



**Alzheimer's Disease
International**

The global voice on dementia

World Alzheimer Report 2019

Attitudes to dementia



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We would like to thank the large number of contributors involved in this world report, including the survey translators, from 32 countries, without whom this would not have been possible.

The views expressed in the essays, case studies and programmes to reduce stigma are those of the authors.

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Due to the diverse nature and number of contributors to this report several key phrases are used interchangeably, including:

Carers / caregivers / care providers / care partners

Healthcare practitioners / healthcare providers / healthcare professionals

ADI Global survey on attitudes to dementia

Almost 70,000 respondents from 155 countries



2 in 3 people think that dementia is caused by normal ageing

1 in 4 people think that there is nothing we can do to prevent dementia

95% of the general public think they could develop dementia at some point in their lifetime

Just under **40%** of the general public think that there are adequate community services in place for people living with dementia and carers

54% of respondents think lifestyle factors play a part in developing dementia

91% of respondents say that people should not hide the fact they have dementia



Men are more likely to hold stigmatising views about dementia than women

Although they were more likely to let a relative with dementia move in with them



Attitudes of healthcare practitioners to dementia

62% of healthcare practitioners still believe that dementia is part of normal ageing



Around **40%** of the public think healthcare practitioners ignore people with dementia



“My neurologist ignored my presence when my diagnosis was discussed with my husband.”

“Neurologist diagnosed me with Alzheimer's at 56, telling me to go home and get my final affairs in order and wait until my premature death.”

“They sometimes talk to my wife about things like I'm not even there, but I'm sitting right there.”

“Many healthcare practitioners often do not believe I have dementia - which is abusive and offensive. But, also, they then talk over me, about me, and never to me...”

Experiences of carers



Over **50%** of dementia carers expressed positive sentiments about their role



Over **50%** of dementia carers said their health suffered as a result of their caring responsibilities



35% of carers globally have hidden the diagnosis of a person with dementia



Over **60%** of dementia carers said their social life suffered as a result of their caring responsibilities

Dementia: not a laughing matter?

63% of respondents living with dementia in South-East Asia said their dementia symptoms were joked about by others

67% of respondents living with dementia in Africa said their dementia symptoms were joked about by others

Carers of people with dementia said:



"So-called Alzheimer's humour does much more than annoy and hurt those who work hard to make life better for the 50 million plus people in the world living with dementia. It trivialises the disease."



People with dementia said:

"It is 100% offensive, and inexcusable to joke about my symptoms (unless it is me joking about it)."



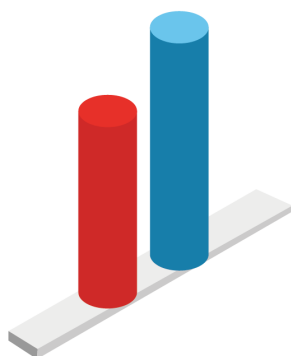
"When others who also have a dementia diagnosis joke this is just an expression that we are able to maintain a sense of humour and is a great stress reliever."



"Laughter is good for the soul and if you can laugh about your circumstances it can reduce anxiety. So we laugh from time to time when something incoherent comes out of my mouth."

Dementia, intimacy and relationships

Between **35%** in high income and **57%** in low and lower-middle income countries reported being treated unfairly in dating or intimate relationships



People with dementia said:

"To be honest, NO ONE wants to date a 58-year-old guy with Alzheimer's."

"I call it the friendship divorce. I have lost a fair amount of people in my life that at one time considered friends."

"... my wife and I divorced due to my Alzheimer's... her decision."

"I don't date at all now. As soon as I mention I have dementia, they presume the worst... My last boyfriend wanted to hide me away and I spoke openly about my dementia. Hence why that relationship didn't work..."

Foreword

Paola Barbarino, CEO

Time to roll our sleeves up (again, and again!)

I cannot express enough pride at being able to introduce this year's World Alzheimer Report on global attitudes to dementia. This report belongs to all the 70,000 of you who replied to our survey, so first of all, **thank you.**



When you look back at our international movement, which started in 1984, you see how a group of committed and energetic doctors and of professional and family carers, decided they had had enough of Alzheimer's being hidden in society and that the time was right to bring the disease to the attention of governments, politicians and the public at large.

