

# Women and Dementia

## A Global Challenge



Global Alzheimer's and  
Dementia Action Alliance

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### **About GADAA**

The Global Alzheimer's & Dementia Action Alliance (GADAA) connects a broad spectrum of international civil society organisations (iNGOs) including international development organisations, health-focused NGOs, disability rights champions, older people's networks, human rights organisations, faith based groups and women's organisations. Through the GADAA network we aim to champion global action on dementia and to support iNGOs in responding to the global challenge. Alzheimer's Society, Alzheimer's Disease International, Age International and Dementia Alliance International form the GADAA Steering Committee. Alzheimer's Society hosts the GADAA secretariat.

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# Summary

Around the world, more women than men live with dementia. As a known risk factor for dementia, the global ageing population will contribute to a rapid increase of dementia, particularly for women. The economic and social disadvantage that women face in many societies can stop those living with dementia from receiving sufficient health and social support. Globally, women – in both paid and unpaid capacities – provide the bulk of care for people living with dementia. The strain of caring also proves greater for women than men; informal female care partners are more likely to reduce paid work and develop physical and mental health issues. People living with dementia in every culture can face stigma and even abuse due to their condition, but for older women, age and gender-discrimination can compound this treatment.

At least 29 countries now have national dementia action plans or strategies in place. These plans often include a country's policies on dementia, outlining the objectives and changes they wish to accomplish to improve the lives of those living with or affected by dementia. These national dementia plans reveal that there are very few gender-sensitive responses at this moment in time.

**Top 10**

In 2015, dementia was **one of the top 10** global causes of death for women

Source: WHO, 2015

To develop dementia plans and strategies that will work for women at every stage of their life, national policy makers and civil society advocates can utilise a range of international policy frameworks including the World Health Organisation's draft Global Plan of Action on the Public Health Response to Dementia, European and Pan-American resolutions on dementia, the Sustainable Development Goals and the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). These frameworks give clear guidance – and in some cases obligations – as to how national dementia responses can take on a gendered-perspective.

The absence of gender-perspectives in current dementia policy and programming points to the vital significance of women-focused non-governmental organisations (NGOs) collaborating with dementia specialists and government policy makers to mainstream gender-equality into future responses. They must utilise international dementia and gender-focused frameworks to guide national dementia plans and initiatives towards providing gender-appropriate responses. Mechanisms need to be in place to monitor these frameworks to ensure implementation protects the rights and needs of people living with dementia and to identify the most suitable methods to drive women up the dementia agenda.

### About Dementia

Dementia is a collective name for progressive brain syndromes which affect memory, thinking, behaviour and emotion. Affecting almost 50 million people worldwide, dementia is the leading cause of disability and dependency among the elderly but is not a natural part of ageing. Dementia does not exclusively affect older people, with young onset dementia (defined as the onset of symptoms before the age of 65 years) accounting for up to 9% of cases. Although each person will experience dementia in their own way, eventually those affected are unable to care for themselves and need help with all aspects of daily life.

There are over 100 forms of dementia. The most well-known form of dementia is Alzheimer's disease, which accounts for 50–60% of all cases. Other forms of dementia include vascular dementia, dementia with Lewy bodies and frontotemporal dementia. Symptoms may include:

- loss of memory
- difficulty in finding the right words or understanding what people are saying
- difficulty in performing previously routine tasks
- personality and mood changes

There is currently no cure for most types of dementia, but treatment and support are available.

Source: Alzheimer's Disease International, WHO



Every **3 seconds**  
someone in the world  
develops dementia

Alzheimer's Disease International, World Alzheimer's Report 2015

# Summary

## KEY STATISTICS

- Worldwide, 47.5 million people have dementia. There are 9.9 million new cases every year, which translates to one new case every three seconds.
- The total number of people with dementia is projected to rise to 75.6 million in 2030 and almost triple by 2050 to 131.5 million. Much of this increase is attributable to the rising numbers of people with dementia living in low and middle income countries (LMICs).
- An estimated 58% of people with dementia live in LMICs; by 2050 this proportion is predicted to rise to more than 71%.
- Dementia currently costs US\$818 billion worldwide, it will soon hit \$1 trillion.
- Almost one in four all women globally are aged 50 and over.
- In East Asia, Asia South, the Caribbean, Western Europe and Latin America the predicted prevalence rates for women are between 14 and 32% higher than that for men.
- In 2014, women accounted for 62% of people aged over 80 around the world.
- Globally, two thirds of primary dementia caregivers are female, rising to more than 70% in LMICs.

Sources: Alzheimer's Disease International, 2015; Erol et al, 2015; Age International 2016

# Introduction

Dementia is increasingly recognised as an urgent public health priority. On the global stage, momentum is beginning to build through improved collective work on research, policy making and community action. Dementia is recognised by the World Health Organisation (WHO) as a public health priority and momentum is building around the draft Global Plan of Action on Dementia (WHO, 2016). The draft Global Plan of Action will provide an international response to the predicted 131.5 million people living with dementia by 2050.

As this plan becomes reality, we must keep one thing in mind: the impact of dementia will be much greater for women than for men. Dementia affects many stages of a woman's life. Throughout the world, women experience higher dementia prevalence rates than men and face gender-specific barriers to living well with dementia. Dementia is now the biggest cause of death for women in some parts of the world (Alzheimer's Research UK, 2015). Women provide the vast majority of both unpaid and formal care to people living with dementia, with around two thirds of primary caregivers around the globe being women (Erol et al, 2015). The stigma surrounding dementia exists universally and extreme forms of discrimination can lead to the abuse of older women.



