The Commonwealth

CommonAge
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Dementia In The Commonwealth

A REPORT BY COMMONAGE
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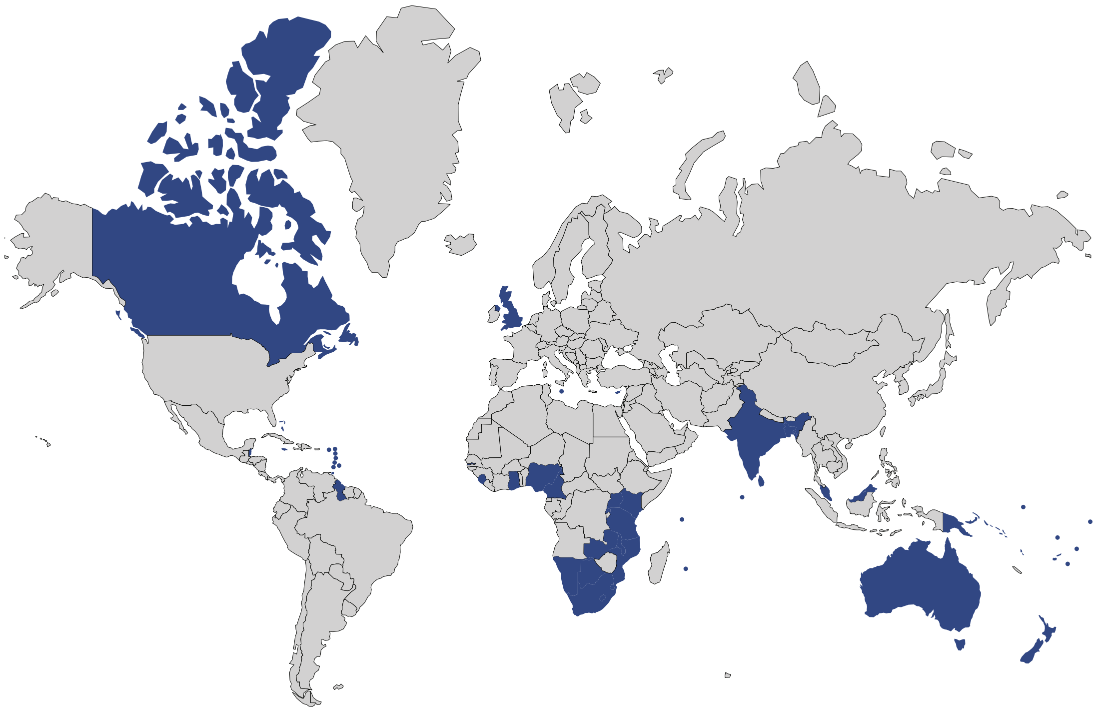
Commonwealth Association for the Ageing



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.

While great care has been taken to ensure the accuracy of information contained in this report up to the date of publishing, CommonAge cannot accept any legal responsibility for any errors of omission that may occur. Users should take appropriate steps to verify information contained and take appropriate professional advice if relevant. CommonAge does not make any warranties, representations or undertakings about the content of any websites or documents referred to in this report.

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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
Alford, Marie and Morris, Dr Tom	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

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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
Shankardass, Dr. Mala Kapur	Creating dementia friendly society in asian countries with specific reference to India

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

Acknowledgements

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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


India
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Global
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Nilanjana

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.

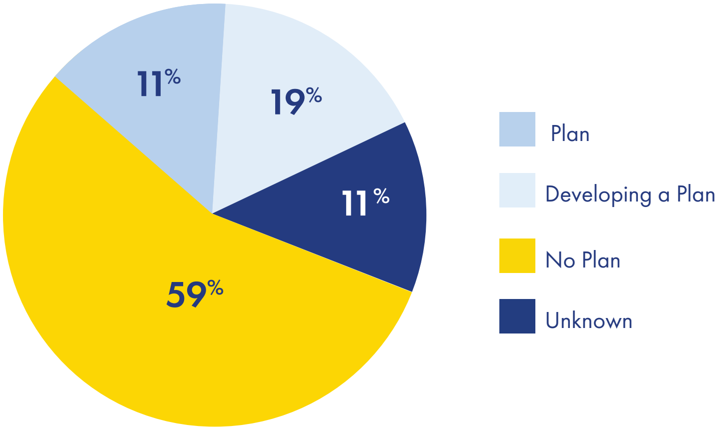
The survey data combined with the extensive global picture contained within *"From Plan to Impact VII: Dementia at a Crossroads"* enabled an overall view of the Commonwealth's progress towards having NDPs in place[5].

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.