Behind the foundation of an International Non-Governmental Organisation like ADI there is always the feeling that things could be much better and a sense that if we campaign strongly enough, if our voice is loud enough, we **will** be heard, and things **will** change.

At times I wonder why we did not start sooner. Alzheimer's disease was first described in 1906 but ADI was only founded in 1984. If we look at the Union for International Cancer Control (UICC), which is the equivalent of ADI, that was founded in 1933, about 50 years before us. The UICC is now a multimillion-pound organisation and the driving force behind cancer de-stigmatisation.

We, on the other hand, are running 50 years behind and still have a mountain to climb. In the words of one of our survey respondents:

"Shunned by hundreds in my home town. People would sooner have stage 4 breast cancer than my diagnosis. (They) couldn't look me in the eye."

Today people march together against cancer and support each other through cancer. We all talk about it as the last frontier. We talk of battles and of survivors. We appropriate a military language which, whilst not quite suitable to the people going through the disease (who can resent the idea of having to fight the inevitable), it certainly works from an awareness raising perspective. It also gives people a sense that they can be proactive and not just passive victims of the disease.

If society feels that they play a positive role then they will demand a solution. Last year's World Alzheimer Report¹ – which focused on research – stated unequivocally

that for every 12 studies on cancer there is only one on neurocognitive disorders (not just on Alzheimer's disease!). This is the size of the research gap - but there still isn't enough funding in Alzheimer's and dementia research - despite civil society's collective efforts.

Going back to the genesis of this report, one of my biggest challenges, as I stepped into my role at ADI, was my Board and my members' desire to see a decrease in stigma and heightened awareness. The thinking was that if we manage to raise awareness, then we will have a more determined grassroots movement. People will understand that Alzheimer's is a disease, not just old age, and ask their governments to acknowledge that we have a crisis on our hands. This in turn could mean the creation of dedicated services for those going through the disease and for their carers, for better diagnostic and post-diagnostic support, as well as an increased focus on finding a disease-modifying treatment. In short, all the actions described in the World Health Organization (WHO) Global action plan on dementia², which we fought so hard for but that is so difficult to implement.

ADI already runs World Alzheimer's Day and Month awareness campaigns, which get a lot of traction in the public and in the press, and it publishes the World Alzheimer Report, which is possibly the most quoted and trusted source of information on Alzheimer's and dementia globally. But, for all this output, there isn't a corresponding measurement that can tell us how well we are doing at changing attitudes to dementia, and not just globally but nationally and locally.

In Alzheimer's and dementia there has undoubtedly been a great increase in awareness in higher income countries - certainly in the last 10 years - pretty much since ADI promoted the global figures on prevalence and incidence of the disease for the first time³⁻⁴. However, in low- and middle- income countries there are still reports of stigma felt by people with dementia and by carers – I need only recount the appalling stories of physical restriction and murder in Africa, as reported by our members there.

Even in high income countries (and this really comes into sharp focus in the survey) the general public, healthcare professionals, our members and other advocacy organisations report widespread shortages of services as well as noticeable differences in service provision between rural areas and urban areas. Also, despite high-profile awareness campaigns people still delay seeking out help, advice and support when they first start to worry about their memory or that of a family member. If this was a physical or visible ailment, how much more quickly would people react?

Back in 2018 however, our problem was that because much of this evidence was anecdotal, we did not know

how we could measure whether these issues were sporadic or consistent throughout the world, or peculiar to a particular region; whether some issues were real for everyone or just perceptions; and, crucially, whether anything was getting better as a result of our advocacy efforts.

This report was borne out of a resounding need to establish a strong baseline so we could start measuring whether we really are doing better and making a difference once and for all. But we did not want to focus just on those countries where there are resources and means of taking action. In the spirit of solidarity and love that is the bedrock of ADI, we wanted to know more about those countries where there is little or nothing.