Internationally **two out of three** primary dementia care partners\* are women

Source: Prince, 2004

Civil society collaboration is now needed to inform, shape and drive forward a gendered approach to dementia. This report provides a brief overview of the key dementia-related issues facing women around the globe, highlighting more comprehensive literature on the subject. It then considers the next steps urgently needed to address these challenges. It identifies where national dementia strategies have begun to take gender perspectives; and analyses which international policy frameworks must be used to construct gender-sensitive responses. The time is now for gender-equality advocates and those involved in dementia policy and practice to put women at the front and centre of global dementia action.

\*Throughout this report the term 'care partner' is used to denote informal and unpaid individuals, typically family members and spouses, who support people living with dementia.

# Introduction

## Methodology

To identify the dementia-related issues facing women internationally, a systematic literature review was conducted. Databases searched included Alzheimer's Society Knowledge Centre; the International Longevity Centre – UK online publications; the European Health for All Database; The Kings Fund; The Health Foundation and Google scholar, alongside relevant civil society websites and a general internet search. Key search terms were dementia OR Alzheimer\* AND women OR female OR gender OR sex. The results of this review are presented in Chapter One.

In order to analyse current domestic responses to gender-specific dementia challenges, the national dementia plans and strategies collated by Alzheimer's Disease International (ADI) were systematically reviewed for gender-perspectives. All plans and strategies available in English, French, Spanish and Portuguese that discussed the following key words were considered: wom\* (fem\*/mujer\*/mulher\*), female (femelle/hembra/fêmea), gender (genre/ género/ gênero) and sex (sexe/ sexo). The outcome of this analysis is discussed in Chapter Two.

International legal and policy frameworks that had been identified during the literature review stage of research were then analysed to identify if they provided guidance for gender-sensitive dementia responses. The findings are summarised in Chapter Three.



# Key Challenges

Dementia disproportionately affects women throughout the world. Cultural and personal variations naturally mean that every woman's interaction with dementia is unique. However, three main themes emerge from the existing global literature that looks at dementia through the lens of gender:

- Compared to men, women are more likely to live with dementia.
- Women can face many barriers to accessing health and social care services.
- Women are less likely than men to influence dementia health and social care policy.
- Women provide the majority of both familial and formal care for people living with dementia and the impact on their lives is more marked.
- Gender-discrimination can compound the stigma and abuse people living with dementia face.



# Key Challenges

## Section 1: An Overlooked Majority

- Around the world, more women than men live with dementia.
- The prevalence rate of dementia is higher for women than for men.
- Women may be more at risk of developing dementia but more global data is needed.

### High Prevalence Rates

Age is the greatest risk factor for dementia. As women have longer life expectancies worldwide than men, a greater number of people with dementia will be women (Alzheimer's Association, 2014). Dementia is now one of the main causes of ill-health among older women in many countries (WHO Regional Committee for Europe, 2016a). Additionally, across the globe, women demonstrate higher prevalence rates for dementia than men, revealing that this is an issue that disproportionately affects women across all countries, regardless of income levels (Braun, 2012; Takeda et al, 2011).

Evidence is starting to suggest that longevity alone is not the only explanation for the higher prevalence rates of dementia among women. Biological differences between women and men may contribute to dementia-related changes (Snyder et al, 2016). Factors such as a reduction in oestrogen levels after menopause have been linked to Alzheimer's disease (Carter et al, 2012). However, the clinical and epidemiologic data is limited and more investigation is needed in this area (Rocca et al, 2007).

### Risk Reduction

Socialised gender-norms can also indirectly affect the prevalence rates of women living with dementia. Early cognitive development and education has a preventive effect on developing dementia later on in life. In many, countries women are less likely than men to have both access and opportunity to take up much education. Young girls are frequently removed from schooling at an earlier age than boys (Ochayi and Thacher, 2006). Adolescent girls are also often less physically active than their male counterparts, possibly due to societal expectations of male and female genders, exposing them to key risk factors for developing dementia later in life (WHO Regional Committee for Europe, 2016a).

## Differing Impact

Dementia is one of the greatest causes of disability and dependency for older people globally (WHO Regional Committee for Europe, 2016b; WHO, 2016). The higher prevalence rates of dementia among older women mean that they are more likely than other groups to experience the physical and mental effects of living with a disability. In 2015, dementia was one of the top 10 global causes of death for women globally and is the biggest cause of death for women in some countries (Alzheimer's Research UK, 2015; WHO 2015). In addition, certain types of prescribed medication can negatively impact the health of a person living with dementia. A recent UK study identified that women living with dementia are more likely than men to be prescribed psychotropic medication that can negatively affect their physical health (Cooper et al, 2016).

The subjective experience of living with dementia can also be negatively affected by societal expectations of a woman's role in light of her gender. In societies that define female members by their caring abilities, women can find it difficult to accept their changing role. Some women have reported that going from the main family care partner to the one being cared for gives rise to concerns about losing their identity and being a burden (Borley et al, 2016). However, in comparison to men, women often report feeling more comfortable reaching out to health professionals and social networks about their own wellbeing concerns.

For lesbian and bisexual women living with dementia, maintaining identity can prove especially difficult if health and care facilities make heteronormative assumptions about their service users. This can lead to the avoidance of community services and so risk delayed diagnosis or post-diagnostic support (Westwood, 2014).

## Barriers to Health and Social care

At the point of being classified as living with dementia, women are less likely to access health and social care systems, and experience worse outcomes when they do. Across all economies, the wider societal disadvantage women experience continues into health and social services in terms of economic and social resources (Anand, 2006; Sen, 2010).



