A large green rectangular area with several white five-pointed stars scattered across it, serving as a background for the title text.

Sex, gender and sexuality in the context of dementia: a discussion paper





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Preface



Dear Alzheimer Europe members, friends, colleagues and all interested in the topic of this ethics report.

The current report addresses a topic that is often discussed, but very often without proper information, which leads to mis-

understandings, even in the public sphere. Therefore, I think that it is very important to provide information, definitions and explanations when reflecting on important related issues.

This report clearly highlights that Europe is still heavily influenced by heteronormative assumptions i.e. the taken-for-granted assumption that men and women have male and female gender identities respectively (whereas in reality many people don't relate to that male-female binary or do not relate to the sex attributed to them at birth) and that everyone is heterosexual and eventually has children. It looks at how such assumptions affect not only attitudes towards people but also structures of support and care that are not well adapted to the needs and wellbeing of many people with dementia and their carers. Issues related to heterosexual men and women and LGBT* people are well covered in the report. The focus of this report has therefore been on recognising and challenging prejudice, discrimination and injustice, not only towards marginalised minority groups but also towards women (who make up the majority of the population in most countries).

Drawing on the concept of micro-aggression, the authors have provided examples of subtle discriminatory treatment

and hostile attitudes and behaviour towards certain groups in society. This does not exclude or discriminate against men whose needs and interests must also be recognised and who may also be adversely affected by heteronormativity.

I think that the information in the report will be helpful to the targeted groups, namely health and social care providers (and students) as well as policy makers because of the information provided, how various inequalities and injustices are highlighted, but also by provoking self-reflection and hopefully contributing towards a greater awareness of these very important aspects of people's identities and lives. A big underlying thread, I feel, is about promoting awareness and acceptance of diversity and contributing towards a fairer society. There are recommendations throughout for the various readers targeted by this report.

I would like to thank the authors of what in my opinion is a quite special report. My special thanks goes to people with dementia who actively contributed towards this report. It is important that their voices are heard when raising awareness and lobbying for change. I hope that this report has contributed towards raising greater awareness about the complexity of people's identities and experience of life, including those of some of the most invisible, marginalised and ignored groups of people, and therefore towards a greater sensitivity towards and a greater acceptance and appreciation of diversity.

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1. Introduction

About this report

Sex, gender and sexuality are fundamental aspects of people's lives. When a baby is born, one of the first things that people tend to ask, after checking whether the mother and child are well, is whether it is a boy or a girl (i.e. the sex of the child as determined by the observation of physical attributes). Increasingly, such information is even sought prior to the birth of a child. This label, which is recorded on birth certificates, follows most people for the rest of their lives. It serves to some extent as a basis for how they are treated and for all kinds of assumptions about their interests, needs, capacities and wishes. As they make their way through life, their sex, gender identity and sexual orientation may further influence how they are perceived by other people, but also their self-perception, how they position themselves within society and how they are positioned by society. These attributes, in interaction with other factors, both at the level of the individual and society, are not the sum total of who people are, but may come to the fore and impact on people's lives at certain times and in certain contexts or situations.

In this report, we will be looking at how sex, gender and sexuality impact on the everyday lives of people with dementia. Our aim is to promote the right of every person with dementia, irrespective of their sex, gender identity and sexual orientation, to be treated with respect and to have access to timely diagnosis, treatment and good quality care and support. We will not be addressing issues related to the impact of biological sex on the development and progression of dementia or on biomedical research or drug development. These are important issues which are currently being addressed by biomedical researchers in the field of dementia, but beyond the scope of this report. We will be teasing apart issues related to sex, gender and sexuality even though these concepts are inter-related. It is not always clear whether certain issues are related to sex or gender (especially in cases where the two concord). When looking at issues related to personal relationships (sexual, romantic or platonic), it is not always clear whether the issue is about gender or sexual orientation (being straight, lesbian, gay or bisexual) or simply about physical and emotional contact between people with dementia. Moral judgements based on ageist or disablist assumptions about what is appropriate for older people and people with cognitive difficulties can also cloud the picture. We will therefore be exploring very complex issues from a range of perspectives. We do not wish to suggest that sex, gender and sexual orientation can be neatly separated into distinct categories but emphasise the need to recognise and accept people with dementia and their friends, family and possible carers as

gendered beings for whom masculinity, femininity and/or sexuality (hence also their sexual orientation) may be relevant to their sense of identity.

The report is the outcome of work carried out by experts in the fields of dementia, gender studies, ethics, ageing, service provision, training of healthcare professionals and psychology. The group is composed of men and women with and without dementia, and with different gender identities and sexual orientations, some of whom also have contact with people from gender and sexual minority groups. Please see Figure 1 for details of the members of the expert working group and Appendix 1 for a brief biography of each person. Some members of the group interviewed a few people with dementia about certain issues that are addressed in this report and we have included several testimonials from them.

The target audience of the report includes policy makers, health and social care students and healthcare and service providers because they are the people who can make the necessary changes to improve the lived experience of people with dementia of all sexes, gender identities and sexual orientations. For the benefit of readers who are unfamiliar with this topic and related terminology, we are not assuming any prior knowledge or experience in this domain and will try to avoid the use of jargon. Nevertheless, it is sometimes necessary to use terms that some readers are not familiar with. We have therefore included a glossary of terms, which can be found in Appendix 2. With regard to the term 'family', unless otherwise stated or clear from the context (e.g. when reporting certain studies), it should be understood as referring to 'biological or nuclear families' and 'families of choice'. The former includes people who are biologically

Figure 1: Members of the expert working group

- Dianne Gove, Chair (Luxembourg)
- Aileen Beatty (United Kingdom)
- Andrea Capstick (United Kingdom)
- Patrick Etenes (United Kingdom)
- Jean Georges (Luxembourg)
- Fabrice Gzil (France)
- Phil Harper (United Kingdom)
- Helga Rohra (Germany)
- Linn Sandberg (Sweden)
- Anthony Scerri (Malta)
- Charles Scerri (Malta)
- Annemarie Schumacher Dimech (Switzerland)
- Karin Westerlund (Sweden)

related or related through marriage and the latter includes non-married partners, friends and ex-lovers.

At the end of each main section of Parts 2, 3 and 4 of this report, you will find some recommendations. These were made by the expert working group based on their evaluation of the literature (both peer-reviewed scientific articles and non-academic reports e.g. produced by NGOs) and their professional and personal experience, and with the consensus of all involved.

What sex, gender and sexuality mean/cover

Before going any further, let's have a look at some of the key terms used and concepts addressed in this report (these and several other key terms are also described in the glossary in Appendix 2). Terminology linked to sex, gender and sexuality is constantly evolving. Terms such as sex and gender are often used interchangeably even though they reflect quite different concepts. **Sex** (being male or female), for example, is determined on the basis of biological and physiological characteristics (such as hormones, chromosomes and internal and external sexual organs) that are linked to the process of reproduction, irrespective of people's desire or ability to bear children. **Gender**, on the other hand, refers to the social differences between men and women (or boys and girls). This is often described in terms of male/female or masculine/feminine but also as man/woman or boy/girl (in the sense of self-positioning within society as a man, woman, boy or girl rather than on the basis of biological attributes).

However, many people do not identify with the strict female-male binary. **Non-binary identifications** can lead to a variety of public gender expressions from a neutral androgynous appearance/positioning, to more masculine or feminine expressions. There is a plethora of terms used by people who are not heterosexual or do not conform to 'traditional' male/female gender identities, 'opposite sex' sexual identities and non-binary gender and sexual identities (e.g. LGBT, LGBTI, LGBT* LGBTQ, LBTTI, LBTT, LBTTQI etc.). We have used quotation marks here to emphasise that these terms are in themselves representative of a certain understanding of sex, gender and sexuality.