A prior survey on stigma by ADI in 2012⁵ had 2,500 participants. A laudable effort (and a first) but statistically a very low sample to consider it as a strong baseline for global attitudes. Looking at other diseases and how they had addressed stigma was also interesting and frankly a bit disheartening. I remember some of my early conversations about HIV/AIDS and cancer with professionals who had been working in those areas at the time of greatest stigma, and almost everyone pointed out that the real change in attitudes (both from the point of view of people seeking a diagnosis and from the point of view of the general public acknowledging the disease) had happened when a drug-based treatment and a cure started appearing on the horizon. Well, we still don't have a cure and have had no treatment breakthrough for almost 20 years for Alzheimer's and dementia. We are yet to have that light at the end of the tunnel, but this is not a good reason to let go and do nothing.

As the Dementia Friendly Community⁶⁻⁷ movement has demonstrated, time and time again, there is so much we can do to make life for those who have dementia and their carers immensely better by making them feel supported, loved and understood by our society and wherever possible by empowering them in every aspect of dementia activity, including advocacy. This makes a marked contrast to feeling shunned, hidden or ashamed, as in the quote above.

Indeed, the word love is something that comes out strongly from one of this report's essays, the one focusing on Canada's First Nation's attitudes to dementia:

"... Reminds us that the person with dementia, who is being cared for, is in need of a lot of love. He urges the use of 'loved one' to refer to the person with dementia so that we remember that they are loved. He shared that using the words 'loved one' serves as a reminder of how care providers should be treating and respecting the person with dementia".

Ironically, and sadly, the enormous swelling of population with the disease is on our side. When people ask me what I do for a living, and we start a conversation, it's rare they don't have a case in the family, wherever I am in the world.

When we commissioned this ambitious survey, we asked several universities and I am delighted that the London School of Economics and Political Science (LSE) was enthusiastic to pick up the gauntlet. They share our vision and our passion and as the numbers for our survey went up and up, there was a shared sense of joy undeterred by the enormity of the analytical task ahead.

I should not underestimate the size of the challenge faced by ADI and its members and partners in distributing the survey globally to so many different audiences. Nobody had ever attempted such a large survey in this field, and we were not sure whether we would have the capacity to mobilise our network to a whole new level.

A smidgen under 70,000 people later we can say that we certainly did! But it did take a huge amount of work on the part of everyone involved and I would particularly like to thank Australia, Brazil, Canada, China, India, Indonesia, Italy, Mexico, the Netherlands, New Zealand, TADA Chinese Taipei, Vietnam, the UK and USA who really went for it and helped us drive the numbers up globally. This survey, and its dataset, will now form part of the freely available shared resources we can use from now on to measure our performance on attitudes and hopefully make stigma a thing of the past – in all countries. It is our intention to repeat this research process after 5 years.

I know if you have picked this up that you will read the report in detail and I don't want to pre-empt it, but I leave you with a few thoughts.

- **Almost 80% of the general public are concerned about developing dementia at some point and 1 in 4 people think that there is nothing we can do to prevent dementia.** Clearly the messages on the importance of risk reduction highlighted recently by a WHO report are not getting through.⁸ People don't know what to do. We need to do more to spread this message at every level.
- **35% of carers across the world said that they have hidden the diagnosis of dementia of a family member from at least 1 person.** Our next target will be to get to 0%.
- **75% carers globally say "I am often stressed between caring and meeting other responsibilities" even whilst expressing positive sentiments about their role and over 50% of carers said their health suffered as a result of their caring responsibilities.** Are we doing enough for carers? Obviously not. Help and support for carers should be a fundamental lynchpin of any national dementia plan and we will continue to advocate towards it and empower our members to do so at national level. In the report it is clear that even in high income countries, most categories of survey respondents felt there were not enough services available.

- **Health Care Professionals in lower income countries were most positive about their willingness to work with a colleague with dementia. However, the public (most of whom will not work in a health setting) were least willing to work with a colleague with dementia.**

We need to change that, and we will work in the next few years both on the issue of the rights for carers in the workplace and the issue of disability rights for people living with dementia.

- **Almost 62% of healthcare providers worldwide think that dementia is part of normal aging.** Our message that dementia is NOT part of normal aging but a disease, is loud and clear, but is clearly not getting through. We must work much harder at this with all our members.
- I see a worrying trend developing with **36% of all respondents saying they would seek help on the internet.** There is so much unreliable information over the web, and it is an area with exponential growth, so we do need to be proactive and create trusted repositories of real information. We give the example with our website where all resources are freely available and so do our members.
- And last but not least around **40% of the general public think doctors and nurses ignore people with dementia** – time for primary healthcare practitioners to look closely at their practice and for governments to increase dementia training.