Women make up **70%** of the world's **1.3 billion** poor and poverty can become even more extreme in old age

Source: Bamford, 2011

## Financial

Women are often indirectly penalised where access to health and social care is linked to social insurance schemes which rely on having a history of paid employment (Bamford, 2011). In addition, inheritance and property laws in some countries further women's economic and social disadvantage. These laws create a barrier to financial solvency or prevent access to credit that may be necessary for private health and social care services that are not provided by the state. Women make up 70% of the world's 1.3 billion poor and poverty can become even more extreme in old age (Bamford, 2011).

# Key Challenges

The result of this economic marginalisation is that women are less likely to have financial resources for formal care later on in life. This impact on women's finance is particularly significant in lower and middle income countries (LMICs), where fewer than half of people living with dementia receive any kind of pension (Prince et al, 2004). However, it is worth noting that some LMICs run pension schemes not tied to earnings or provide extensive access to public health services for example South Africa, Brazil, Nepal and Lesotho (Age International, 2014). These policies go some way toward mitigating the challenges faced by women living with dementia who do not have financial reserves (HelpAge International, 2013).

## **Living Alone**

In many countries, older women are more likely to live alone, particularly due to the death of a partner. In the UK, for example, 22% of women aged 65–74 are widowed compared to 9% of men of the same age. For those aged 75 and over, the percentage of women widowed increases sharply to 60%, while the percentage of men widowed increases to 29% (Office for National Statistics, 2015). Research into dementia diagnosis rates demonstrate that living alone can make people less likely to seek a timely diagnosis, and so less likely to be diagnosed than those living with a spouse. Therefore, as women are more likely to live alone, their exclusion from health and social care services is further entrenched (Wilkins et al, 2007; Savitch et al, 2015). Moreover, the effects of isolation, loneliness and social exclusion have been shown to have the same negative effect on health as taking up smoking (Holt-Lunstad et al, 2010). In summary, living alone can also increase risks to health, as well as potentially delay seeking help for symptoms and diagnosis.

## **Gender-norms**

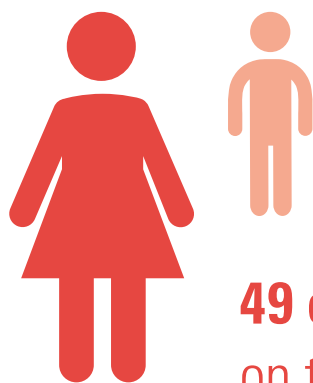
As outlined previously, the change of role from caregiver to one being cared for can cause a negative emotional experience for women living with dementia. In many societies, a woman's location in a traditional family structure can be framed as a care partner and this can be a defining characteristic. If a caring-role is central to a woman's identity she may resist any adjustment and so be less likely to reach out for help or accept support when needed if experiencing dementia symptoms (Ward-Griffin et al, 2006).

External gender stereotypes can also play a role in late diagnosis of dementia, with some women reporting they are told they have depression before receiving a correct diagnosis (Cadbury et al 2015; WHO Regional Committee for Europe, 2016a). Once diagnosed, gendered-assumptions can influence the type of support people living with dementia receive. One study identified that women are more likely to be assessed as lacking capacity than men (Boyle, 2013). The result of applying gendered norms to those living with dementia is that women can be left out of decisions made concerning their own care and lives simply due to their gender (Boyle, 2013; 2005; Bamford, 2011). Additionally, female targeted social support services for people living with dementia can be overlooked, and women can be left to their own devices in group settings, as in many societies they are seen as more social than men (Jaques et al, 2015).

## Influencing health and social care

### Policy

In most countries, political representation is not gender balanced; in 2016, only two countries had female parliamentary representation of 50% or more (UN Women, 2016). Women's leadership in political decision-making processes is linked to championing issues of gender equality (Inter-Parliamentary Union, 2008). Internationally, far more women than men live with and support those living with dementia. One female dementia care partner in the UK gave her view on the political status of dementia: '[dementia care has] become a thing that women do, and women are the recipients of, and therefore men, who tend to be policy makers, don't make it a priority, it's not important to them' (Cadbury et al 2015).



**49 of 78** national Alzheimer's associations  
on the 2017 ADI council have female chairs

Source: Alzheimer's Disease International

### Advocacy

There are many growing national and international user movements in dementia that are making sure crucial viewpoints get heard. However, men tend to be overrepresented in acting as spokespeople for this movement (Ludwin and Parker, 2015). Women living with dementia can feel that their voices are not heard as loudly as those of men – whether they are women living with dementia, female care partners or women in the care workforce. The lack of balanced gender representation in dementia advocacy groups can be read as just another reflection of a woman's status in many wider societies. (Cadbury et al, 2015). In contrast, Alzheimer's Disease International (ADI) counts 49 female chairs among 78 national Alzheimer's associations on the 2017 ADI council. This trend clearly offers great opportunity to incorporate gender-sensitive responses into national advocacy strategies and amplify women's voices on the subject.

# Key Challenges

## Section 2: Women as Care Partners

### KEY STATISTICS

- Internationally, around two out of three primary dementia care partners are women.
- This figure rises to more than 70% in developing countries.
- In the UK, women care partners report feeling less supported than their male counterparts.
- In the US, 20% of female care partners have gone from working full-time to part-time, compared with only 3% of working male caregivers.
- 19% of working women care partners had to leave work to provide dementia care in the US.

