

**World Dementia
Council** Leading the Global Action
Against Dementia

Global dialogue on care: Reflections

The dementia landscape
project

Essays from international leaders in dementia

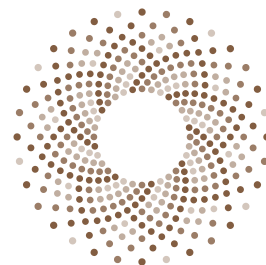


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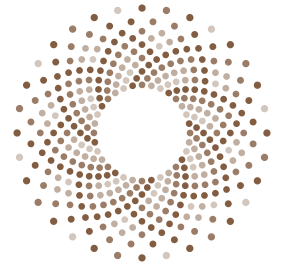
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1. Introduction



Acting now to reimagine how we provide care

Paul Hogan

Chairman, Home Instead® and member of the World Dementia Council



Today, more than 40 million people around the world living with Alzheimer's disease and other forms of dementia will be supported by a caregiver. The care will be provided in a nursing or residential setting, in the community, or in the home.

The caregiver may be an employed, professional caregiver, volunteer, family member or a friend. The support provided typically includes tasks such as bathing, dressing, meal preparation and medication management. The caregiver most likely also provides companionship and a shoulder to lean on.

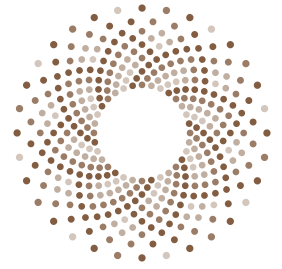
Today, tens of millions of people around the world will be giving care – offering their time and support to help a person with Alzheimer's disease live a fulfilling life. The best place to begin a conversation about care is to acknowledge the enormous contributions made by caregivers.

The contribution caregivers make to health and social care systems is invaluable and their importance to care systems around the world is growing exponentially.

We live in an aging world. Globally, 1 in 11 people are over 65 years old, and by 2050 it will be 1 in 6. Today, some countries are considered to have "ageing societies." There are currently 17 countries with more than 20 percent of their populations over 65. But, by the end of this century, that will be the case for 155 nations.

We should not be intimidated by this. People living longer is something to celebrate. Ageing should not be viewed as a societal detriment, but as an opportunity. As global societies age and the prevalence of Alzheimer's disease continues to grow. There will be more people who need care, and that need will be accompanied by a commensurate demand for caregivers – family caregivers, care partners and professional caregivers.

So, how will we deliver care in the future? It starts in the home. It is typically more socially desirable and cost-effective to provide care for people living with dementia



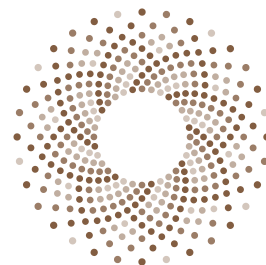
in their homes. What is true of healthcare, is true for care. It is better for the person receiving care, and more cost-effective, to enable someone to live in their own home for as long as they want and is possible. So, how can we do that? At Home Instead, we have been caring for people living with dementia for more than 27 years. Today, we have nearly 100,000 professional caregivers providing life-enriching care to clients in 14 countries.

Home care represents a positive shift in caring for people living with dementia. In order to improve the care system, however, we must do more to support caregivers. In many cases that means the informal caregiver – the family caregiver or a care partner. In the United States alone it is estimated 18 billion hours of informal care were provided for Alzheimer's and other dementias, valued at \$221 billion.

The mechanism will vary. We heard in the World Dementia Council dialogue on care that I co-chaired with Professor Lawlor from Trinity College Dublin about new models of care where effective coordinated care among the many people involved leads to better outcomes. We heard of the benefits technology brings to enhance the care experience and provide support and ongoing training. And we heard about how therapies using music and creative arts reduced stress and agitation.

We hope and pray for a day when there are more effective treatments for dementia and new research looks promising. But until we can eradicate dementia, there is care. We must act now to not only improve, but reimagine how we provide care. By supporting a strong care ecosystem, we can ensure people living with Alzheimer's disease and other dementias live well.

2. Supporting people living with dementia and caregivers



Why care, caring and caregivers really matter



Professor Brian Lawlor

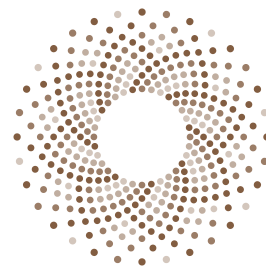
Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

Dementia is one of the greatest health and social care challenges facing our ageing world. By 2050, without the advent of a cure or the availability of disease modifying treatments, it is estimated that 1 in 85 of the world population will have dementia. About 40% of people living with dementia will be in the moderate to severe stages of the illness and require the level of care equivalent to what is currently provided in a nursing home. Furthermore, the majority of the world's population of people with dementia will be residing in low- and middle-income countries (LMICs) where the health and care systems have much less capacity to cope and care.