There are a few problems with strict adherence to binary divisions of sex and gender such as male and female or masculine and feminine. Firstly, there are naturally occurring variations in sex characteristics which means that sometimes, people are born with hormones, chromosomes, anatomy or other characteristics that are neither exclusively

male nor female. Usually, people are officially declared male or female but they may identify themselves as male, female or intersex (which covers a wide range of bodily variations), and consider themselves to be a man, a woman, an intersex person or to have a non-binary identity. The concept of **cisgender** (a person whose sense of personal identity and gender corresponds with their birth sex) has been proposed and defined as the opposite of **transgender**. The cisgender/transgender binary has, however, been criticised for its narrow and exclusionary focus which erases or miscategorises some people (Ansara 2015) such as intersex people, and people who are agender, gender fluid, gender neutral or who have non-binary gender identities.¹

Secondly, men and women are often perceived and treated in accordance with their gender but characteristics that are considered predominantly feminine or masculine may vary across different cultures and periods of time. In addition, **intersex people** cannot always relate to the gender attributed to them by others or may object to being socially positioned in this way. Not only are some characteristics or behaviour considered predominantly feminine or masculine, but men and women are expected to behave in ways that are considered as masculine or feminine. Although such expectations are perhaps less rigid than in the past, **traditional gender roles** may impact on the experience of giving and receiving care. Women may be expected to take on a caring role regardless of whether they have any experience of caring or whether a man might be a more obvious choice (due to proximity or relationship to the person with dementia). Men are not generally subject to such expectations with regard to care (traditionally seen as a feminine task).

Gender identity describes a person's own, internal and personal sense of being a man, a woman or someone with no gender or with a non-binary gender. It is a deeply held internal sense of self and is typically self-identified. A person may therefore be treated by others as if they were female and a woman but they may self-identify differently (e.g. as a male or gender fluid).

The term '**sexuality**' encompasses a person's gender identity, their body image and their sexual desires, needs, experiences and behaviour. It also includes their **sexual orientation** (i.e. to which sex they are physically, emotionally or romantically attracted), which could be to the opposite sex, the same sex, both sexes, neither sex or totally unrelated to a person's sex). Sexual expression, acts and wishes could be directed to other people involving sensuality, physical intimacy, romance and physical attraction and/or to oneself in the case of masturbation. Sexuality may also be expressed

¹ The term non-binary is often used when referring to people who don't accept or feel that the male/female and masculine/feminine categories are appropriate to their experience of being a person.

through personal dress, body image, makeup and how the body or parts of the body are presented.

For consistency and clarity, in this report we will use the abbreviation **LGBT*** whereby LGB refers to people who are lesbian, gay or bisexual and T* refers to people who are transgender, transsexual, transvestite, genderqueer, gender fluid, non-binary, genderless, agender, non-gender, third gender, two spirit and bi-gender (Westwood and Price 2018). Whereas lesbian, gay and bisexual are sexual identities, the terms covered by the T* are mainly gender identities or expressions of gender. A transgender person, for example, could be gay, straight, lesbian, bisexual or asexual. Being transgender is about identity but also involves a range of decisions about transitioning which can be a matter of changes in clothing, grooming, name, sex designation, identity documents, hormone treatment and surgery.

Interestingly, the term cisgender only refers to a person's gender identity corresponding to the sex attributed to them at birth (e.g. a person who considers themselves socially female and was declared to be a female, biologically speaking, at birth). This person could, however, be straight, lesbian, bisexual or asexual. The term 'cisnet' means a person who is cisgender and heterosexual but this term is not widely used. The fact that there is no commonly used term to refer to cisgender heterosexual people suggests that this is taken for granted and perceived as the norm against which all other forms of sex, gender and sexuality are named and considered as 'other'. This is relevant to the issue of heteronormative assumptions which forms part of our guiding theoretical framework and is explained in Appendix 3.

Terminology surrounding gender and sexual identities is quite complex. Sometimes, however, the issue we are discussing is simply about sex (being a male or female human being) but inextricably linked to gender. It might, for example, be about the risk of overlooking the experience of men with dementia, as there are far fewer men than women with dementia, or about differences in help-seeking behaviour. It could be about the fact that both men and women are more likely to be cared for or supported by female relatives, partners and friends. This could have implications for the lives of women who may initially be informal carers and later have dementia themselves, with some women with dementia continuing to be carers for other people.

Also, when we use the term LGBT* it is important to bear in mind that people who identify themselves as LGBT* or would fall into this category that we are using are not members of a homogenous group. There is a lot of diversity within the LGBT* group. Also, some issues are the same

as for non-LGBT* people and others not. Taking the example of the criminalisation of gender and sexual identity, gay men have historically been discriminated against. This has also been the case in some countries for lesbians and bisexual women who have been subjected to arrest or threat of arrest even where same sex relations between women is not an offense. The expression of gender identity of transgender people is criminalised in some countries through so-called 'cross-dressing', 'impersonation' and 'disguise' laws, as well as through laws that criminalise same-sex activity and vagrancy, hooliganism and public order offences (Human Dignity Trust 2021).²

We hope to highlight and explore the different experiences as well as common issues that cut across one or more gender or sexual identities. We also need to bear in mind how other factors, such as ethnicity, disabilities, levels of literacy and education, religiosity and spirituality, as well as socio-economic status, affect the experience of men and women of different gender/sexual identities. Increasingly, it is being recognised that dementia policies and support need to be gender-sensitive and that gendered assumptions in research must be exposed and examined (Bartlett et al. 2018). There has been a gradual move away from neutral terms that hide important differences between men and women but the experiences of non-binary and non-heterosexual people remain largely hidden. A lot of research has been (and still is) carried out on heterosexual (often married) couples and has focused on carers' perspectives, with much less attention having been paid to people with dementia from different ethnic groups, gender identities and sexual orientations. This means that many people may be receiving support, care or treatment which does not reflect their needs and interests. It also has implications for research itself because as research findings are not representative of the broader population of people with dementia and do not capture the diversity of that population, they are not generalisable, trustworthy or meaningful to that population. Consequently, much current dementia research is fundamentally flawed.

² For details about the situation regarding the criminalisation or persecution of LGBT* people in different countries, please see: <https://www.humandignitytrust.org/lgbt-the-law/map-of-criminalisation/>

Guiding theoretical framework and structure of this report

The rationale for this work was to ensure equal and fair care, support and treatment of people with dementia regardless of their sex, gender identity and sexual orientation. This reflects an ethics and human rights perspective (see Appendix 3). However, the group was also aware of key concepts which underlie most of the issues addressed. These include:

- heterosexism and heteronormativity,
- homophobia, transphobia, violence and micro-aggressions,
- intersectionality and
- feminism.

These concepts, ethics and human rights issues and the related terms are not widely used in everyday life or likely to be familiar to everyone reading this report. We have therefore explained them fully in Appendix 3 and Appendix 4 and most are also briefly summarised in the glossary.

In the following sections of this report, we will:

- explore the different experiences of men and women with dementia with a range of gender identities (e.g. male, female, bi-gender, gender fluid, transgender and non-binary etc.) and a range of sexual identities/orientations (e.g. straight, gay, lesbian, bisexual, asexual and pansexual) from an ethical and human rights perspective,
- draw on the literature, the expertise of the group and the afore-mentioned guiding theoretical framework to try to tease out relevant issues and influences which affect the support, treatment and care that people with dementia receive (or should receive), if needed, and their quality of life (as well as that of their friends, family and possible carers) and
- provide recommendations from the expert working group on how to ensure equity in the provision of care, support and treatment to people with dementia regardless of their sex, gender identity or sexual orientation.

2. Seeking and obtaining a diagnosis

The importance of diagnosis

Much progress has been made in recognising the broad impact that dementia has on people's lives. When it comes to diagnosis and to some extent to service provision, however, dementia is mainly considered as a biomedical condition with its social, psychological, spiritual and emotional consequences given less importance. Tom Kitwood fundamentally questioned the medical model of dementia which gave little importance to the experience of people with dementia. His work emphasised the unique experience of people with dementia and the interplay between neurological impairment and psychosocial factors. This led to the development of person-centred care in the 1990s. Kitwood's psychosocial model of dementia was influential in drawing attention to the tendency to attribute all experiences to medical changes and in emphasising the importance of addressing other factors affecting people's experience (e.g. attitudes, practices and behaviour of other people) and of internal resources (Kitwood 1990). He described the experience of dementia as the result of a complex interaction between five factors, namely, neurological impairment, health, biography, personality and social psychology (expressed in the form of the equation: $D = NI + H + B + P + SP$).