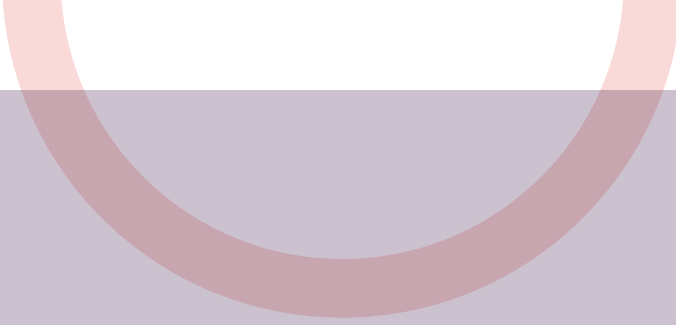
Source: Alzheimer's Association, 2014; Alzheimer's Research UK, 2015; Prince, 2004

### Informal Care

Globally, women provide the majority of informal caring to people living with dementia (Erol et al, 2015). Being a care partner to a loved one living with dementia can be a rewarding and fulfilling experience, if the right support is in place (Watt et al, 2014). However, informal and unpaid caring responsibilities can result in financial hardship and social isolation as well as mental and physical health problems. Women in the UK are 2.3 times more likely to provide care for someone with dementia for more than five years and 2.5 times more likely to provide intensive 24-hour care (Alzheimer's Research UK, 2015). These patterns are reflected around the world, though in LMICs it is typically daughters and daughters-in-law of those living with dementia who provide unpaid care (Prince et al, 2004).

Care partners of people living with dementia often have to make changes to their employment situation. Women are more likely than men to reduce their hours to part-time, or stop work completely, to provide care (Erol et al, 2015). For instance, 17% of women in the US felt they had been penalised at work because of their caring role and 10% have lost job benefits. In countries with limited financial support systems available for care partners, this can push female care partners into outright poverty. The majority of care partners in LMICs reported having to reduce their hours or stop working altogether to care for a person living with dementia, despite no official financial support available for them (Prince et al, 2004).

Informal care partners of people living with dementia are more likely to develop mental health problems. In the US, care partners of individuals with dementia have 46% more physician visits, 71% more prescribed medications, a 63% higher mortality risk, poorer self-rated health and a higher incidence of depression and anxiety compared to their peers who do not provide informal care. US care partners also report feeling significant stress because of high levels of dependency (Dang et al, 2008; Sink et al, 2006). For a person living with dementia, having a care partner means the difference between living in the community or living in residential



care. In the US and Canada, the leading reason for institutionalisation of older people living with dementia is care partner distress (Kane et al, 2001; Sivananthan et al, 2016). Informal care partners of individuals living with dementia in the US often describe feelings of isolation, anger, limited social support and being overwhelmed in addition to physical and psychological distress (Dang et al, 2008; Sink et al, 2006). Female care partners are especially likely to feel high levels of stress and depression. This gendered experience of caring for someone living with dementia is reported across different cultures and nationalities (Erol et al, 2015).

Most societies expect women to take on caring roles within families, and to have caring professions, while at the same time devaluing the attributes that inspire women to take up these roles. In addition, women are often expected to care for young children as well as the older generation, sometimes alongside paid professional work. These multiple layers of pressure and responsibilities can compound feelings of stress. Caring skills are often undervalued by society and it is difficult not to conclude that this is because of assumptions that caring comes naturally to women (Savitch et al, 2015). Often a society will encourage women to tie their identities into their caring roles. Although this can be a positive thing, it can also lead to unhelpful expectations around women taking on caring responsibilities. Women can also experience caring as a moral, religious or even legal duty. At the societal level, women remain a forgotten and largely invisible workforce, their contribution unrewarded and overlooked (Bamford, 2011).

While the majority of high income countries have community services available to help people living with dementia, few services are available in rural areas or LMICs. (Erol et al, 2015). Gender roles can also play a part in how care partners feel about accessing health and social services; women are usually carers within their families, but they may not always have high levels of authority within the family structure. A care partner may struggle to cope with caring, but not have the capacity to reach out for support (Rauf, 2011). Alternatively, when family care is seen as superior to residential care, women can feel that their caring abilities are being rejected if a family member initiates access to external support services (UK All-Party Parliamentary Group on Dementia, 2013; Wezel et al, 2014).

Worldwide, however, women are attaining higher levels of education and participation in the workforce. Paired with increased labour migration, it cannot be assumed that there will continue to be sufficient women available, ready and willing to assume caring responsibilities which will have dramatic repercussions for the future of informal care (Erol et al, 2015).

## Formal Care

Around the world, where it exists, the formal dementia care workforce is predominantly female. Women provide the majority of health and social care in community settings as well as in hospitals and care homes. Social care work is universally one of the lowest paid sectors of the labour market. Additionally, the gender pay gap means that women typically earn 10% less than men undertaking comparable work (Erol et al, 2015). Social care is often seen as an undesirable profession, with little prospect for training and career development. The experiences of paid carers in LMICs are not well known, but the evidence available suggests that the profession in these countries is often unregulated with little training or development provided (Erol et al, 2015).

Recent international population migration patterns see scores of women leaving LMICs to work in the caring profession in higher income countries (Tilki, 2016). These movements can create vacuums of professional caregivers in the LMICs. They also present formal caring challenges in higher income countries, with low job security, agency exploitation and language barriers possibly preventing continuous and person-centred care.



# Key Challenges

## Section 3: Stigma, Discrimination and Violence

### KEY STATISTICS

- A 2010 US study found that 47% of participants with dementia had been mistreated by their care partners.
- Of these participants, 88.5% had experienced psychological abuse.
- 19.7% of them had experienced physical abuse and 29.5% had experienced neglect.
- A 2009 study based in the UK found that 52% of care partners reported some abusive behaviour towards family members with dementia.
- It is estimated that 1 in 10 older people experience abuse each month around the world.
- A study across five European countries showed that more than a quarter of women aged 60-97 had experienced violence or abuse in the past year.