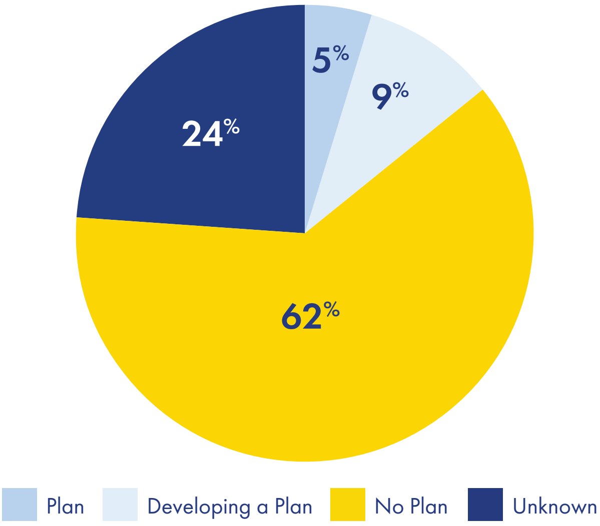
Summary of status of Commonwealth National Dementia Plans



The following charts are a breakdown by Commonwealth region.

Africa

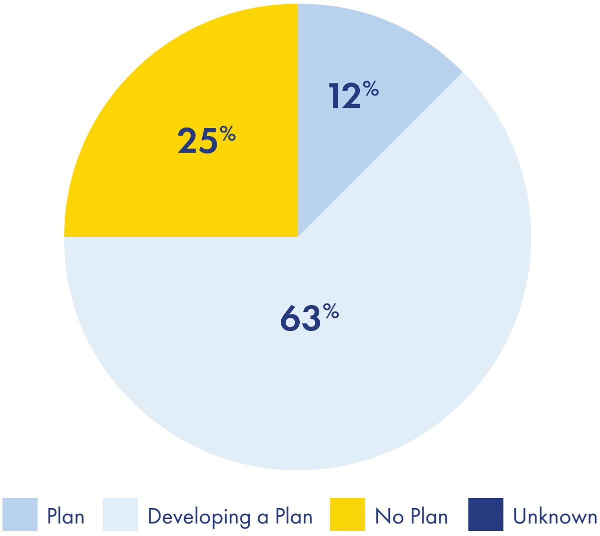
There are many positive contributions from Africa within this report, however there are still several countries where little is known about their approach to developing a NDP. Whilst South Africa, Botswana and Uganda are listed as having 'no plan' there are pro-active organisations leading the call for 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.

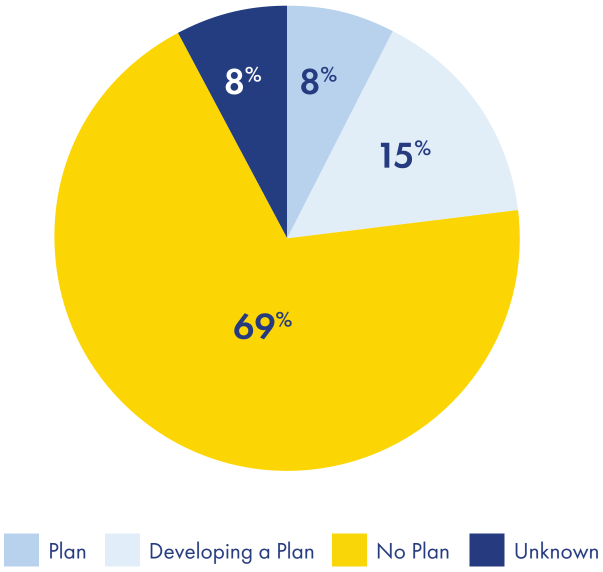


Country	Status of National Dementia Plan
Bangladesh	No Plan
Brunei Darussalam	Developing a plan
India	Developing a plan
Malaysia	Developing a plan
Maldives	Developing a plan
Pakistan	Developing a plan
Singapore	Plan in place
Sri Lanka	No Plan

The development of National Dementia Plans in the Commonwealth

Caribbean and Americas

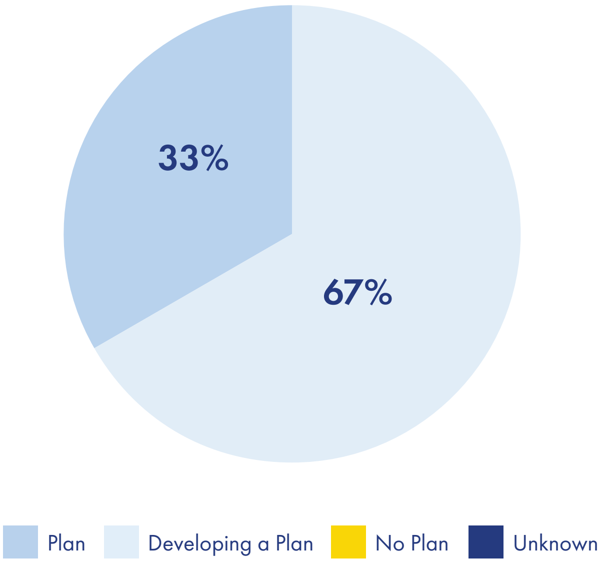
Further exploration is needed to understand the approach to dementia in this region of the Commonwealth.