World-wide, family caregivers play a vital role in delivering support and care to people with dementia. Around the world every person with dementia is receiving, on average, 6 hours of care a day.¹ In high income countries (HICs), approximately 70% of people with dementia are still living in the community; this figure approaches 95% in LMICs¹ where there are no long-term care models and family care is the only option available. Accordingly, informal care costs are inequitably distributed with family caregivers providing over two thirds of informal care costs in LMICs compared to about one third in HICs. And with the changes in family structures that are occurring in many LMICs, family care options for people with dementia are under further threat. Added to this is the prediction that we are facing a major shortage of paid caregivers for older people. The bottom line is that informal care and informal caregivers will not meet the rising needs worldwide for people with dementia unless there are regional and global changes in policy and practice. The availability of family caregivers, their needs and the challenges they experience are key issues and will have an increasing impact on health care provision and the health care system and how it addresses dementia in the years ahead.

In addition to the geographical inequity in the distribution of family caregiving in dementia, another stark inequity in dementia caregiving is that the burden falls disproportionately on women. Two out of every three caregivers are female and one in

*J. Wimo A, Prince M, Gauthier S.
Global estimates of informal care.
Alzheimer Disease International
Report 2018*

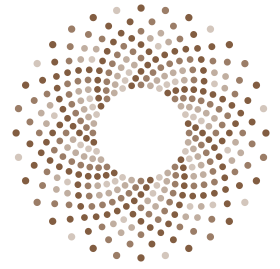


three of these caregivers are actually older people themselves. Women contribute to 70% of all hours of informal dementia care provided globally and not surprisingly, the negative impact of caregiving on women is greater in terms of the mental and physical health tolls that it takes, and the particular difficulties and stresses that arise when behavioral and psychological symptoms emerge. Why is the impact of caring important? The stress and strain associated with caregiving is a strong determinant of the breakdown in the caregiver situation and increases the risk of institutionalization but is potentially alleviated by early intervention and support.

So, what we have is an emerging crisis in care and caregiving that is escalating as the numbers of people with dementia increase worldwide, particularly in LMICs, with the burden falling primarily on women. However, the issues facing caregivers in HICs and LMICs are very different. In many LMICs, in addition to gender biased burden, low literacy and education levels, there are major issues regarding the stigma experienced by caregivers and a general lack of awareness and understanding about dementia. There are few services and supports available for caregivers, minimal access to long term care and respite services and a lack of research about effective culturally appropriate interventions for caregivers.

In order to respond effectively to this crisis in dementia caregiving, it is vital that policy makers first recognise the issue as a major societal problem and then to consider system-wide solutions that must vary according to the country, region and context. Developing and implementing effective interventions and supports for people with dementia must go hand in hand with strategies to identify and address the needs of family caregivers. A fundamental problem that exists is how we currently assess and allocate supports to people with dementia in both HICs and LMICs: we tend to focus on the cognitive and physical care needs of the person with dementia rather than their emotional and psychological needs, a major determinant of caregiver burnout. We also fail to take into consideration the emotional and social health of the caregiver which can be severely impacted by the caring process and contribute to additional strain and to the breakdown in the caregiving process. A more balanced and individualized assessment of dyadic and family needs can lead to improved outcomes. Most importantly, a greater understanding of the drivers of caregiver strain and burnout can inform the appropriate allocation of supports and the type of intervention that best suits the person with dementia and the family caregiver.

Now is the time to focus on what is needed from a policy and practice viewpoint for caregivers of people with dementia so that they can develop agency and have the right supports to continue to care. Caregivers are care partners and must be engaged as key assets in any and every care solution. Most caregivers want to continue to care but need to know that the person they care for will receive effective care and support. In parallel, there is an imperative to develop and implement effective strategies to promote the caregiver's emotional and social health so that a healthy caregiving process can continue. The solution for caregiving is not to diminish the caring role but to collaborate with caregivers in co-producing localized and adapted care solutions that address the needs of the person with dementia while at the same time enhance caregivers' social and emotional health. This requires prioritization and action at a policy level and on a global scale. The time for action and to reimagine and respond to caregivers as partners and supporters of people with dementia is now.



Are informal carers the foot soldiers of dementia-friendly societies?



Stecy Yghemonos
Executive Director, Eurocarers

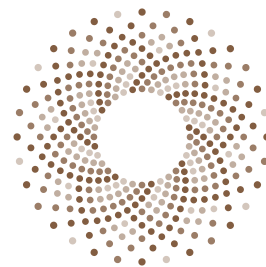
Research has demonstrated that informal carers across the EU play a central role in the provision of care to people with long-lasting needs (age-related dependency, chronic diseases, disability, etc.) According to some estimates, as much as 80% of all care in Europe is indeed provided by relatives, friends and neighbours, outside of a professional context, with women providing the lion's share of care as daughters (in law) and wives/partners.