Source: Downes et al, 2013; Age International, 2016

### Stigma

Universally, the stigma attached to dementia can result in people seeing only the dementia, and not the person living with dementia. Specific symptoms of dementia are powerfully stigmatising both in the community and in care settings, for example disturbed behaviour, poor self-care and incontinence. Some cultures do not yet recognise dementia as a health disorder in its own right, instead seeing it as a natural part of aging. Although age is the strongest known risk factor for the onset of dementia, dementia is not an inevitable consequence of ageing. The term for dementia in some languages can be offensive, framing dementia as something to be ashamed of (World Alzheimer Report, 2012). In many cultures, symptoms of dementia are equated with mental health issues or behaviours that in themselves are heavily stigmatised (World Alzheimer Report, 2012). In extreme circumstances, the lack of awareness and knowledge around dementia can result in communities branding the symptoms of dementia as metaphysical, labelling individuals as 'witches' (Khonje et al, 2015). Women appear to be much more likely to be stigmatised in this way. This connotation can render the people living with dementia in an extremely vulnerable position. Further research is needed into dementia-related stigma that takes a gender perspective.



## Abuse

Research from the US indicates that people living with dementia are at greater risk of elder abuse than those not. Impairments in memory, communication and judgment can make people living with dementia particularly vulnerable to abuse (National Centre on Elder Abuse, 2016). The family of those living with dementia can also face stigma by association. Known as courtesy stigma, societal judgment can pressure family care partners to treat those living with dementia inappropriately. Even with the best of intentions, family members risk the dignity of people living with dementia (Chandra et al, 2006). Individuals can experience degrading treatment and even violence due to the health condition of dementia (Mushi et al, 2014; SKJ Travel). Moreover, in communities that classify individuals as witches due to dementia-related symptoms, women are at risk of being 'mistreated, hit, or even burned' or forcibly removed to exorcism camps (WHO, 2012). Women living with dementia in these communities are at risk of having their assets seized or facing assault or even death (Ferreira, 2004; Kohnert, 2003; Gorman, 2000).

In countries that allow assisted suicide, dementia also throws up complex ethical considerations around capacity and freedom. Cultural diversity and individual choice cannot be dismissed outright, however, in light of the already vulnerable social position of many older women; safeguards are needed to ensure they are protected against abuse (Bamford, 2011).

## Gender and Age

Age discrimination against women is well-documented in many societies. Many older women are vulnerable due to the accumulation of gender discrimination and denial of rights throughout their lives (Age International, 2017). Older women affected by conditions such as dementia are exposed to what we could term a 'triple jeopardy' (Graham et al, 2003), discriminated against as a result of their age, sex and condition. Violence against women can occur at any age yet older women's experiences are frequently discounted. For instance, the Sustainable Development Goals (SDG) target to 'eliminate all forms of violence against women and girls' only collected data on women up to the age of 49 until February 2016 (Age International, 2016). People diagnosed with younger onset dementia also anecdotally report experiencing the negative effects of ageism, due to being diagnosed with what is commonly thought of as only an older person's disease.

## Conclusion

Overall, dementia should be seen as a global public health and social care issue that provides distinct challenges for a majority of women. Increased longevity alone may not explain the higher prevalence rates of dementia in women, so factors that increase women's risk of developing dementia later in life need to be taken seriously and further explored. Gendered expectations of caring can create unbalanced responsibilities within families; without adequate support, female caregivers are left undervalued, overstretched and ignored. More research is needed into the impact of gender on the experiences of women living with dementia. This is especially the case in countries that are experiencing new labour migration patterns or do not provide universal financial or social support to people once they reach retirement age.

Going forward gender-specialists should question why dementia is only recently becoming a global public health priority and still receives comparably little attention to other international health concerns. With this in mind, the responses and solutions to dementia should take a gender-perspective and place women at the centre of policy and programme interventions.

# National Responses

Dementia clearly affects women disproportionately at every stage of their lives. Globally, national public health and social care policy-makers – and those who influence them – need to be aware of the gender-specific challenges that dementia presents and respond appropriately.

At the time of writing, 29 countries have now adopted national dementia action plans. These plans often include a country's policies on dementia, outlining which specific objectives and policy changes they wish to accomplish. A further five national dementia strategies have been developed by civil society groups in countries which do not yet have national dementia plans.

Existing and future national dementia action plans and strategies must recognise and react to the gendered-challenges dementia entails. A review of all the national dementia plans and strategies available in English, French, Spanish and Portuguese (collated by Alzheimer's Disease International), reveals that there are very few gender-sensitive responses (Alzheimer's Disease International, 2016).

Many of the national plans and strategies reviewed provide gender-disaggregated dementia prevalence rates. By presenting the higher rate of women living with dementia, these countries acknowledge that dementia disproportionately affects women. However, only 12 of the 29 national plans or strategies surveyed went on to analyse the gender-specific challenges posed by dementia or offer gender-sensitive responses.



## Prevalence

National plans from Malta, Ireland and Northern Ireland identify that gender is a non-modifiable risk factor associated with Alzheimer's disease and dementia (Empowering Change: A National Strategy for Dementia in the Maltese Islands 2015-2023, 2015; The Irish National Dementia Strategy, 2014; Improving Dementia Services in Northern Ireland: A Regional Strategy, 2011). Portugal and Northern Ireland highlight general gender differences in dementia prevalence rates (Plano Nacional de Intervenção Alzheimer, 2009), while England's Equality Impact Assessment of its dementia strategy makes reference to differences in the incidence of dementia according to gender (Equality Impact Assessment, 2009). Puerto Rico's national plan highlights that the mortality rates as a result of Alzheimer's disease are higher for women than for men and that more women than men of the same age are affected by the disease (Plan de Acción para Puerto Rico, 2015).