In the enthusiasm to include the views and voices of the people with dementia we must never forget the family carers. This extract of the Mexican essay is a sobering reminder of that:

"After about ten days I made the decision that I was going to take my husband who has dementia to the federal highway and I was going to throw myself under the wheels of a trailer, the biggest one I saw pass by, together with my husband, because I was not going to be able to bear everything that was coming. I woke up that day very early with my decision taken, to clean the house and leave everything ready, so they could hold vigil over us afterwards that day."

It is a relief that the person in this stark story lived to tell the tale, but these stories are happening all over the world and we must do something to stop this. It is terrible that a human being should contemplate suicide because they cannot cope caring for another human being by themselves. Respite and care must be made available globally, it is a matter of social justice.

As you have gathered from above, alongside the survey results you will read expert essays and case studies that highlight the scope and scale of the global challenge and the often spirited and galvanising response from people, like us, trying to affect change. Amongst many topics we look at:

- the challenges experienced by some indigenous populations around the world
- stigma in marginalised or lesser heard from communities including prison settings, people with learning disabilities and the LGBTQ community
- the media's role in helping raise awareness or exacerbating stigma
- the history and influence of working groups of people living with dementia and carers
- a philosophical question about the introduction and evolution of dementia friendly communities

I would like to thank the founders of ADI and the hundreds of thousands of you who work so hard day in day out on all aspects of the disease. You are doing so much, but we need to do more. This is just the beginning.

Ultimately, reality is not what governments tell us it is, it is not what experts like us tell us it is; reality is what people on the ground are feeling. Reality is what people feel every morning when they wake up and every night when they go to sleep. We must never forget that, and this is why this World Alzheimer Report is for all of you.

References

- 1 Patterson, C. 2018. *World Alzheimer Report 2018: The state of the art of dementia research; New frontiers*. London: Alzheimer's Disease International.
- 2 World Health Organization. *Global action plan on the public health response to dementia 2017–2025*. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0. online: <<https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1>> Last accessed 20 August 2019.
- 3 Alzheimer's Disease International. 2009. *World Alzheimer Report 2009: The Global Prevalence of Dementia*. London: Alzheimer's Disease International.
- 4 Prince, M., Wimo, Guerchet, M., Ali, G-C, Wu, Y-T., Prina, M. 2015. *World Alzheimer Report 2015: The Global Impact of Dementia. An Analysis of Prevalence, Incidence, Cost and Trends*. London: Alzheimer's Disease International.
- 5 Batsch, N. L., Mittelman, M. S. 2012. *World Alzheimer Report 2012: Overcoming the Stigma of Dementia*. London: Alzheimer's Disease International.
- 6 Alzheimer's Disease International. 2016. *Dementia Friendly Communities: Key Principals* (1st Edition) online: <<https://www.alz.co.uk/dementia-friendly-communities/principles>> Last accessed 20 August 2019.
- 7 Alzheimer's Disease International. 2017. *Dementia Friendly Communities: Global developments* (2nd Edition) online: <<https://www.alz.co.uk/adi/pdf/dfc-developments.pdf>> Last accessed 19 August 2019.
- 8 World Health Organisation 2019. *Risk reduction of cognitive decline and dementia: WHO guidelines*. Geneva: World Health Organization; 2019.

- the double stigma attached to both age and dementia

Executive summary



In 2019 ADI estimates that there are over 50 million people living with dementia globally, a figure set to increase to 152 million by 2050. Someone develops dementia every three seconds and the current annual cost of dementia is estimated at US \$1trillion, a figure set to double by 2030.

In the World Alzheimer Report 2012 '*Overcoming the stigma of dementia*' we explored the nature of dementia related stigma. The core of the report focussed on the results of a survey of 2,500 people; people living with dementia and carers, in a limited number of countries around the world. The report helped define dementia related stigma and offered recommendations to tackle it, alongside a series of case studies and practices aimed at stigma reduction.