The estimated economic value of this unpaid care is huge. As a percentage of the overall cost of formal long-term care, it ranges from 50 to 90 %, depending on the member state. When considering dementia alone, informal care accounts for more than 1/3 of the costs associated with the disease in the European region.¹ Yet, recent data suggests that attempts to replace informal by formal/professional care would amount to financing an additional formal care system while sustaining the one in place already proves a challenge. Against this backdrop, it will be very difficult to meet the growing care needs of an ageing population without acknowledging the vital role played by millions of informal carers across Europe.

The provision of informal care does not come without a cost for carers themselves and society as a whole, though. Without proper support, many carers are faced with additional expenditures as a result of the condition of the person they care for, and their caring responsibilities can be a barrier to entering education and paid employment. Working carers often have to perform a difficult balancing act and may be forced to reduce their working hours (involuntary part-timers) or drop out of the labour market, thereby reducing their income and pension entitlements. The gender dimension of this phenomenon is particularly clear. Caregiving can also heavily impact on carers' health and wellbeing: it often requires physically demanding work over a long duration, which may cause injuries and chronic illnesses, and may lead to psychological distress symptoms, such as anxiety and depression. Carers also tend to neglect a healthy lifestyle (e.g., diet and exercise).

These adverse consequences are especially prevalent in the context of high-intensity caregiving situations and dementia, due to its specific symptoms (agitation, anxiety, irritability, lability as well as night-time behavioural disturbances) is a prime example of this phenomenon. Moreover, the lack of confidence regarding the management of behavioural and psychological symptoms related to dementia is very frequent amongst carers.

1. Prince M, Wimo A, Guerchet M, Ali GC, Wu YT, Prina M, et al. World Alzheimer Report 2015: The global impact of dementia: An analysis of prevalence, incidence, cost and trends. London: Alzheimer's Disease International; 2015.



The important role played by carers across Europe – as well as the challenges attached to it – were made particularly apparent during the Covid-19 crisis. The policy responses to the pandemic and, in particular, the lockdown measures put in place across Europe and the reallocation of care services to patients with urgent needs have often exacerbated the challenges facing carers. The crisis has indeed increased their isolation and deprived them from many of the tools at their disposal to maintain an acceptable balance between their social, professional and caregiving responsibilities (e.g. home care services, respite care, etc.)

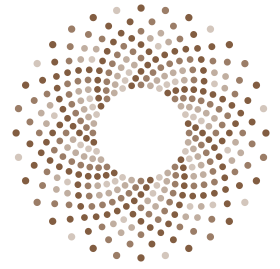
While greater investment in formal care remains the cornerstone of universal and good-quality care, it is now more urgent than ever to develop a comprehensive European strategy to support and empower informal carers. Experience shows that the success of initiatives aiming to address the needs and preferences of carers largely depends on the interplay between a broad set of policies in the social, health and employment fields. This much-needed EU Strategy on care and caring should therefore seek to address all aspects of both formal and informal care. Moreover, it should be structured around choice for both care recipients and their carers: people should have the right to choose freely whether they want to be a carer, and to what extent they want to be involved in caring, just like people in need of care should have the right to choose who they wish to be their carers.

Over the last few years, much has been done to take forward the carers' agenda at international, EU and – to some extent – national and regional level. But policy developments of relevance for carers have often been implemented in a fragmented manner and have not always resulted in real improvements in the daily life of carers. This applies to the dementia sector: the increased recognition of carers' role in recent EU action on dementia² is welcomed but much more could be done to raise awareness of the crucial role played by informal carers in the care of persons living with dementia.

For example, self-recognition remains a challenge since many informal carers do not see themselves as such and do not reach out for help early enough, when in need. On their side, healthcare professionals rarely consider their needs and preferences of carers before a crisis arises. These aspects are nevertheless key for the implementation of the WHO Global action plan on the public health response to dementia.

If society expects informal carers to keep providing care, their vital role and contribution must be recognised and their support needs must be addressed without any delay. This should be a policy priority when rebuilding from Covid-19.

2. e.g. The Council's conclusions on 'supporting people living with dementia' call on Member States and the EC to 'recognise the important role of families and caregivers' (2015)



Providing optimal support to caregivers



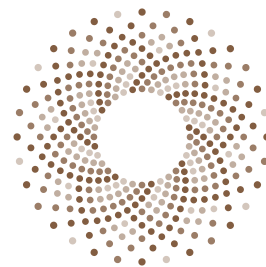
Professor Sheung-Tak Cheng
Professor, The Education University of Hong Kong

Many interventions for informal caregivers have been developed and evaluated in scientific studies. In the year 2019 alone, at least 40 studies of dementia caregiver interventions were reported in scientific journals. Over the past few decades, we have accumulated considerable knowledge about what works and what does not, but we have not done very well in translating this knowledge into actual benefits for the families at large.

The large amount of data testifying the effectiveness of interventions stand in contrast to the fact that many caregivers do not utilize community services to support their role, with lack of time and incompatibility with the needs/preferences of themselves or the care-recipients among the most commonly cited reasons. This suggests that existing services do not cater well for the needs or circumstances of the families, even if accessibility is not an issue. This may be why active attempts to advocate for the families (i.e., case management) or to coordinate services for them have not been found to be beneficial in controlled studies in general, based on findings of a recent meta-analysis.