**Only 12 out of 29 national dementia plans and strategies offer gender-sensitive responses**

Source: Alzheimer's Disease International

Canada's national research strategy (a precursor to the national plan currently in development) draws attention to the 'vast implications' dementia has for women (The Canadian Alzheimer's Disease and Dementia Partnership: Strategic Objectives, 2015). In addition, India's dementia strategy engages with recent epidemiological research to consider gender-sensitive prevention strategies, taking into account gender differences in hormone levels in older age (The Dementia India Report, 2010). Note that both are non-governmental dementia strategies developed by NGOs.

By singling out women as a disproportionately affected group, the above national plans and strategies signal that they are aware dementia affects more women than men. However, many of these plans do not analyse the implications of the higher prevalence rates for women, nor explore specific actions or initiatives that address the distinct health or social care responses women may require.

## Differing Impact

Malta was the only country to discuss gender in terms of informing national policy. The Maltese plan identified that of those living with dementia who were surveyed to shape the national plan, the majority of respondents were female (71.5%) (Empowering Change: A National Strategy for Dementia in the Maltese Islands 2015-2023, 2015).

England's Equality Impact Assessment realised that women may require different approaches to being cared for compared to men (Equality Impact Assessment, 2009). Both India and Luxemburg considered living arrangements of women living with dementia. The Luxemburg plan noted that '[m]en are predominantly cared for at home (4/5), while women represent 77% of those who receive external care (Le Plan d'action National Maladies Démentiellles, 2013). In contrast, the Indian strategy highlighted that widowhood was a particular social challenge in Asian countries as most women living with dementia are widows (The Dementia India Report, 2010).

# National Responses

## Caring

India, Malta and Uruguay all noted that most primary dementia caregivers are women (The Dementia India Report, 2010; Empowering Change: A National Strategy for Dementia in the Maltese Islands 2015–2023, 2015; Plan Nacional de Demencias para la República Oriental del Uruguay, 2016). The Maltese and Uruguayan plans went on to discuss the negative impact of caring stress, particularly on female care partners. Switzerland's national strategy revealed that the proportion of informal care partners who reported a significant lack of support is higher for those caring for women with dementia than it is for those caring for men (Stratégie Nationale en Matière de Démence 2014–2019, 2016).

The equality impact assessment undertaken as part of England's strategy differentiates male and female care partners' responses to their caring roles in terms of 'depression, [...] stress, and substance abuse' and refers to the support needed for all care partners. Additionally, the assessment calls for professional dementia care training to reflect on gender differences (Equality Impact Assessment, 2009).

The plans from India and Uruguay recognise the caring crisis that can accompany traditional family structures breaking down due to 'social and economic changes that accompany economic development and globalization across the world', including increased female participation in the paid workforce. India's strategy sees an increasing demand for formal caring and recommends better training and regulation of the industry.

## Implementation

Scotland, Northern Ireland and Taiwan all frame the implementation of their dementia plans in terms of equality, endorsing equal rights to services and interventions regardless of gender (Scotland's National Dementia Strategy 2013–2016, 2013; Improving Dementia Services in Northern Ireland: A Regional Strategy, 2011; Taiwan Dementia Policy: A Framework for Prevention and Care, 2013). Malta's national plan is unique in pledging to mainstream gender dimensions through all of its objectives and deliverables (Empowering Change: A National Strategy for Dementia in the Maltese Islands 2015–2023, 2015).

Finally, only the national strategy of Uruguay has concrete objectives to support the families of those living with dementia (especially women, as they make up the majority of care partners). The Uruguayan strategy is informed by a case study of AUDAS, the Alzheimer association of Uruguay that provides psychological and cognitive care to people living with dementia, runs a day centre and supports the families and care partners to manage stress and maintain their quality of life (Plan Nacional de Demencias para la República Oriental del Uruguay, 2016).

## Conclusion

Currently, very few published national plans or strategies offer any kind of gender-sensitive responses considering the challenges discussed in Chapter One. While many national plans and strategies incorporate gender-disaggregated prevalence rates, the majority do not conduct any detailed analysis of the data or its implications for women. The plans that do consider the role of gender in dementia responses emerged primarily from dementia strategies developed by NGOs (from Canada, India, Switzerland and Uruguay), demonstrating the importance of dementia NGOs recognising and engaging with gender-disparity in their work. The absence of gender-perspectives also points to the vital significance of women-focused civil society organisations collaborating with dementia-specialist NGOs and government policy makers to mainstream gender-equality into future dementia responses.

# International Frameworks

At a national level, there are few gender-sensitive responses to the disproportionate impact of dementia on women. To develop appropriate dementia plans and strategies that will work for women at every stage of their life, national policy makers and civil society advocates can utilise a range of international policy frameworks. These frames give clear guidance, and in some cases obligations, of how national dementia responses can take on a gendered-perspective.



# International Frameworks

## WHO Global Action Plan

The Global Plan of Action on the Public Health Response to Dementia 2017–2025 is under consultation. The 140th WHO Executive Board unanimously approved a decision to recommend adoption of the draft plan by Member States at the 70th World Health Assembly in May 2017. The plan sets out strategic action areas and a set of recommended actions which, when performed collectively by Member States, international partners and the WHO Secretariat, aim to improve the care and quality of life of people with dementia, their care partners and their families. Ultimately, the plan aims to decrease the impact of dementia on society. The draft has been developed under consultation with Member States, UN agencies and other non-State actors such as relevant nongovernmental organizations, private sector entities, philanthropic foundations and academic institutions.