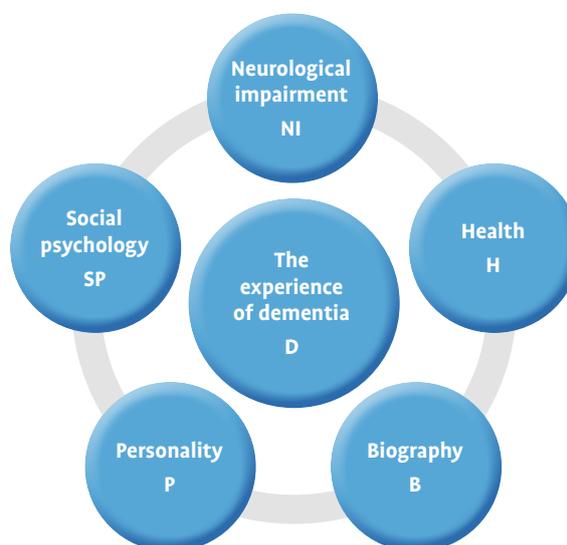
Nevertheless, diagnosis remains a largely biomedical and clinical process which focuses on cognitive and biological factors. Social and emotional factors continue to receive less attention. However, these, as well as people's life experience,

positioning in society (by self and others) and structural inequalities, are often incompatible with taking the necessary steps towards a potential diagnosis of dementia. They often also interfere with achieving equal and appropriate assessment, diagnostic work up and a precise and timely diagnosis.

Whilst the terms 'timely' and 'early' diagnosis are often used interchangeably, 'timely' refers to a diagnosis that is made at the right time for a particular person, whereas 'early' focuses on a diagnosis that is made as early as possible (i.e. in the chronological sense) (Dhedi et al., 2014). According to Woods et al. (2003, p.321) timely diagnoses "prevent crises, facilitate adjustment and provide access to treatments and support". In keeping with a person-centred approach (see subsection on person-centred care in Part 4 of this report), timely diagnosis is not linked to a particular disease stage but to benefit to the individual patient (Brayne, 2012 in Dhedi et al. 2014).

The benefits of receiving a timely diagnosis of dementia include access to support, care and treatment, and the possibility to plan for the future (e.g. with regard to health, finances and personal issues). It may also bring peace of mind, sometimes, following a period of concern about various symptoms and of uncertainty about one's health. These benefits apply to everyone irrespective of their sex, gender identity or sexual orientation, but women are more likely to have dementia than men and are

Figure 2: The enriched model of factors affecting the experience of dementia (Kitwood, 1997)



more likely than men to support or care for a person with dementia (Alzheimer's Disease International 2015). Some other groups in society also have a higher risk of developing dementia, such as African-American and Hispanic people in America (CDCP 2008) and people with Down's Syndrome (Alzheimer's Association 2021).

There are, however, potential disadvantages to early diagnoses of dementia that are not timely. Support and services are not always available or appropriate to the person's individual needs, particularly in the case, for example, of people with young-onset dementia or LGBT* people. Not infrequently, people who receive an early diagnosis are merely monitored until their problems become more serious. Even where there are services, people sometimes do not feel that they currently need services or care. Nevertheless, lack of post-diagnostic support may mean that they do not know what services and care are available and how they can obtain them at some point in time. Another problem is that of 'diagnostic overshadowing' (Nash 2013). This happens when any other problems with physical or mental health are explained away as a progression of dementia, without proper investigation, so that the person in question no longer has access to the full range of health and social care services they would have had prior to a diagnosis. People who belong to socially marginalised groups, such as older women and people from minority ethnic groups are particularly at risk of being referred to inappropriate services and subjected to diagnostic overshadowing. People with cognitive difficulties and their families should not be placed in a situation where they doubt the value of going through the upheaval and potential trauma of a dementia diagnosis, only to be stigmatised and receive inadequate or inappropriate services. Similarly, it is important to avoid 'therapeutic nihilism'. This involves the belief, held by some healthcare professionals, that it is pointless to diagnose dementia as there is no treatment, a risk of stigma and as they feel they have nothing to offer (van Hout et al. 2000; Vernooij-Dassen, Moniz-Cook et al. 2005).

Prevalence of dementia and risk factors

A recent meta-analysis of 16 epidemiological studies revealed a higher prevalence of dementia in women, the most significant difference being in the over 90 age group (44.8% of women being likely to have dementia compared to 29.7% of men) (Alzheimer Europe 2019). The figures in Figure 3 on the following page reveal a higher prevalence of dementia for women than men in every 5-year age group (Alzheimer Europe 2019).

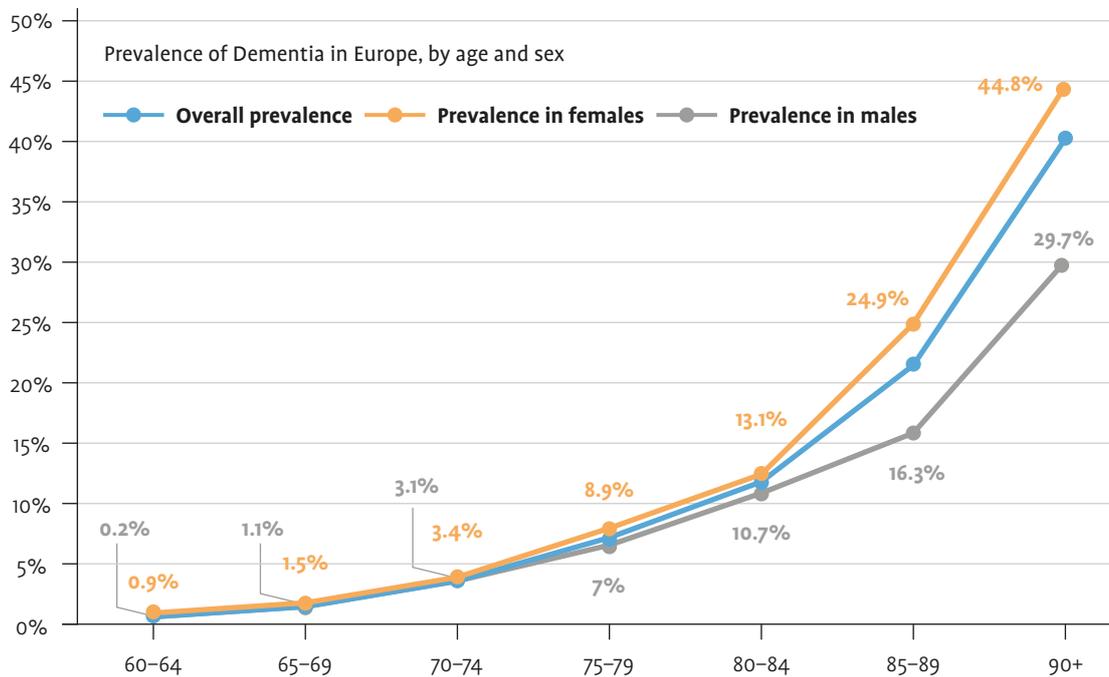
Recommendations

1. Health and social care professionals should adopt a proactive but sensitive approach to the early detection and timely diagnosis of dementia amongst people of all sexes, gender identities and sexual orientations.
2. Governments should take measures to ensure equity in the timely diagnosis of dementia for people of all sexes, gender identities and sexual orientations.
3. Health and social care practitioners should ensure that following a diagnosis of dementia a person continues to receive the full range of services and referral options, and that all potential physical and emotional causes of any new symptoms are investigated, following the same procedures as for a person without dementia.
4. Governments should ensure that every person with dementia has access to post-diagnostic support that is appropriate and suited to their individual needs, personal characteristics and situation. People from different marginalised groups should be involved in the development and roll-out of such support.