Many interventions, though found to be effective and translatable, are not taken up by service providers. For interventions to make a real public health impact, they need to move beyond “demonstration projects” and become a regular fixture in the community, and be accessible by families disregarding financial status. However, in reality caregivers receive little beyond a local support group (which in itself has not been found to benefit caregivers according to a meta-analysis) and education and referral resources, while the more effective interventions, usually more intensive and costly to run, are seldom made available to the community after the completion of the clinical trial. Although translation and pragmatic trials are starting to get some attention so as to improve the prospect of changing practice, they are a rarity compared to the vast outcome evaluation literature.

Resource limitation and lack of policy or organizational support are probably the most common reasons for the lack of clinical uptake of caregiver intervention programs. Sometimes, a program may receive endorsement by the government or major NGOs, but decisions are not reviewed as new evidence emerges. In spite of the variety of intervention programs currently available, we lack an established decision-making mechanism to determine what to offer to the families. Some scholars advocate a more or less comprehensive approach to address the varying needs of caregivers throughout the course of illness, which may or may not be practical for low- and middle-income



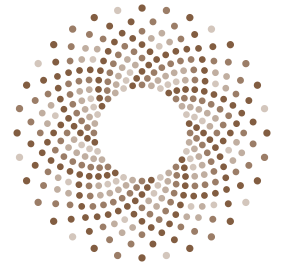
countries. Other factors aside, we will continue to see economic divide in terms of how countries respond to this escalating public health problem. Finding ways to provide effective support to the increasing number of families with dementia, but without overwhelming the system, is a challenge for which there is no readily available answer yet.

Interventions may not be seen as user-friendly by caregivers as well if they impose specific requirements on their schedule. Typically, caregivers' contacts with service providers are limited to follow-up visits for the care-recipient. Finding time to attend extra intervention sessions is often difficult, especially for those employed or having multiple family members to care for. Interventions delivered personally to their residence at a convenient time would be more welcome. These interventions have the advantage of being more individually tailored to the needs of the family. Yet, they are costly and the issue of long-term sustainability must be addressed. For both families and service providers, it seems to make more sense if interventions are readily incorporated into routine clinical practice in a flexible manner, using existing resources and manpower. Such an approach would be ideally suited for embedded pragmatic trials, a nascent development in the field.

One issue that has not been addressed in this literature is dosage. Testing dosage in behavioral interventions is a very challenging endeavor and requires larger sample size than is usually available in this field. Given the general difficulty in recruiting caregiver samples, the fact that this issue has not been subject to research is not surprising. Yet, this is perhaps a million-dollar question as we confront this increasing public health crisis.

For behavioral interventions, dosage may mean number of contacts/sessions or duration of exposure. Varying these parameters and actually evaluating their relative effectiveness is quite unlike a Phase 1 pharmacological trial. Yet, for both providers and caregivers, the issue is critically important. Caregivers have needs that change from time to time, and their subjective needs can diverge considerably even if objectively, they appear to be facing the same issues. This raises a question: Do caregivers need to go through interventions in exactly the same manner? It is often said that interventions should be tailor-made to the needs of the caregiver and the care-recipient. Stretching this axiom further, caregivers should be allowed to "come and go"; that is, they should be allowed to choose the topics (or intervention components) that match their needs most, and skip the others until they become relevant. The field may require a change of mindset from seeing caregivers as patients or pseudo-patients to be treated with a regimen, to regarding them as consumers of assistance. After all, their main goal is to learn caregiving skills.

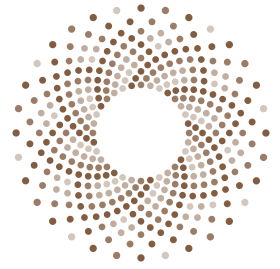
For service providers, variable dosage means that they can serve more families with the same resources. Caregivers who elect to receive the particular intervention module are likely to be more motivated and responsive to it. Guidelines may be drafted to recommend different intervention components (and even different dosages of the same component) vis-à-vis different needs, and let caregivers determine what is most suitable for them. But would such a flexible approach be seen as significant deviation from the intervention protocol? Rather than seeing such deviation as undesirable, I am inclined to believe that there are more pros than cons in backtracking from a rigid plan.



That said, it is also possible that caregivers, when given the flexibility, do not obtain enough dosage of the intervention to make it effective. In reality, it would not be possible to know whether this is true as some caregivers will not respond anyway even with the right dosage. It is also important not to overestimate this risk given the fact that drop out is not uncommon among caregivers enrolled in interventions.

Standardization and manualization are naturally favored by researchers for the purpose of data interpretation and by clinic/agency managers for the purpose of service planning and management. But are they favored by caregivers? It dawns upon me that we have never asked caregivers that question. Perhaps it is also time to work out new interventions with user-based flexibility built into the design and a new research paradigm to evaluate such interventions.