The draft plan recognises that more women develop dementia than men overall (para 3). The plan explicitly calls for each country's dementia response to 'support gender equity and take a gender-sensitive perspective, keeping in mind all vulnerabilities specific to each national context' (para 10.f) and develop innovative health technologies to meet the needs of those living with and affected by dementia in a gender-sensitive manner (para 97).

Under Action Area 6 of the plan, a target has been set that '50% of countries routinely collect a core set of dementia indicators through their national health and social information systems on which they report every two years by 2025'. It is further outlined that the data needs to be disaggregated by sex and age.

The WHO Secretariat will advise countries on a set of core indicators on dementia for which data can be collected from Member States as part of the activities of the WHO Global Dementia Observatory (GDO). The GDO will provide the mechanism to monitor and facilitate the use of data from the set of core indicators, offering a platform for the exchange of data and knowledge in order to support evidence-based service planning, sharing of best practices and strengthening of both policies on dementia and health and social care systems.

The Plan proposes that Member States, in collaboration with relevant stakeholders, organise public health and awareness campaigns to, among other outcomes, emphasize the need for gender-appropriate responses (para 36). The plan further recommends that dementia awareness-raising campaigns should also be aimed at locally-identified vulnerable groups, such as women (Appendix, Action Area 2).

To reduce dementia risk internationally, the plan recommends that Member States 'develop, deliver and promote evidence-based, gender-sensitive interventions' (para 51). In addition, the plan proposes that international, regional and national partners 'encourage all stakeholders to promote and mainstream population health strategies that are gender-sensitive and equity-based at national, regional and international levels in order to support a socially active lifestyle that is physically and mentally healthy for all, including people with dementia, their carers and families.' (para 54).

To improve dementia diagnosis, treatment, care and support, the plan urges Member States to 'enhance access to a range of person-centred and gender-sensitive services including liaison with local non-governmental organizations and other stakeholders in order to provide information that empowers people with dementia to make informed choices and decisions about their care' (para 65). The plan identifies the



need for the WHO Secretariat to 'build evidence on and articulate the importance of carers in the lives of people with dementia, while raising awareness about the disproportionate effect on women' (para 80). Additionally, the plan urges international, regional and national partners to 'increase awareness of the involvement, and its consequences, of carers and families in the lives of people with dementia, protecting them from discrimination, supporting their ability to continue their caregiving in a gender-sensitive manner, and empowering carers with opportunities to develop self-advocacy skills to be able to meet specific challenges in accessing health and social care, including long-term care services' (para 82).

## Regional Frameworks

The 2011 European Parliament resolution on the European initiative on Alzheimer's disease and other dementias provides European Union Member States guidance on incorporating a gender-perspective into dementia responses. The resolution calls on Member States to take into account the specific needs of women, 'who account for twice the number of [people living with dementia in Europe] and a disproportionate number of carers, in the areas of medical and social research, health, employment and social policies' (para 23). The resolution goes on to highlight the importance of researching the connection between gender differences and the various types of dementia (para 30).

The Pan American Health Organization (PAHO, 2015) plan of action on dementias in older persons, unusually, focuses on the importance of valuing and supporting the contribution of informal female care partners in the region. The plan recognises that female relations of people living with dementia are overwhelmingly the ones to respond to long-term care needs and often cut back on paid work to do so. The PAHO plan also examines the link between informal care partners and physical, psychological, social, and financial well-being. The plan goes on to consider how a lack of support for this group of caregivers can increase the risk of neglect and abuse of the elderly (paras 4, 16, 21). The plan also looks to the future of the region, noting that 'changes in family structure and the increased participation of women in work and social life make it difficult for the family alone to ensure care, exponentially increasing the likelihood of older people being institutionalized' (para 17). PAHO proposes actions to provide care and protection for families and care partners; formal, informal and non-remunerated (para 5).

# International Frameworks

## Sustainable Development Goals

The Sustainable Development Goals (SDGs) of the 2030 Agenda for Sustainable Development are United Nations (UN) led targets to mobilise efforts to end all forms of poverty and fight inequalities. Adopted by world leaders in 2015, the SDGs are not legally binding, but all UN Member States are expected to establish national frameworks for their achievement.

Goal five of the SDGs aims to achieve gender equality and empower all women and girls by 2030. One strand of goal five (SDG 5.4), proposes to accomplish this by recognising and valuing the ‘unpaid care and domestic work through the provision of public services, infrastructure and social protection policies and the promotion of shared responsibility within the household and the family as nationally appropriate’. This SDG clearly guides all UN Member States to increase national social protection programmes in order to reduce the burden of unpaid work undertaken by women.

While SDG 3.4 aims to reduce premature mortality from non-communicable diseases through prevention and treatment by one third, prevalence rates of dementia-related diseases are not counted as indicators of success, nor are any gender-sensitive approaches proposed. Therefore, SDG 3.4 may not be relevant for forming a global gender-sensitive dementia response framework.

## CEDAW

The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), defines what constitutes discrimination against women and outlines action required at national levels to end this discrimination. States that have ratified or acceded to the Convention are legally bound to put its provisions into practice. They are also committed to reports on how they are complying with their treaty obligations.

Regarding women and health, Article 12 mandates State Parties to ‘take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services [...]’. Additionally, Article 14 of the Convention obligates signatory states to focus on the problems faced by rural women, including as a result of working in unpaid sectors. States are obligated to ensure rural women in unpaid work have the right to ‘benefit directly from social security programmes’ (Art. 14, 2(c)).