Sex, gender and sexuality, along with other defining characteristics shared by many people, do matter. Several studies suggest that risk factors for dementia are not evenly distributed as can be seen from the examples in Figure 4 overleaf.

However, findings are not conclusive and further research is needed to confirm a possible association between sexual identity and increased dementia (Nowaskie & Sewell 2021). The above examples are comparative group trends and care should be taken to avoid reinforcing stereotypes. Also, it should not be assumed that observed differences in behaviour or biological factors that increase the risk of dementia simply reflect poor lifestyle choices or bad luck (potentially leading to blame or pity). According to Mejia-Arango et al. (2021), several studies emphasise how lower levels of education for women, for example, have been linked to higher cardiovascular risk factors, fewer years of good cognitive health and more years with dementia. This ties in with the cognitive reserve hypothesis³ which states that high cognitive reserves provide resilience against cognitive decline and dementia. This reserve is not acquired solely through education but also through cognitive, social and physically stimulating activities.

³ See glossary in Appendix 2.

Figure 3: Sex differences in prevalence rates for dementia**Figure 4: Examples of differences in risk factors by sex, gender and sexual orientation**

Group	Behavioural, biological or socio-economic differences
Men	tend to engage in higher levels of risky behaviour (e.g. smoking, drinking alcohol, insufficient fruit and vegetable intake, having too much salt and eating too many processed foods),
	have risk factors linked to the andropause, but more research is needed into the possible influence of genetic factors in this process (Pertesi, Coughlan, Puthusseryppady, Morris & Hornberger 2021, Sindi et al. 2021),
Women	have higher biological risk factors (e.g. obesity, raised blood pressure and higher glucose and cholesterol levels),
	potential causal relationship between menopausal factors (especially changes in oestrogen levels) and cognitive decline, including dementia,
	often have a higher risk because of lower levels of education, income and access to healthcare, and a higher prevalence of depression (Byers & Yaffe 2011, Pertesi, Coughlan, Puthusseryppady, Morris and Hornberger 2021, Sindi et al. 2021),
Older women	have on average had less education than older men and this is likely to impact on their income (Livingston et al. 2017),
LGBT* older people	tend to have poorer physical and mental health, and higher rates of disability, substance use (such as alcohol and tobacco), obesity, loneliness, isolation and HIV seropositivity (compared to their cisgender, heterosexual counterparts) (Fredriksen-Goldsen et al. 2018, Nowaskie & Sewell 2021),
	may, if they have HIV (as may non-LGBT* people), have HIV-associated cognitive disorder, but those taking effective HIV treatment do not generally progress to HIV-associated dementia. HIV-associated dementia is possible but rarely seen nowadays except in people who are diagnosed with HIV at a very late stage with a very low CD4 (Pebody 2021),
Gay and bisexual men	other sexually transmitted diseases are more common. Syphilis, for example, which is curable with a shot of penicillin, can, if left untreated, cause neurosyphilis and in turn lead to cognitive decline (Brophy Marcus 2017),
Lesbian and bisexual women	are at higher risk of dementia than straight women because of higher levels of smoking, alcohol use and depression (Westwood 2018).

Ferretti et al. (2018) point out that women tend to have lower incomes than men and most carers of dependent adults are women, many of whom have had to reduce their paid employment in order to provide care. This may result in them having fewer financial means to pursue stimulating activities and look after their own health. We therefore need to look at structural factors within society (i.e. political, economic, social and ideological) which impact on women's risk of dementia and at how socio-economic disparities shape health trajectories into old age (Mejia-Arango et al. 2021), resulting in some groups of women being less likely to benefit from timely diagnosis of dementia. Similarly, with regard to risk factors for men linked to behaviour and lifestyles, we need to consider broader societal influences linked to socio-economic factors, as well as attitudes, education, traditions and especially hegemonic masculinity (see also page 14). It is essential to look at broader societal influences so as to understand better why and in what context risk factors for dementia arise which affect men and women differently, often disproportionately, so as to be able to tackle those issues at their roots.

Recommendations

1. Measures should be taken to raise awareness amongst the general public as well as amongst health and social care professionals of various risk factors for dementia linked to sex, gender and sexual orientation.
2. Measures should be taken to address risk factors for dementia, paying particular attention to issues and structural inequalities that might contribute towards a higher occurrence of such risks within sub-sectors of the population based on sex, gender and sexual orientation.
3. People with a broad range of gender identities and sexual orientations should be involved in the development of those measures.

Inequity and barriers linked to access to diagnosis

The impact of living alone on timely diagnosis

There are more women than men in most parts of Europe and the prevalence of dementia is generally higher amongst women. Germany, France, Spain and Italy have higher populations of women than men, but in Ireland, Luxembourg, Malta, Serbia and Sweden the opposite is the case (Statista 2021⁴). Women have a higher life expectancy than men. This partly

explains the higher ratio of women to men with dementia but there are also several other factors which contribute towards this imbalance (as mentioned in the previous section). Yet although there are more women than men with dementia, many women do not receive a diagnosis.

There are also sex differences with regard to where and with whom older men and women live and this may have some implications for diagnosis. Living alone may lower the chances of obtaining a timely diagnosis of dementia. More women than men live alone. In the European Union, 40.2% of women compared to 21.8% of men lived alone in 2018 (EUROSTAT 2020). The total number of women living alone is also much higher but there are considerable national differences in that the percentage of women living alone varies from 23.4% in Cyprus to over 50% in Denmark and Estonia (EUROSTAT 2020).⁵ This is important as it is often people who are close to the person with dementia, such as partners, relatives and close friends, who notice subtle changes and encourage the person to consult a doctor. Sometimes, people with occasional contact with people with dementia also recognise that they are experiencing problems and urge them to seek medical attention (McLeary et al. 2013), but people with dementia can often hide the difficulties they are experiencing in the early stages for short periods of time. Also, the social networks and family structures of LGBT* people often differ from those of their heterosexual counterparts. They may have less contact with relatives and it is less common for LGBT* people to have children (Guasp 2011). This means that they run the risk of not being diagnosed because they may lack the network of relatives in whom they can confide, who may have regular contact with them and who are able to spot subtle differences in their behaviour which might lead to them consulting a doctor.

One study suggests that for heterosexual men and women living as couples, traditional gender roles may affect whether and when they seek diagnosis (Béliard 2019). For women, difficulties with household tasks may be noticed but partners may conceal these difficulties by taking over or may interfere with the female partner seeking diagnosis. Consequently, the difficulties may only come to light when the partner dies, and even then, their possible children may be slow in supporting the mother to seek a diagnosis. Conversely, women, together with their children, may play a key role in taking steps to ensure a diagnosis for their male partners, for whom the first noticeable signs are often linked to difficulties handling finances and tax declarations (Béliard 2019). Most older people are married but a disproportionate number of older women are widowed (Livingston et al. 2020).

Lesbian and gay people are more likely to live alone than their heterosexual counterparts and to be estranged from

⁴ <https://www.statista.com/statistics/611318/population-of-europe-by-country-and-gender/>

⁵ https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Ageing_Europe_-_statistics_on_housing_and_living_conditions#cite_note-2

their biological families (Musingarimi 2009 in McParland & Camic 2018). Older LGBT* people are more likely to be single and live alone. A UK survey of over 1,000 straight people over the age of 55 and over 1,000 LGB people over the age of 55 revealed that the latter were:

- “More likely to be single. Gay and bisexual men are almost three times more likely to be single than heterosexual men, 40 per cent compared to 15 per cent,
- More likely to live alone. 41 per cent of lesbian, gay and bisexual people live alone compared to 28 per cent of heterosexual people,
- Less likely to have children. Just over a quarter of gay and bisexual men and half of lesbian and bisexual women have children compared to almost nine in ten heterosexual men and women,
- Less likely to see biological family members on a regular basis. Less than a quarter of lesbian, gay and bisexual people see their biological family members at least once a week compared to more than half of heterosexual people” (Guasp 2011, p.3).