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

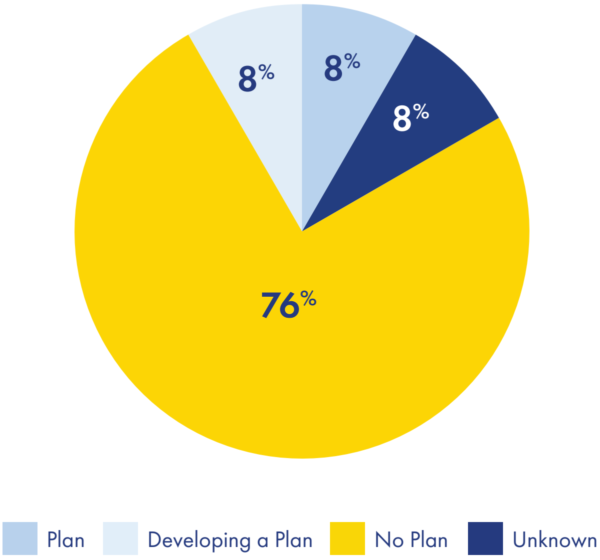
There are only three countries within this Commonwealth region, there is good progress with all either having or developing a plan.



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 USD11 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].

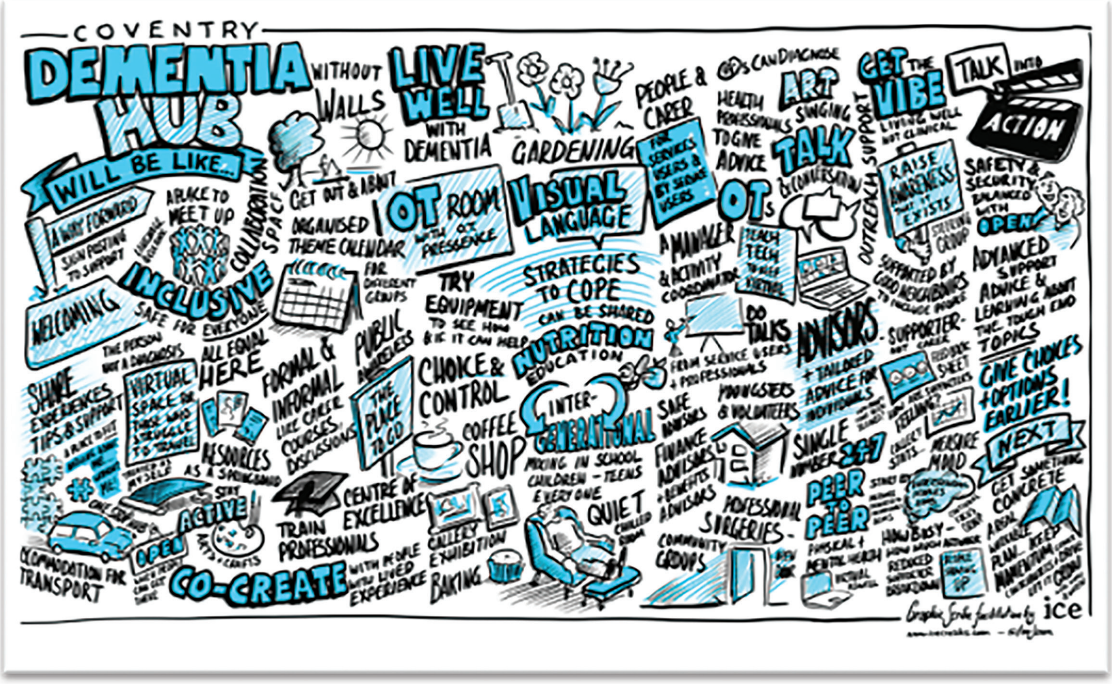
In **Brunei**, demensia Brunei (dB) offers medical and nursing students' sessions about dementia and dementia care skills. These students are then involved in public awareness roadshows, community screening programmes and the use of art, and media channels to raise awareness of the *10 Signs of Dementia*. 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.

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.

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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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