This entry is rightly placed in a volume of “global dialogue”, because it is a dialogue on how to optimize the impact of evidence-based interventions that is very much needed, and the dialogue should be a global one in order to formulate an international consensus to guide the field towards the next steps.



Reflections on the use of technology to support those with lived experiences of dementia



Professor Anthea Innes

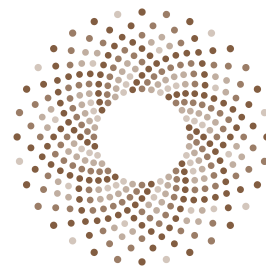
Professor of Dementia, University of Salford

People living with dementia and their care partners face an increased risk of social isolation and loneliness. Technology cannot substitute for in person care and support, but it certainly offers opportunities to enable people with lived experiences of dementia to remain connected and to support independent living.

There are many kinds of technology available to people living with dementia, from simple everyday ‘technologies’ such as equipment to ensure that a gas burner on the hob is turned off, to cups and plates that may be easier to identify and use independently. There are also increasingly sophisticated technologies, such as sensors that can monitor movement and falls and the patterns of movements that could signal a problem and trigger a response from someone who does not live with the person with dementia. There are also technologies to support people to be independent outside their own homes. Devices that use GPS tracking technologies can offer the person with the diagnosis and their family members reassurance that if the person with dementia is out and about on their own and gets lost they know that someone will be able to locate the person with dementia, and that the person with dementia has the option to push a ‘panic button’ to ask for help if required.

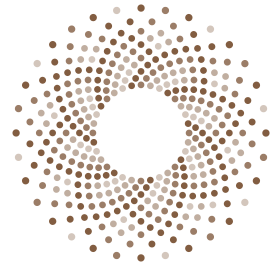
Communication technologies also enable people to remain connected even when living at considerable distances. Or, as has been the case during the Covid-19 health pandemic restrictions on freedom of movement that began in 2020, a way for people to remain part of groups they had previously attended in person. This has involved many learning to use platforms such as Zoom or Teams for group virtual meet-ups; or groups on their mobile phones such as what’s app groups for in the sharing ‘in the moment’ events promoting social connection and sharing of experiences.

As such technology offers many ways to support the person living with dementia. However, it does not come without its challenges. There is a digital divide in society whereby some people have access to equipment such as laptop computers, tablet/ipad devices or mobile phones with sufficient storage, processing ability and power to support apps to enable communication other than by phone conversation or text messaging. In addition, some people have the skills and knowledge to use technology or to help the person living with dementia begin using such technologies, whereas others will need access to resources to enable them to learn and retain information about how to use communication technologies that are new to them. Covid-19 has led to many individuals



using communication technologies that they had never used before, but it has also led to many feeling increasingly isolated if they either do not have the equipment to access online virtual ways to connect with others, or if they are unable to learn to use such technologies when in-person contact that may have facilitated such learning has been limited. In our work with people living with dementia in the North West of England we have used virtual meetings, app groups on mobile phones, but also sending cards and conventional phone calls to retain contact and connection with people who had previously attended in-person groups at our purpose refit Dementia Hub.

Covid-19 has taught us all many things, the importance of our relationships with others, the importance of appreciating the small things in our everyday worlds (such as our gardens and local outdoor spaces), being creative in how we occupy time that might previously have been spent in the company of others. Care partners of people living with dementia have been at increased risk of stress and strain as they seek to provide support and care to the person with dementia due to a lack of opportunities to get out and about and meet others and share their challenges and learn from others. Similarly, people living with dementia have reported fear of losing their abilities when they are unable to practice routines and activities that helped promote and maintain their skills. Moving forward in a post-Covid recovery period offers us the opportunity to provide in person skills training for people to learn to use technologies to join groups and retain connections should another wave (or other circumstances that restrict freedom of movement) hit different countries at different points in time. It also offers us the opportunity to consider what people might need to regain and retain their wellbeing. Technologies are part of this, but so is adequate health and social care provision, and Covid has thrown into stark relief the disproportionate impact that adverse conditions can have for an already potentially vulnerable group.



The devastating impact of Covid-19 on people with dementia in care homes: A stress test that high income countries failed



Professor Sube Banerjee

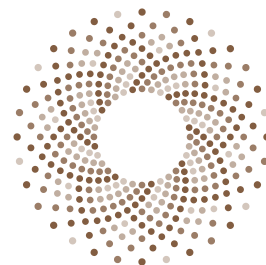
Professor of Dementia and Associate Dean, Brighton and Sussex Medical School

In the 2020 BBC Reith Lectures Mark Carney, the former head of the Bank of England, identifies how society has lost track of value and what things are worth in this age of Covid, crashes and climate. There can be no doubt that the impact of the pandemic on people living in care homes, most of whom have dementia, has been devastating. At least half of all Covid deaths in middle and high income countries have been of care home residents with this rising to 70% in Canada. This excess in mortality and destruction of quality of life in the most frail members of society shows that this failure of value is as true at the individual level as it is in macroeconomic terms.