Consequently, the pathway to diagnosis for older women in general and for lesbian, gay and bisexual people may be more complicated than for straight men.

Poor rates of diagnosis in residential care facilities

There are cultural traditions and differences with regard to institutional, community and family-based approaches to care in Europe (Ilinca et al. 2015). However, some of the factors mentioned above (such as the longer lifespan of women and the greater likelihood of those who are married becoming widows) mean that many women with dementia live in residential care settings where diagnoses of dementia are not always prioritised. A study into rates of diagnosis and treatment of dementia in nursing homes in Italy, for example, found high rates of underdiagnosis and lack of access to state-of-the-art diagnosis for dementia. It was suggested that this may have been due to the lack of systematic assessment of cognitive functions, limitations to antedementia drug reimbursement, the complexity of the reimbursement procedure itself and a high prevalence of residents with severe dementia (Cherubini et al. 2012). Twice as many women over the age of 65 live in residential/care homes (3.8% compared to 1.9% men according to the 2011 consensus data from EUROSTAT). The number of women actually living in care homes may be even higher as there are a lot more women than men in that age group. Many go undiagnosed, with staff suspecting that they have dementia but no one ensuring that they undergo all the necessary tests to confirm whether this is the case, and if so which form of dementia they have.

“When a person is told that they have dementia or a touch of dementia, then they have not been given a

proper diagnosis. A proper diagnosis is when you are told exactly what type of dementia you have. Then you can get the proper treatment and medication. Different types of dementia need different treatment, just like cancer. Different types of cancer require different treatment so why should a dementia diagnosis be any different?” (testimonial from Kevin, 58, who has Lewy Body Dementia).

There may be financial issues at stake (as suggested in the Italian study) but there is also a possibility that failure to diagnose residential care home residents sometimes reflects paternalistic attitudes, particularly towards older women. It is assumed that they do not need to know the cause of their problems as they are receiving adequate care. This totally ignores their right to be consulted and involved in decisions surrounding their health and care and represents discrimination. As pointed out by Keeble, Cartmell and Burns (2015), care home managers and doctors have a duty to follow up on people who are suspected of having dementia and to assess their needs. Moreover, they need to understand exactly how many residents they have with dementia if they are to upskill staff, create suitable environments and better respond to people’s needs, rights and entitlements (i.e. reducing the likelihood of recourse to anti-psychotic drugs) (Keeble, Cartmell & Burns 2015). At the same time, they point out that care homes may decide to charge more for appropriate support to the residents with dementia and in some cases, this may even result in the person having to move to another facility. This has financial implications for care providers, people with dementia and their partners/families. Apart from peace of mind for the people affected, such proactive and timely diagnosis is of course only beneficial if accompanied by appropriate services, support and treatment. Otherwise, it could serve merely to stigmatise residents and lead to diagnostic overshadowing. This means that once diagnosed, residents’ behaviour and emotions (subsequently seen as ‘symptoms’) are attributed to dementia, and staff fail to seek the cause or try to determine what support to offer.

Gender identity, sexuality and childlessness

Older single women, who have never married and who have no children, are more likely to go into residential care (compared to women who have married and have children) and consequently to risk poor access to diagnosis. This includes many lesbian and bisexual women, especially of the older generation. It is difficult to estimate the number of lesbian and bisexual women in care homes as they do not necessarily reveal their gender identity and sexual orientation.

It should not be assumed that all married women are straight or that straight women all can have, or want to have, children. People often say to girls “When you have children” not “If you have children”. There is often an assumption that older women with dementia have children who may

be willing and able to provide some degree of care and support (e.g. accompanying them to appointments, sorting out social support or providing hands-on care) or contribute financially to formal care. This is not the case for many women. Even for men with dementia who have daughters, the latter may sometimes have a better contact with their mothers (e.g. supporting them during medical visits) so men may also sometimes lack support they are assumed to have.

Similarly, it should not be assumed that lesbian, trans and intersex women do not want children or cannot bear children, or that it is not biologically or morally 'natural' for them to do so. Many lesbian and bisexual women have children but many others, as well as straight single women, are denied the opportunity by society to adopt children or to access various medically assisted methods to enable them to bear children. Although we have focused in this sub-section on women (linked to the observed higher percentage of women in residential care homes), the issue of childlessness also applies to men. The increased likelihood of LGBT* people having no children to support them and thus being at greater risk of having to move into residential care, where diagnosis rates are poor, is not necessarily natural or a result of personal choice. It may also be a matter of structural discrimination and inequity.

Culturally inappropriate diagnostic tools and procedures

Several diagnostic tools have been developed that are suited to people from minority ethnic groups and are not biased in terms of language, literacy or education (Gove et al. 2021). However, these are not yet widespread and have not been validated on people in all the groups for which they are likely to be used. In some ethnic groups, women have fewer opportunities to perfect the language of the country in which they live because they do not move in social and professional circles which would enable them to perfect the national language. Amongst those with a direct migratory background, some may also have had little or no formal education (e.g. having grown up in countries where girls do not receive as much formal education as boys). Women with a migratory background from certain countries and cultures may therefore sometimes fall through the net, either not being sufficiently informed about dementia because of language and literacy difficulties, not having the health literacy to know whom to contact, or not being detected because of culturally inappropriate tests.

There is some evidence of inequity in access to memory evaluation services and subsequent diagnoses of dementia linked to both gender and ethnicity (Ogliari et al. 2020). Ogliari et al. (2020) estimated that South Asian older women

in the UK were least likely to be referred to dementia services and Pham et al. (2018) detected an 18% lower incidence of dementia diagnosis among Asian women compared to white women, and 25% higher incidence among black women. For men, the incidence rate was 28% higher in the black ethnic group and 12% lower in the Asian ethnic group, relative to the white ethnic group. These figures were contrasted with data and projections of incidence amongst people living in the community where it was estimated that 42% of black men would develop dementia compared with 53% of white men (in 2015 in the UK). It is unclear whether certain groups of people, or men and women from certain groups, are missing out on diagnosis or being wrongly diagnosed, or whether these differences reflect the actual number of people in those groups who have dementia.

Homo/transphobia and persecuted minority groups

LGBT* people face additional challenges to help seeking. These are often directly or indirectly linked to homo/transphobia and to historical as well as current interpersonal and structural discrimination (e.g. to a history or fear of prejudice and lack of understanding from healthcare professionals). Many of the older generation (e.g. born before the end of the Second World War) experienced discrimination and homophobia when younger. They were considered as having a mental disorder and some were subjected to inhumane medical treatment, were estranged from their families with no substitute 'family', led a life of secrecy, were socially isolated and did not have the same legal rights and protection, including the right to have children (McGovern 2014). In Sweden, until 1 July 2013, it was mandatory for people who changed their gender in the population register (regardless of whether they were having related medical treatment) to undergo sterilisation (Hofverberg 2018).⁶

Homosexuality was classed as a pathological condition by the American Psychiatric Association until 1974 and was only removed from the World Health Organization's list of mental disorders in 1990. It is still criminalised in over 70 countries, and a death penalty is imposed or at least a possibility in 11 countries (Statista 2021). Some people with dementia may have migrated to Europe from countries where this is still the case. Older gay men with a migration history may sometimes be hesitant to reveal personal information about themselves and problems in their daily lives because of fear of their homosexuality becoming known, if homosexuality is still illegal in their country of origin or if gay men are still persecuted. Whilst this may not be the case in Europe, it is possible that they may have memories of such persecution or may be aware of friends or relatives

⁶ <https://www.loc.gov/item/global-legal-monitor/2018-05-10/sweden-law-providing-compensation-to-sterilized-or-infertile-gender-change-surgery-recipients-takes-effect/>

having been oppressed or arrested. Also, religious and cultural attitudes and beliefs about homosexuality may still be prevalent in some minority ethnic groups.