In this 2019 World Alzheimer Report, we revisit attitudes to dementia and stigma to better understand the role they play and to set a baseline against which we can gauge future changes. This report details the scale of the challenge we face where attitudes to dementia, and specifically stigma, are still a major barrier to people seeking out information, help, advice, support and even a diagnosis; preventing or delaying people from putting plans in place; progressing to a stage of acceptance and being able to adjust to live with dementia. Stigma may be overt; in some countries it is still associated with witchcraft resulting in people being restrained and isolated. Or it can be more subtle; even in countries

with national dementia plans and profile awareness campaigns, many people still delay seeking help when they first become aware that something is wrong.

The 2019 World Report:

At the core of the 2019 report are the results of a global survey, commissioned by ADI and undertaken by the London School of Economics and Political Science (LSE). Almost 70,000 people globally engaged with the survey, making it the biggest of its kind ever undertaken.

LSE developed the survey to target four key groups, (1) people living with dementia, (2) carers, (3) healthcare practitioners and (4) the general public, with analysis being provided in three categories: knowledge, attitudes and behaviour. In the survey analysis we highlight the behavioural element first, giving prominence to the voices and experiences of people living with dementia as direct assessment of actual behaviour is central to discrimination and is the closest representation of the true impact of stigma on people living with dementia.

The report also poses the question "*what is stigma?*", looking to define dementia related stigma and to better understand the component parts based on power, stereotypes, prejudice and discrimination. Then, through a series of expert essays, case studies and programmes, the report sheds light on the nature and complexity of attitudes and stigma; it looks to other sectors for

guidance and inspiration; showcases examples of the different challenges and responses at global, regional, national and local levels; and offers some examples of programmes developed to improve awareness and to tackle stigma.

Key findings

Knowledge

- 95% of the public think they will develop dementia in their lifetime
- 78% are concerned about developing dementia at some point
- 1 in 4 people think that there is nothing you can do about dementia
- 2 out of 3 think dementia is caused by normal ageing
- 62% of healthcare practitioners think that dementia is a normal part of ageing
- 82% of people would take a genetic test to learn about their risk
- 54% of respondents think that lifestyle factors play a part in developing dementia
- Just under 40% of the general public think that there are adequate community services for people living with dementia and for carers
- Just under 70% of the general public think there are adequate competent physicians for the diagnosis and treatment of dementia

Two years into the WHO Global action plan on dementia, 35 years into the life of ADI, and longer for many associations around the world, should we be surprised at these findings? There is evidently underlying fear in global populations about developing dementia - 78% expressing concern – and some media portraying dementia as the most feared illness. Journalist Pippa Kelly, in this report, articulates that *“Stigma stems from fear. Fear breeds silence, which in turn perpetuates ignorance and misunderstanding”*.

A key reason for developing this survey and establishing a baseline for future review is to help us understand the scale of the challenge in informing and educating the 2/3rds of people who still think that dementia is a normal part of ageing, rather than a neurodegenerative disease and a leading cause of death; in some countries the leading cause of death.

Perhaps an even bigger challenge, and more worrying, is the staggering 62% of healthcare practitioners that think dementia is a normal part of ageing.

With an increasing focus on risk reduction research and messaging, and in the continued absence of a disease modifying treatment, we now have a clear understanding of how important people think that lifestyle factors are. The stark finding of this survey reveals that currently just over 50% of people think that lifestyle factors are influential. These figures form a baseline from which we can measure the impact of future global risk reduction efforts.

Behaviour

- Over 85% of respondents living with dementia stated that their opinion had not been taken seriously
- Around 40% of the general public think doctors and nurses ignore people with dementia
- 67% of people living with dementia in Africa, and 63% in South East Asia, said their dementia symptoms were joked about by others
- Between 35% in high income countries and 57% in low-middle income countries reported being treated unfairly in dating and intimate relationships
- Around 30% of people in Europe are willing to have a person with dementia move in with them, rising to 62% in South East Asia and 71% in the Eastern Mediterranean region

We wanted to better understand the stigma and discrimination experienced by people living with dementia, and particularly, what kinds of treatment they felt were unfair and the outcomes associated with these negative experiences. Unfair treatment can be experienced in many ways – at home, in the community, even in healthcare settings – and include things like being denied choice, being ignored, unfair treatment in dating and intimate relationships, lack of privacy, joking about dementia, and of particular interest, inappropriate treatment by healthcare practitioners.