Dementia is one of the greatest health and social care challenges we face. There are over 50 million people worldwide who have dementia now and by 2050 that will increase three-fold to 150 million. It has profound effects on both the people with dementia but also family members who support them who are often old and frail themselves and societal impacts are profound. Dementia already costs over a trillion dollars worldwide per year and this is set to triple in the next 30 years. Much of that money is spent on long term care for the elderly such as care homes. Around 85% of the people who live in care homes in high income countries have got dementia, although many may not have that dementia formally diagnosed, care home care is essentially long term care for people with dementia.

In the past decade things have changed for people with dementia. Through the fantastic work of organisations such as the Alzheimer's Society (UK), researches and campaigners it became clear that there were real problems with the treatment and care of people with dementia and their families. People with dementia received worse care than people with other conditions. Only a third of people with dementia were ever diagnosed at any stage of their illness and without diagnosis all sorts of possibilities to help them and their families live well with dementia were denied them and when they were diagnosed it was often late in the illness when it was too late to prevent crises, too late to support families. Starting in the UK and France national dementia strategies were formulated that accepted that dementia should be a priority and things started changing and changing for the better.

Memory diagnostic and care services were developed, diagnosis rates started to increase, the quality of care started to improve right through from diagnosis right through to the



end of life, there was amazing public creativity from the formation of dementia cafes to singing for the brain. The public awareness campaign Dementia Friends has reached 20m people worldwide across 56 countries driving an increased understanding of dementia and an increased demand for good quality care.

Everything seemed to have changed and then Covid-19 happened, a profound shock to the system that showed underneath, particularly for the particularly vulnerable population living in care homes, little had really changed. The challenge of Covid-19 made clear that little had changed in the priorities and fundamental values, attitudes and beliefs of the health system, of politicians and even of well meaning, hard pressed practitioners on the front line faced with making difficult decisions. We managed pressure on general hospitals at the costs of the lives of tens of thousands of older people dying in care homes.

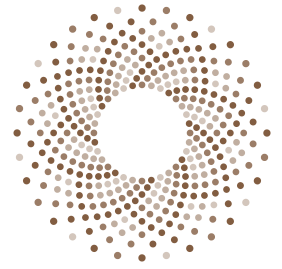
This devastating loss of life happened because, as societies across the world, we valued older people in general and people with dementia in particular less than other people. We valued care homes less than general hospitals, by conscious and unconscious discrimination. We have decades of reports on scandals in care homes revealing poor quality of environment and care caused by chronic underfunding. But it is more than that, care homes were last in line for personal protective equipment, they were last in line for testing, and they were told not to send their residents to hospitals and to accept ill and sometimes untested people back from hospitals to clear hospital beds for other apparently more deserving cases.

The English Elizabethan Poor Law of 1601 created the concept of the deserving poor, whose needs should be met, and the undeserving poor whose needs could be ignored. In our second Elizabethan age, presented with the Covid crises, we have reverted to a mind-set of conscious and unconscious discrimination against older adults and people with dementia and created a class of the “undeserving ill”. The undeserving ill could be denied treatment, not only for Covid but for other conditions that required hospital care. The undeserving ill could be turned away from hospitals because they had dementia or because they lived in care homes. This has happened because how we value people has not fundamentally changed, because underlying beliefs and attitudes have not changed. In this crisis, behaviour reverted to a largely unthinking belief system where the lives of old and frail people are worth less than those who are young and fit. Care homes and their residents were used as a human shield to protect the rest of the health system, governments and society. They were sacrificed to protect us.

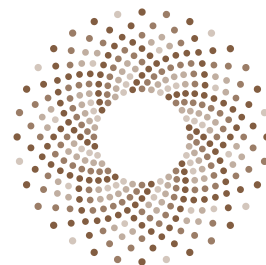
This cannot be the end of the story. We must, learn from this. We can change the way we organise and deliver care homes. All developed countries have the resources to do things better if they choose to do so. We must act to change the way we value people with dementia and those that live in care homes. The spotlight shone by Covid-19 on the fragility of our care home system cannot and must not be ignored, just as the light shone on racism by the Black Lives Matter movement cannot and must not be ignored. We need to reengineer our health and care systems so that the health and social care systems work together and are treated with parity of esteem and parity of funding.

The vaccines that are being rolled out are a ray of light in dark times and we hope that they will in time return things back to normal. But they will not address the underlying

faults in the system uncovered. The normal is not good enough for those living in care homes. Our values need to change. We need to use the ultimate sacrifice made by older people in this crisis to put providing great quality care for people with dementia right back at the top of the political agenda. We need the hearts and the minds of politicians and policy makers to change so that they have the moral courage to enable them to do what generations before have not done in terms of grasping this nettle and changing the values and actions of the system as a whole. One of the legacies of Covid can be to build empathic, person-centred care home systems where the oldest and frailest in society can live well and thrive. We know how to do this, we just need to get on with it. The American novelist and Nobel laureate Pearl Buck (1892-1973) wrote that “the test of a civilization is the way that it cares for its helpless members.” Covid has shown that we have failed that test for people in care homes, but it also gives us the chance to right this wrong for the generations ahead.