It is therefore understandable that LGBT* people are often reluctant and uncomfortable about drawing attention to themselves, talking about difficulties in their everyday lives or disclosing information that might reveal their gender identities or sexual orientations to healthcare professionals. Concealment of LGBT* identity may also be part of lifetime habit of living a double life for a variety of reasons, including anticipated or experienced discrimination (McParland & Camic 2018). It can, however, be difficult for LGBT* people to conceal information about their private lives during the diagnostic process which involves contact with a lot of different healthcare professionals and support staff (this also applies to the experience of care). In some LGBT* communities, ageism may render the prospect of being diagnosed with dementia (a condition that is typically associated with older people) particularly daunting (Age Platform Europe & ILGA-Europe 2012) but there are mixed reports on this issue. Some studies report how LGBT* people often experience a sense of solidarity and a source of support from LGBT* friendships and support networks (Price 2008, McParland & Camic 2018). Some studies emphasise the experience of discrimination linked to identities associated with being “old,” “female,” and “lesbian,” leading to some lesbian women creating a public image of heterosexuality but often having an informal network of support (Averett & Jenkins 2012).

There are some estimations of the number of LGBT* people in the general population, but estimates of the number of LGBT* people who are diagnosed with dementia are lacking. Consequently, people with certain gender identities and sexual orientations, who may be at increased risk of dementia, are not being adequately and appropriately monitored. It is a complex issue because asking for such information, even with the best of intentions, could be considered as unethical (e.g. amounting to an invasion of privacy, putting people at risk of discrimination and failing to respect their autonomy). In some countries, this is done on a voluntary basis but even asking the question may make people uneasy and concerned about how a refusal to disclose such information could be interpreted. On the other hand, taking the example of the 2021 UK census, some LGBT* people and associations have welcomed the addition of questions about gender with opinions ranging from it being a token gesture (albeit in the right direction) to the belief that it will enable better support of LGBT* people through greater awareness of their numbers.

“Census data on age, ethnicity and a range of other characteristics have been key to showing inequality and the need for support, and the same will be true for tackling barriers that LGBT+ people face.”

“At the moment non-binary people don’t have legal recognition in law, which it makes it difficult for them to navigate society, because when your gender identity doesn’t match your ID or when you’re mis-gendered it can make interactions with our mostly cis, heteronormative society difficult to say the least.”

“Having an idea of how many trans people are in the UK will give an idea for people who do control funding and hopefully they’ll allocate more” (Bryan 2021).

Impact of perceptions of masculinity on seeking diagnosis (and support/care)

There are certain biological and sociobiological arguments about masculinity which suggest that some behaviours are ‘natural’ (e.g. linked to testosterone). These arguments have been criticised for serving to excuse negative behaviour and explain positive behaviour (Hagedorn 2019). Without wanting to deny biological/anatomical differences between men and women, masculinity can alternatively be considered as a social construction. This means that masculinity is socially constructed within different power hierarchies that have served historically to maintain men’s dominance over women and are interwoven into culture, institutional practices, symbols, and the “interplay of gender dynamics with race, class, and region” (Connell & Messerschmidt 2005, p.839). The concept of hegemonic masculinity lies at the heart of discussions about male dominance, power and socially constructed masculinities. Hegemonic masculinity is a culturally idealised form of masculinity based on a set of values, established by men in power. It serves to include, exclude and organise society in ways that subordinate women and some other men (particularly men who are not heterosexual because hegemonic masculinity more or less equates with ‘not female’ and ‘not gay’) (Jewkes et al. 2015). It is a way of asserting power over women and over other marginalised and subordinated men, not through brute force but through relative consensus. This also includes consensus from many of the people who are oppressed by it (namely many women for whom it is a cultural ideal of manhood). This is not always to the advantage of men. The collective dominant position over women and competitiveness with other men, combined with the stereotypes of hegemonic masculinity, may have serious repercussions for men’s health and quality of life (Jewkes et al. 2015).

Stereotypes, which help people to process huge amounts of information by attending to certain information, over-simplifying and over-generalising group differences, operate at the unconscious level and reinforce unequal power relations. They influence expectations and self-conceptions affecting self-esteem, notions of personal identity and the desire for acceptance from others (Robeyns 2007). Traditional gender roles, stereotypes and norms, particularly

in relation to perceptions of masculinity, may have a negative impact on men looking after their health, engaging in preventative behaviours and seeking diagnosis (World Health Organization 2018). Courtenay (2000) found that men often associate or enact masculinity (in the context of healthcare) through risk taking behaviours such as avoiding medical care, refusing to take time off for illness, driving after consuming alcohol, and bragging about not needing sleep. This is in keeping with the concept of 'toxic masculinity' which is not just about behaving like a man or about social pressure to behave as a man but about how such behaviour can actually be harmful to the men concerned. Toxic masculinity involves:

- "Toughness: This is the notion that men should be physically strong, unemotional, and behaviourally and sexually aggressive.
- Anti-femininity: This involves the idea that men should reject anything that is considered to be feminine, such as showing emotion, appearing weak or accepting help.
- Power: This is the assumption that men must work toward obtaining power and status (social and financial) so they can gain the respect of others" (Kupers 2005, Morin 2020).

It is perhaps not surprising that many men are keen to engage in what is considered as masculine behaviour, even though some typical masculine behaviours are in fact risk factors for dementia (e.g. football and boxing). Help seeking, which would include checking out symptoms and screening, is perceived by some men as weak or feminine and in direct contradiction with the perceived ideal of the self-reliant, independent man. It could therefore be viewed as breaching masculine norms and could trigger gender role conflict (Christy, Mosher & Rawl 2014). These powerful incentives to comply with 'masculine' behaviour are not conducive to men seeking diagnosis and support or care when needed. There has, however, been some criticism of the concept of toxic masculinity. Waling (2019) argues that it positions men as victims and overlooks their agency in the reproduction of masculinity, and could be seen as recognising masculinity as the only legitimate expression of gender that men can engage in.

Sex, gender and ethnicity in relation to the outcome of diagnosis

There are possible cultural differences, including differences in stereotypes and perceptions of masculinity, which may impact on men's readiness to seek diagnosis. There may also be differences between men and women in the outcome of consultations. According to Béliard (2019), who

carried out an ethnographic study in France, activities and interests that are common amongst people from higher socio-economic groups and men in general (e.g. in relation to hobbies, concentration, words, interest in the outside world etc.) tend to correspond more to factors that are considered relevant and important by doctors in the early detection of dementia. This, combined with lower expectations for women, may contribute to a more rapid detection of dementia amongst men based on their cognitive difficulties in relation to these activities.

Béliard's study revealed that the outcomes of the consultations were different for men than for women. For the women who consulted early, they were more frequently diagnosed as having psychological or psychiatric problems. For those who consulted later, doctors frequently decided against a full differential diagnosis to determine the aetiology of the symptoms, concluding that this was of no interest. Moreover, the women did not often return for a follow-up (which is perhaps not surprising if the importance of their problems was downplayed and no concrete details given of the cause). Men, in the French study, tended to follow-up on their initial consultation.

The diagnosis of dementia is a complex process, with additional challenges for the diagnosis of people from minority ethnic groups which were addressed in Alzheimer Europe's earlier report on intercultural care and support⁷. There are differences not only in whether people from minority ethnic groups receive a diagnosis but also in the quality of the diagnostic work up, consisting of well-conducted diagnostic tests and evaluations such as a detailed history of cognitive symptoms, a cognitive test, neuroimaging, blood tests and a test of activities of daily living. Nielsen et al. (2011c) found that only 23% of patients diagnosed with dementia from minority ethnic groups in Denmark had received an acceptable workup. This suggests that they received a sub-standard diagnostic evaluation.

In addition to the lack of culturally appropriate assessment and diagnostic tools mentioned earlier, many people from minority ethnic groups are not being referred by their GPs to a specialist. In some cases, diagnoses are higher than expected (Olafsdóttir, Foldevi & Marcusson 2001, Nielsen et al. 2015). In others, there is a significant underdiagnosis in the 60+ age group with only one seventh of the general rate for men and one third of the general rate for women from minority ethnic groups receiving a diagnosis (Nielsen et al. 2011). Clearly, there is a need for further investigation into equity in access to and quality of diagnosis for people from minority ethnic groups in Europe and to look closely at factors linked to sex and gender.