To clarify States’ obligations created by CEDAW, the Committee on the Elimination of Discrimination against Women (Committee) periodically releases General Recommendations. These recommendations are not legally binding; however, they are considered highly authoritative interpretations of the convention. General Recommendation 24 from 1999 considers Article 12 in more detail and recommends that ‘special attention should be given to the health needs and rights of women belonging to vulnerable and disadvantaged groups, such as [...] older women [...]’ (para 6).

Moreover, the Committee expresses its concern ‘about the conditions of health care services for older women’, not only because women often live longer than men and are more likely to suffer from disabling and degenerative chronic diseases, such as osteoporosis and dementia, but because they often have the responsibility for their ageing spouses. Therefore, State Parties should take appropriate measures to ensure the access of older women to health services that address the handicaps and disabilities associated with ageing’ (para 24).



In addition, the Committee advises states to keep a gender perspective in all policies and programmes that affect women's health and involve women in their planning, implementation and monitoring. (para 31(a)). In terms of reporting, the Committee urges States to measure how national health care policies and programmes address factors which differ for women and eliminate barriers that women face accessing health care services. They highlight the barrier that high fees for health care services can present (paras 12,21).

## International Civil Society Responses

These frameworks are most powerful when harnessed by international civil society groups (iNGOs) to influence national policy makers and hold governments to account. iNGOs concerned with gender equality, women's health and female empowerment do not yet appear to publicly engage with the challenges that dementia poses to women around the world. An initial internet search of women-focused iNGOs reveals limited focus on addressing the impact of dementia from a gender perspective. However, many of these organisations do currently focus on urgent topics that overlap and intersect with the dementia-related challenges women face. These areas include women living with long-term health conditions or disability; the economic and social positions of female care partners and professionals and violence against women.

International dementia focused organisations have started to address the gender-dimension of dementia, with research and online resources discussing the specific challenges faced by women. One key example is Alzheimer's Disease International's 2015 global research review into women and dementia. This research brings to light many of the key challenges outlined in this work and offers a resource for other iNGOs in the field to draw on. More importantly, gender-focused organisations can build on the specialist work completed by international dementia bodies and initiate collaborations. Together, cross-cutting civil society action will ensure that the implementation of global dementia plans provide gender sensitive responses.

## Conclusion

There are multiple frameworks and tools that national policy makers, civil society and other stakeholders can utilise to guide national dementia plans and initiatives to provide gender-appropriate responses. In addition, for countries signatory to CEDAW, there are legally binding provisions that mandate governments to provide gender-equity in public health care policy and programming.

# Conclusions

Overall, dementia should be seen as a global women's health, social care and rights issue. While both genders are profoundly affected by dementia, it creates distinct challenges for women and women are frequently the ones responding. The intertwined factors of high prevalence rates, universal economic suppression and gender-stereotyped social norms mean that internationally, women often bear the impact of dementia, with insufficient state support.

More research is needed into the impact of gender on the experiences of women living with dementia around the world. This is particularly the case for countries that are experiencing new labour migration patterns or do not provide universal financial, health or social support services to people once they reach older age. Additionally, the literature would benefit from a gendered analysis of the global status of dementia compared to other health conditions.

Currently, very few published national plans or strategies offer any kind of gender-sensitive responses considering the challenges women face. While many national plans and strategies incorporate sex-disaggregated prevalence rates, the majority do not conduct any detailed analysis of this data nor its implications for women. The plans that do consider the role of gender in dementia responses emerge mainly from dementia strategies developed by non-governmental organisations (NGOs), demonstrating the importance of civil society in the dementia sector recognising and engaging with gender-disparity in their work. The absence of clear gender-perspectives also points to the vital significance of women-focused NGOs collaborating with dementia specialists and government policy-makers to mainstream gender-equality into future responses.

The draft Global Plan on the Public Health Response to Dementia is the perfect opportunity for iNGOs to engage with WHO Member States to improve the lives of everyone living with dementia and their families. With this in mind, there are multiple frameworks and tools that civil society members and national policy makers can utilise to guide national dementia plans and initiatives to provide gender-appropriate responses. Mechanisms need to be in place to monitor these frameworks to ensure implementation protects the rights and needs of people living with dementia and to identify the most suitable methods to drive women up the dementia agenda.



## Recommendations

### **Civil Society Organisations**

- International civil society involved in women's health and equality work should incorporate the disproportionate impact that dementia and associated caring role has on women into policy and programming.
- A broad-spectrum of iNGOs should support efforts to raise awareness of dementia as a global health priority and tackle stigma associated with the condition which can especially affect women.
- Gender-focused iNGOs should engage with civil society groups working on dementia to ensure that dementia's disproportionate effect on women is recognised and responded to throughout their policy and programming.
- Dementia-focused civil society must ensure gender-perspectives are researched, discussed and acted on at every level of their influencing.

### **International, Regional and National Policy-makers**

- A gender-perspective should be included in all dementia policies and plans, with sufficient resource allocation to ensure their implementation.
- Women, including those living with dementia, should be fairly represented at all stages of developing health and social care policies related to dementia.
- Women, whether living with dementia or as unpaid care partners, should have access to post-diagnostic support and benefit from social security programmes, especially in rural areas
- Special attention needs to be given to supporting women with dementia that live alone.
- The WHO secretariat should monitor the impact on women of the Global Plan of Action on the Public Health Response to Dementia's implementation.
- Countries, regional bodies and international bodies should collaborate to share best practice and develop comprehensive gender-responses to dementia.

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