Respondents reported feeling “avoided”, “ignored” and “ostracized” in their social life due to having dementia where many of them “no longer get invited to social gatherings”. Poignantly, one respondent captures this with:

“I call it the friendship divorce. I have lost a fair amount of people in my life that at one time considered friends”.

Half of the respondents living with dementia from lower-middle income countries reported that they had experienced their rights or responsibilities taken away from them unfairly.

Over 85% of respondents living with dementia stated that their opinion had not been taken seriously. One respondent reported being told *"your opinion no longer matters"*.

Unfair treatment by health or medical staff is an area of concern, as are the attitudes of some healthcare practitioners – with around 40% of the general public thinking doctors and nurses ignore people with dementia. *"My neurologist ignored my presence when my diagnosis was discussed with my husband"*.

Joking and humour around dementia is a very sensitive subject. Respondents in the African region (66.7%) and South-East Asia (62.5%) reported the highest prevalence of their dementia being joked about. However, this is a tricky area, humour can be therapeutic, but it is often permission based. The challenge is evidently how difficult it is to judge appropriateness. *"It is 100% offensive and inexcusable to joke about my symptoms, unless it is me joking about it!"*

Attitudes

- 91% of respondents say that people should not hide the fact they have dementia and the vast majority of carers never hide the person with dementia
- However, around 20% of respondents would keep their own dementia a secret when meeting people
- Concealment of dementia varied regionally - with the general public in Europe (25.7%) and the Americas (24.5%) reporting they would keep their dementia a secret. Healthcare practitioners also reported higher levels of concealment in Europe (19%) and the Americas (17.4%)
- Respondents stating they would hide their dementia when meeting people was highest in Russia (66.7%), Poland (57.9%), and Puerto Rico (51.1%),
- 45% of people living in South-East Asia and 48% of healthcare practitioners in the region feel that people with dementia are dangerous.
- 60% of people felt it was important to remove responsibilities of people living with dementia

Dating and intimate relationships are another sensitive area. Respondents with dementia reported unfair treatment in relationships, the highest figures in low / lower middle-income countries (57.1%) and upper-middle countries (50%). *"To be honest, NO ONE wants to date a 58-year old guy with Alzheimer's"*.

A very high proportion believe that people should not hide the fact that they have dementia, supported by

a high number of people (80%) agreeing that people with dementia can participate in a variety of activities. Attitudes to concealment, however, varied regionally – in Europe and the Americas around 25% saying they would keep their dementia a secret, with Healthcare practitioners also reporting higher levels of concealment in Europe (19%) and the Americas (17.4%).

Concealment and secrecy are key examples of stigma surrounding dementia and some specific country level figures warrant attention – with people in Russia (66.7%), Poland (57.9%), Puerto Rico (51.1%) saying they would hide their dementia when meeting people.

In relation to attitudes and views around danger 45% of people living in South-East Asia, and 48% of healthcare practitioners, think that people with dementia are dangerous, however, this is interesting considering relatively high proportions of people living in the South-East Asia region are willing to have a family member living with dementia to move in with them.

Around 60% of people felt it was important to remove responsibilities of people living with dementia which is interesting in the context that many of the experiences of discrimination reported by people living with dementia pertain to loss of status and loss of roles.

Around 40% of the general public think that healthcare practitioners (physicians and nurses) ignore people with dementia (38% in high-income, 49% in upper-middle income and 32.5% in low/lower middle-income countries).

Ironically, respondents had a vastly more negative opinion of the behaviours of others than about their own behaviour. Both healthcare practitioners and the general public believe that other people are likely to engage in stigmatising behaviours.