⁷ <https://www.alzheimer-europe.org/reports-publication/2018-alzheimer-europe-report-development-intercultural-care-and-support-people>

Recommendations

1. Measures to ensure equal access to diagnosis of dementia for men and women, and for all residents in care homes, should be reflected in policy and constitute a legal responsibility, and not left to chance or to the dedication of individual care home managers.
2. Research, policies and support services should recognise and respond to the different experiences of discrimination that some groups have endured in the past and often still experience.
3. Gender awareness, sensitivity and competence should be promoted and reflected in the fields of policy, education and healthcare.
4. More high-quality research studies need to focus on gender differences in risk factors for dementia and on factors influencing diagnosis and access to services across genders and sexual orientations.
5. Research studies need to pay particular attention during their planning and execution to avoid gender bias.
6. Healthcare staff working in sexual health clinics need to be aware about the cognitive status of people accessing their services and refer them for further testing if a diagnosis of dementia is suspected.

3. Living one's sex, gender and sexuality with dementia

The first half of Part 3 looks at how sex, gender and sexuality affect the experience of having dementia, not so much in relation to care (which is addressed in Part 4) but more in relation to continuing to live one's life and to being an equally valued and respected member of society. The second half of Part 3 looks at the impact of dementia on relationships for people with dementia as well as their partners, who are also sometimes their carers.

Managing and negotiating societal expectations and personal identities

Living and ageing well with dementia

Sex, gender and sexuality are related to and part of the more global experience of living with dementia. The likelihood of getting dementia increases with age and there is increasingly an emphasis on successful and healthy ageing. In view of this, people are being encouraged to live well and age well. We are constantly exposed to assumptions and messages about living well, and about healthy and successful ageing, combined with images of happy, hetero older couples with grand-children who supposedly make their lives meaningful and positive (Sandberg 2017). This is not conducive to people with dementia feeling free, accepted and valued, as they are (however that is) and to being supported, to express gender and sexual identities that do not necessarily conform to that contrived norm. It does not reflect the hopes, expectations, fears and experiences of the many people with dementia (of all sexes, gender identities and sexualities) who do not fit into this narrow mould.

Images and ideals are often also culturally biased and have little relevance for the lives and wellbeing of people from minority ethnic and other marginalised groups. People with dementia from these groups cannot necessarily relate to these images and little is known, both within and outside of those groups, about their experiences of living with dementia. However, numerous aspects of people's identities and personal characteristics or situations (e.g. ethnicity, socio-economic status, age, profession, religion etc.) interact and affect the experience of having dementia. There is already a distinct lack of research on the experiences of lesbian and bisexual women, as well as trans people and people with non-binary identities. This further hinders research into the experience of people with dementia from these groups, alongside other intersecting identities.

The impact of stigma

Attributes (i.e. qualities or features regarded as a characteristic or inherent part of someone or something) that differ from the established norm, and are perceived as being socially significant in some way, often become social stigmas. Such attributes are first identified and labelled. Negative stereotypes are then attached to them and people with those attributes are devalued and discriminated against by others who consider them to be fundamentally different to themselves (Link & Phelan 2001).

With regard to dementia, attitudes and mentalities are gradually changing. This is perhaps partly due to people with dementia speaking out about their experience of having dementia, to dementia being recognised as a disability, to a more rights-based approach to dementia and to governments recognising the need to address dementia, having led to national dementia strategies in most EU countries. Nevertheless, a lot remains to be done and many people still consider dementia as a stigma. Experiencing dementia as a stigma can be further compounded by other factors, some of which are also considered as stigmas, such as ethnic identities, gender/sexual identities, being older, having other impairments or disabilities and social class. This does not only mean that some people have higher levels of stigma, but it makes the experience of having dementia qualitatively different and raises issues that other people with dementia may not have.

Practically any attribute can become a stigma as it is the meanings and social significance that are important, not the specific qualities or features of the attribute *per se*. This means that their significance may change over time and in different settings. Attitudes towards people whose parents were not married or towards people with ginger hair, tattoos or prosthetic limbs have gradually changed in many societies where those attributes are no longer considered as stigmatising as they used to be. The social acceptance of LGBT* identities varies significantly (Alzheimer's Association & SAGE 2018). Some stigmatised attributes, such as being old, having a mental disorder or older people openly expressing their sexuality, remain fairly stable over time and in different cultures. As stigmas are socially constructed, they can be and are increasingly challenged, but challenging them is hindered by the heteronormative assumptions described earlier. A lot of the issues discussed in this report and specifically in this and the next chapter are directly or indirectly linked to stigma and heteronormativity. However, on a more positive note, some LGBT* people experience a diagnosis of

dementia as liberating as the following testimonials from lesbian women with dementia in Germany show.

“I think I was my whole life a lesbian – but it was shameful to ‘live’ this inclination or even talk about it. When I got diagnosed I did not stick to ‘rules’! I simply felt free to live it!” (Brigitte, 73).

“I already talked about my inclination to my parents when I was a teenager. After getting diagnosed, I felt free!! I even show my preferences in the social media” (Martina, 51).

“My whole life I lived open-minded and free! My dementia did not change my inclination – I am the same woman with feelings. What changed is my cognition” (Daniela, 38).

The right to define oneself

A key issue with regard to support, treatment and care is that of self-determination. Self-determination is often described in terms of people’s ability to make choices and manage their lives. It is more than just a matter of making decisions. It is about how decisions about oneself (i.e. about personal identity and self-expression) are acknowledged and accepted by other people. The German Ethics Council (2013) points out that the German term for determination, which is ‘Bestimmung’, also means definition. They suggest that when people ‘determine’ themselves by stating their name, age and gender, that is an indication of how they would like to be perceived and recognised in their individuality. Such characteristics must not only be known but also accepted by others.

People with dementia experience various symptoms, not always the same ones and not always to the degree or in the same order. Because of stereotyping and the persistence of a biomedical approach to dementia (which focuses on pathological processes in the brain), dementia and its presumed personal and public consequences often become a person’s chief defining characteristics (Price 2008). The things that made them unique, and who they are still, are often given less attention. In some cases, dementia engulfs all other personal characteristics, with the result that someone is ‘a person with dementia’ and that statement is considered self-explanatory and all that needs to be known. Everything else about the person is thus reduced to their dementia diagnosis; their actions and reactions in the present day are categorised as ‘Behavioural and Psychological Symptoms of Dementia’ (BPSD) rather than pain, hunger, fatigue, sensory problems, other health conditions etc. (as mentioned previously, this is sometimes described as ‘diagnostic overshadowing’). In the same way, with regard to gender and sexual identity, John is reduced to being a person with dementia and not a retired deep-sea fisherman who spent

his whole life on a small island before moving into care. Ayesha becomes a person with dementia and not an accomplished pianist and founder of a home for retired police dogs.

Sometimes, personal details that people with dementia share about their lives are met with disinterest (as they are not considered relevant) or treated as confabulation (‘just the dementia talking’). Sex, gender identity and sexual orientation are amongst the characteristics that are key aspects of people’s identities but tend to be considered as less important. It is assumed that men with dementia are all biologically male, identify as men and are heterosexual, and vice versa for women with dementia. LGBT* people are thus silenced, ignored or rendered invisible. When it comes to research and planning services and support, sex, gender and sexual identities are often overlooked or not considered relevant to people’s experience, needs, wishes or rights. At times, they are nevertheless noted, namely when they clash with heteronormative assumptions. Jacques becomes ‘Jacques who used to be Jaqueline’ and has dementia, and not the hairdresser, avid football fan and loving father of three children, and Annabel becomes the lesbian woman with dementia and not the retired nightclub singer and botanist. Moreover, for staff charged with providing dementia services, confusion or ignorance about the right terminology to use in connection with LGBT* issues can lead to inappropriate ‘banter’ and trivialisation.