3. National perspectives



The current status of dementia care in India

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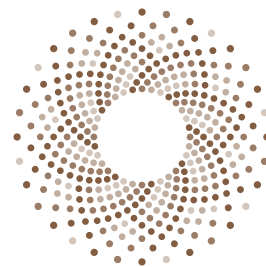


As India goes through a demographic transition, the number of older persons above the age of 65 years is projected to increase from 6.4 per cent in 2019 to 8.4 per cent by 2030. This transition will have an impact on many age-related conditions namely the non-communicable diseases, including dementia. Vascular diseases like hypertension, heart disease and diabetes mellitus are risk factors for dementia. As there would be more older persons over the age of 75 years, we could expect a higher prevalence of dementia in the next 20 years.

It was estimated that there were over 4.4 million people with dementia in 2015 in India, with this number expected to double by 2030. India is projected to have the second largest population of people with dementia, next only to China. This doubling of numbers every 20 years would have serious repercussions on the social and financial costs of dementia. It was estimated that the related costs of dementia would triple, putting a large strain on the health care system and the socio-economic demands on families, who are the mainstay of care for persons with dementia.

Early symptoms of dementia are not recognised as an illness as it is thought to be part of normal ageing by the public and general health care providers. Specialist geriatricians, neurologists and psychiatrists are few. Persons with dementia do not come to specialist care as they are seen, but not recognised by family physicians and traditional healers. By the time they reach specialist care and get a diagnosis, it is usually 12 to 18 months later, when the illness is in moderate to severe stage of dementia. The problem has worsened in the past year with Covid-19, as older persons are neither able to go to hospitals to get a diagnosis and treatment nor able to follow up due to the restrictions imposed by periodic lock downs.

In India, families have always assisted and provided support to their older members when they lose the ability to function independently. The role of the family is paramount and is the foundation of informal care in dementia. Caregiving is rooted in the traditional extended family system and constitutes a part of their responsibilities



as members of the family. Family caregiving in dementia is more exhaustive and demanding than caregiving for older adults without dementia. Most of the time family members are poorly equipped to take on caregiving roles. Most caregivers perform the tasks due to family obligation, expectations from the community, or simply because no one else would take on the responsibility.

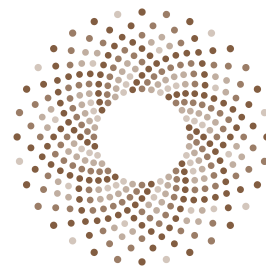
Most of the family caregivers are women (wives, daughters, daughters-in-law) and they are prone to suffer from depression, anxiety or loneliness. The difficulties in caregiving are more in urban families where the family size is smaller, and number of caregivers are less; sometimes another elderly spouse. The problems are also more in families where patients have problematic cognitive or behavioural symptoms and difficulties with ADL and a longer duration of illness. During the Covid pandemic many families have had additional difficulties due to caregivers contracting or succumbing to the virus.

The needs of persons with dementia and their families are varied and not very well studied. Patients and families have many unmet needs in their caregiving roles. They want information about the illness, its treatment, practical ways to manage behavioural symptoms and help with daily activities. Families from a lower socioeconomic status also need to know how to access disability and pension benefits from the government. Caregivers who are spouses have a need to know what would happen to the patient in case the caregiver dies before the patient. Hence, they need provisions for short or long-term care homes for elders, to provide for caregiving after their time.

Family caregivers in low- and middle-income countries, like India, hardly receive any support in taking care of persons with dementia. Lack of mental health infrastructure and scarcity of other resources like day-care facilities, at-home nursing services, short-term or long-term care facilities also contribute to the fact that most of the time, families are the only line of support. This exacts tremendous costs from the caregivers; physically, emotionally, and financially. Also, services that are available may not be accessible or affordable. There is a need for quality support services in the community, which are affordable for all.

As many family caregivers enter their new role unprepared, there is need for training them with knowledge and skills to deal with the challenges in caregiving and to access available resources. Family caregiver training programs focus on improving support and skills for caregivers. Technology based interventions or self-care programs delivered through online modules are also important and are gradually gaining momentum in India. The WHO iSupport for dementia caregivers, an online portal for self-help, was trialled for the first time in India.

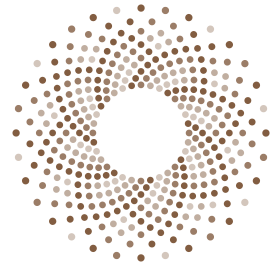
The Alzheimer & Related Disorders Society of India (ARDSI), and other societies and agencies for elders, have done a lot to create public awareness and information about dementia. The publication of the Dementia India Report in 2010 and 2020 was a big step in creating awareness, advocacy and spurring action for dementia care. A Dementia India Strategy Report, 2018 was also provided to the government to make a systemic plan for dealing with dementia. In addition, many of these Societies have advocated with the government to recognise dementia as a public health concern and to create environments for Elder and Dementia friendly communities. The country is yet to adopt



many of these plans or a national dementia strategy. These policies, programs and plans would now possibly be delayed by the Covid-19 pandemic.