Carers

- Majority of carers expressed positive sentiments about their caring role
- 52% of carers said their health had suffered
- 49% of carers said their work had suffered
- 62% of carers said their social life had suffered
- Over 35% of carers globally have hidden the diagnosis of a person with dementia

Although just over half of carers expressed positive sentiments about their caring role, and found it fulfilling, 52% of carers said their health, 49% their work and 62% their social life suffered because of their caring responsibilities. This raises key questions about formal support services for carers and brings into perspective the importance of a resilient response to action area 5 of

the WHO Global action plan on dementia. Attitudes to caring vary by region, by socio-economic grouping and by culture and expectation.

The extent to which work is affected by the provision of care may be influenced not only by the amount of care that is provided and the support available to the carers, but also by differences in the propensity for women (who are most likely to be carers) and older people to work, and by policies to support the employment of people with caring responsibilities.

Recommendations

Stigma and knowledge issues around dementia are evidently still major barriers, not only to people seeking out more information, advice, support and a diagnosis but also in the basic understanding of Alzheimer's disease and related dementias as a medical conditions, that require treatment, support, even rehabilitation. By default, stigma thus also impacts negatively on research and research participation as we strive for a disease modifying treatment breakthrough.

Therefore, it is essential to take action, to improve awareness, to help dispel lingering myths around dementia and ultimately aim to reduce or even eradicate stigma.

Recommendations

- 1 Targeted public health awareness campaigns
- 2 Promotion of timely diagnosis and better post diagnostic support
- 3 Global evolution of dementia friends programmes and dementia friendly/inclusive communities - with people living with dementia and carers at the heart of their design, implementation and evaluation
- 4 Increased public advocacy of people living with dementia – amplifying the voice of lived experience
- 5 Increase advocacy focused on carers experiences – whilst improving the understanding of first-hand experience
- 6 Specialised education about dementia-related stigma and person-centred care practice for healthcare practitioners
- 7 Call for local governments to increase the funding, range and quality of community services for people living with dementia
- 8 Changes to public policy relating to employment, health and insurance for both people living with dementia and their carers
- 9 Full adoption of a rights-based approach to dementia including full compliance with the Convention of Rights of Persons with Disabilities (CRPD)
- 10 Increase funded research – for both a disease-modifying drug as well as further understanding of stigma. We know from other high stigma illnesses, including cancer and HIV-AIDS, that medical treatment breakthroughs can be a catalyst to stigma reduction – and we also need to better understand the complex role stigma plays throughout society in order to tackle it and change hearts and minds.



**Alzheimer's Disease
International**

About ADI

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our 100 members is a non-profit Alzheimer association supporting people with dementia and their families. ADI's mission is to strengthen and support Alzheimer associations, to raise awareness about dementia worldwide, to make dementia a global health priority, to empower people with dementia and their care partners, and to increase investment in dementia research.

What we do

- Support the development and activities of our member associations around the world.
- Encourage the creation of new Alzheimer associations in countries where there is no organisation.
- Bring Alzheimer organisations together to share and learn from each other.
- Raise public and political awareness of dementia.
- Stimulate research into the prevalence and impact of Alzheimer's disease and dementia around the world.
- Represent people with dementia and families on international platforms at the UN and WHO.

Key activities

- Raising global awareness through World Alzheimer's Month™ (September every year).
- Providing Alzheimer associations with training in running a non-profit organisation through our Alzheimer University programme.
- Hosting an international conference where staff and volunteers from Alzheimer associations meet each other as well as medical and care professionals, researchers, people with dementia and their carers.
- Disseminating reliable and accurate information through our website and publications.
- Supporting the 10/66 Dementia Research Group's work on the prevalence and impact of dementia in developing countries.
- Supporting global advocacy by providing facts and figures about dementia, and monitoring as well as influencing dementia policies.

ADI is based in London and is registered as a non-profit organisation in the USA. ADI was founded in 1984, has been in official relations with the World Health Organization since 1996. ADI is partnered with Dementia Alliance International (DAI), a collaboration of individuals diagnosed with dementia providing a unified voice of strength, advocacy and support in the fight for individual autonomy for people with dementia.

You can find out more about ADI at www.alz.co.uk/adi

Alzheimer's Disease International:
The International Federation
of Alzheimer's Disease and
Related Disorders Societies, Inc.
is incorporated in Illinois, USA,
and is a 501(c)(3) not-for-profit
organization

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