audio or audio/ video, his mother would sit up straight in a pious respectful position, demonstrating that though her memory had failed, there remained vestiges of memories buried deep within, which just needed an appropriate trigger to surface and change the environment, her mood, and her behaviour.

3 days after her sad demise in late 2023, was born ELD-ARTM (Experience, Live, Dream Augmented Reality), a novel technology platform for memory triggers, under reminiscence therapy, that runs on Android-or IOS based devices. The solution standardises the collection of biographical information through care team interaction. Digital artifacts (photos, music, videos) are assembled through proprietary interfaces to produce a person-centric digital RT session.

The individualistic memories are sourced from family and/ or individuals themselves, spruced, curated and catalogued in relation to time, events, and other related segments.

Digital RT sessions are shared with the person with dementia, 3-4 times per week, allowing them to experience benefits of reminiscence therapy through an automated interface. Minimal on-staff time is needed. Proprietary AI, which is currently being refined, records their emotional reactions to stimuli presented throughout each session, allowing future sessions to be tailored towards those stimuli producing the highest level of positive response.

The facial expression recognition process is configured for emotions recognition in parameters of anger, happiness, surprise, sadness, or indifference.

Results from proof of concept

A proof-of-concept study was initiated with 250 seniors with dementia and empirical data concerning mood improvement was gathered onsite and collated through 3 metrices of:

- **Mental status**
- **Apathy scale**
- **Carer burden scale**

Onsite facility staff were assisted by the family member, who used to live alongside the person with dementia, but was limited to the initiation of digital RT sessions and their observation.

The evaluation, whilst not independently verified, demonstrated that results were positive. Seniors with dementia demonstrated consistent mood improvement in sessions. In some cases, mood improvement extended beyond therapy time and improved relations and interactions with family and primary care givers. It was found that the care giver "burden" reduced considerably for a significant time after this therapy, demonstrating "positive spill over" effect. Mood improvement and mental status was confirmed by Neuropsychiatric Index evaluations.

The quality of outcomes improved with increased person with dementia/family/carer memory data input. Seniors with dementia experienced immediate and post-treatment benefits as observed by onsite staff/primary family carer. Best results were achieved with closely curated content from their past. Highest cognitive stimulation and mood improvement occurred from the presentation of digital artifacts provided by family members living alongside.

Appendix Three

The primary aim and concept are to provide MEMORIES ON DEMAND™ under Reminiscence Therapy for individuals with dementia by using their photos, audio recordings, videos relating to healthy, younger moments and time. Either in augmented reality or virtual reality formats, with or without a headset, allowing a person with dementia equal opportunity, at home to receive reminiscence therapy without time or spatial limitations.

Apart from the individualistic stream, there is a parallel stream of generic memories trigger, which in our study has shown more promise and created more excitement among people living with dementia and chiefly family members living alongside.

Under generic memories trigger, elders have an audio/video experience of popular songs, curated, and banked by decades, which instantly triggers nostalgic memories.

People living with dementia can also go on a virtual pilgrimage globally cutting across all socio – eco segments and faith, and on holidays, again cutting across all socio-economic segments.

All memories are streamed on any flat media screens or on an AR/VR headset.

This shift towards technology, AI and machine learning in all aspects of elder care, specifically therapeutic and virtual environment is happening across the globe not only in India, though in India it is ELD-ARTM that has initiated the first step.

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