The last few years have also seen the promulgation of various governmental acts, like the Maintenance & Welfare of Senior Citizen's Act, 2007 and the Mental Health Care Act, 2017 to protect the rights and welfare of older persons. The launch of the National Program for Health Care of the Elderly (NPHCE) in 2011 was a big step in creating a health care delivery system for the elderly. It is envisaged that the NPHCE would cover comprehensive health care for the elderly in all the districts of India. There is a need for more inclusive public policies and supportive community practices catering to the needs of people with dementia and their family caregivers.

In summary there are numerous barriers to dementia care in India. Lack of awareness of dementia as a disease, mistaking dementia for normal process of ageing, an attitude of ageism, may all lead to late consultation and treatment or neglect and abuse at the extreme. Emergent symptoms of dementia may lead to feelings of stigma for the patient and their families. In addition, low literacy, and poor use of digital technology by elders would lead to a handicap for the disabled person and family. The large treatment gap that exists due to late diagnosis and treatment, poor skills of health care and other caregivers, lack of hospital and residential facilities, make dementia a huge public health concern for India. What is required for the future of dementia care is a systemic effort and better intersectoral coordination between all the stakeholders; the patient, their families, the health care providers together with the society and government agencies.



Dementia care: A view from Chile

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The history of public policies regarding dementia in Chile has been marked by different moments. Initially, policies were observed from a clinical perspective referring to diagnosis and treatment, with consensus groups and health planning. Over time, to align with World Observatories on Dementia, international NGOs, and the WHO, multi-sectoral planning began to be drawn. This is how Chile adopted the socio-sanitary approach. A Day Centre pilot for people living with dementia and their supportive environments was carried out with national and international expert advice.

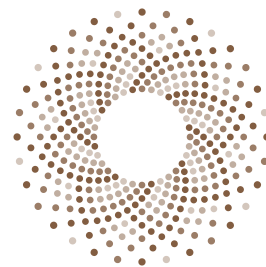
With this successful experience, public policy was escalated towards the country. In alliance with the academia, NGOs, the public and private sectors, the necessary budget request was generated to carry out the diagnosis in Primary Health Care, community treatment in Day Centres, and management of complex dementias in Memory Units. In addition, an exhaustive review of the national regulations regarding dementias was carried out. All interventions were designed with a strong emphasis on meaningful activities and both pharmacological and non-pharmacological treatments.

As a complementary action, in 2016, a National Support and Care System was created, with a pilot plan in 10 municipalities. This system supports people living with dementia and their environments. It is aimed at the most vulnerable population that needs free care, and its coverage has increased over the years.

The third moment was to aim for universal coverage, in 2019 - as an Explicit Health Guarantee - diagnosis and treatment with care packages from the primary care level to the specialty level were incorporated throughout the country. This coverage was part of the Positive Aging Policy led by the First Lady of Chile.

In addition to the abovementioned, more than half of the Chilean municipalities are actively working on developing the WHO's age friendly cities strategy to help older persons to age in place, integrated with the community. At the same time, we are committed with the Decade of Healthy Ageing. At a macro level, the decade proposes a much more comprehensive look at dementias, integrating services, anti-stigma campaigns, and rigorous data collection. On a smaller scale and hoping to obtain positive results, the WHO's ICOPE model of integrated care is being piloted in Chile.

The pandemic has undoubtedly challenged the entire strategy described, and at the same time, has served to model consent and decision-making systems in dementias. An



example of this was the creation of vaccination systems against Covid-19 with informed consents in dementia and tools for detecting decision-making capacity.

Also, from the government's point of view, special permits were issued for dementia patients and their caregivers in the context of confinement. These authorizations were the product multi-sectoral coordination tables.

At the same time, recommendation guidelines were generated for the management of psychological and behavioural symptoms in the confinement situation; psychological counselling to caregivers through remote channels; and controls for home visits to people living with dementia and their supportive environments. Tele-neuropsychology and educational strategies for caregivers were reinforced for the diagnosis.

Despite the advances on this field, in order to reach everyone that demands treatment and care, we still have a long way to implement all the above mentioned processes and action lines throughout the country. Also, it is necessary to develop a combined criteria regarding a regional dementia approach. To advance even further, it is essential to encourage the exchange of good practices, research and knowledge within the region, to share and observe the different countries' implementations, in order to learn from mistakes, and improve the implementation of sound public policies regarding this matter. In a region where integration and care for older persons is still in debt, the message that needs to be spread through actions is: 'it's possible to live well with dementia'.

The World Dementia Council (WDC) is an international charity. It consists of senior experts and leaders drawn from research, academia, industry, governments and NGOs in both high-income and low- and middle-income countries, including two leaders with a personal dementia diagnosis. The WDC has an executive team based in London, UK.

worlddementiacouncil.org

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