The biomedical focus, heteronormative assumptions and restrictive positioning of people with dementia overshadow the richness of their experience, the important factors that define who they are and their needs and interests. It is important to get the balance right so as to ensure that people with dementia of all sexes, genders and sexualities can live and express fully those aspects of their identities, in the same way as other members of society.

Reciprocity and the continuous management of gender identity

People tend to live within webs of relationships (e.g. with partners, friends and acquaintances) and self-identities are constructed collectively in collaboration with those people, including people we don’t necessarily know personally. Self-identity is a complex issue but basically is about who and what people feel they are. In the late 1960s, Mead and Blumer described the construction of self-identity as a process of self-reflection and interaction with other people within society, shaped by attitudes, beliefs and ideas that are created, amended and perpetuated by all members of society (Hayes et al. 2009). Reciprocal exchanges also involve mutual recognition of other people’s needs and behaviour. This is particularly important with regard to close relationships and sexuality (which are discussed later in the section) and for the maintenance of people’s gender identities. People have their own gender and sexual

identities but these are also constructed around, and to some extent dependent on, other people's gender and sexual identities. Consequently, when dementia impacts one person's identity, it may also impact another's as well as the identity of the couple, including its gendered and sexual aspects (Merrick et al. 2016). Accepting losses and changes may threaten people's identity as a couple (i.e. their 'couplehood') (Hellström et al. 2005).

Whilst everyone contributes to defining identities, this process takes place within societies that are heavily influenced by heteronormative assumptions. As explained earlier (see also the glossary in Appendix 2), such assumptions strongly reflect fairly restrictive ideas about sex, gender and sexuality. People with marginalised gender and sexual identities frequently encounter challenges to recognition and acceptance of their identities. As dementia progresses, reciprocity is even more important and necessary because the mutual give and take in social interactions becomes increasingly one-sided. People with dementia start to need more support from other people and greater recognition and understanding of who, and what, they are presenting themselves to be in terms of their gender identities.

The way that people appear and present themselves to others was described by Erving Goffman using the metaphor of theatrical performance. According to this metaphor, a person presents a character to the audience, attempts to guide and control the impressions that the audience has of them, uses certain techniques to guide that performance and relies to some extent on the audience to accept and go along with that performance. The person presents their reality (i.e. their perception of themselves that they want other people to recognise and accept as being who/what they really are). Goffman states,

“When an individual plays a part, he [sic] implicitly requests his observers to take seriously the impression that is fostered before them. They are asked to believe that the character they see actually possesses the attributes he appears to possess, that the task he performs will have the consequences that are implicitly claimed for it, and that, in general, matters are what they appear to be” (p.17).

Amongst the many aspects of the analogy, the personal front is important. It covers, amongst other things, clothing, sex, age, ethnicity, size and looks, posture, speech patterns, bodily gestures, and the like. Some of these are linked to appearance, others to manner. Gender identities are not, as mentioned earlier, fixed but fluid, dynamic and open to transformation. This might not always seem obvious because for most people expressing their gender identities becomes almost automatic over time. Dementia may disrupt the automatic nature of this aspect of presentation of

oneself, and at the same time may restrict people's ability and right to change those aspects of their identity.

The personal front and the inner feeling of being a man, a woman, masculine, feminine or having a non-binary identity, can be supported by a person's partner so that the person is not only recognised by other people as what he, she or they are, but also continues to feel that they are what they are, and has what they need for this to be the case. For cis-gender people (heterosexual people whose gender identity corresponds to their biological sex within the traditional male/female binary system), their ongoing performance is supported by numerous cues and supportive settings. In keeping with heteronormativity, it is taken as the norm. It is no threat to the heteronormative society in which they live and the broad general public is keen to contribute towards and support their performance. If people with dementia wish to diverge from the traditional binary expression of gender, however, not only would they have little support, but also their choices, behaviour and appearance could be challenged and attributed to them having dementia.

Having dementia may gradually make it more difficult for LGBT* people to manage their complex presentations of gender and sexual identity in everyday life in different contexts. Common concerns include the loss of self and of LGBT* identity which reflects the intersectionality of sexuality, stigma and sickness (McGovern 2014). The management of gender identities means attending to a lot of different cues and expectations in the context of interpersonal interactions, including practices, clothing, mannerisms, pitch of voice, make-up, bodily hair and communication styles, to name but a few. Impairments linked to memory, concentration, attention and planning may interfere with the effective management of gender/sexual identity, and there may be little support or understanding outside of the LGBT* community.

Coming out, being outed and passing

Coming out, being outed and passing (please see Figure 5) are key aspects of the management of gender and sexual identity for LGBT* people. They are linked to self-determination, wellbeing, privacy and confidentiality, and often to stigma.

Passing usually involves the concealment of an attribute that is generally perceived within society as being discrediting (i.e. a social stigma). According to Goffman (1963) and Jones et al. (1984), attributes are not inherently discrediting. Rather, as mentioned earlier, they are discrediting because of the meanings that come to be attached to them, and usually this is linked to some kind of perceived threat (e.g. existential, physical, moral, psychological or economic) (Stangor & Crandall 2003). Passing and the management of coming out can become difficult as dementia progresses.

Figure 5: Coming out, being outed and passing

- ‘Coming out’ (from the metaphor ‘coming out of the closet’) describes self-disclosure by LGBT* people of their sexual orientation or their gender identity.
- ‘Being outed’ is the opposite in that it involves the deliberate or accidental disclosure of an LGBT* person’s sexual orientation or gender identity without their consent.
- ‘Passing’ is used to describe a person’s ability to be regarded as having a certain identity or to be a member of a group or category that is different from their own (often in relation to ethnicity, social class, sexual orientation, gender and/or disability status).

Goffman points out that “new contingencies always arise, making former concealing devices inadequate”. He suggests that trans men are constantly scanning the social landscape for fear of being inadvertently outed and thus “alienated from the simpler world in which those around [them] apparently dwell” (1963, p.88). This may also apply to other people within the LGBT* community and even more so for intersex people who, within the context of binary sex and gender identities, have no option other than to pass. Intersex people and some trans people who have fully transitioned may need some degree of medical and physical support to manage their bodies and physical appearance. This could include assistance with vocal coaching, prostheses (to hide or give the impression of having various sexual attributes) and medical assistance linked to long-term hormone replacement therapy for gender affirmation (Ansara 2015). Confusion and loss of inhibition may result in some people unintentionally disclosing their gender or sexual identities (i.e. to the wrong people or in the wrong context) and being uncertain about who does and doesn’t know (Cousins, de Vries & Harrison Denning 2021). This can lead to LGBT* people with dementia fearing outing themselves or being outed to health and social care professionals and, consequently, to them becoming very much reliant on informal carers to prevent this from happening (Barrett et al. 2015). McParland and Camic (2018, p.458) describe an ongoing tension for LGBT* people with dementia based on “giving yourself away vs. holding onto yourself”.

The issue of passing is particularly complex for trans people. The following extract describes some of the challenges faced by transgender people particularly with regard to how they are questioned, judged and often harshly treated by non-trans people.

“Transgender persons are typically judged for how well they “pass” within the binary lens of gender expression. Likewise, they are routinely subjected to detailed and invasive questions about their physical bodies, particularly the size and shape of their genitals, and whether they have had sex reassignment surgeries or are involved in hormone treatments. These judgments “contribute to the perception that transgender persons are ‘others’, rather than legitimate and valued members of our society” (Singh, Hays & Watson, 2011). Negative reactions are endemic while a person is in the early stages of gender transition. However, as Prosser (1998) notes, revealing one’s transgender history is always fraught with uncertainty and can be followed by disbelief, judgment, ridicule, or harm. Consequently discrimination, at the very least in the form of frequent micro-aggressions (Nadal, 2013) and sometimes in the form of verbal harassment or physical violence, may re-occur throughout a trans person’s lifetime, even when “posttransition” (Lombardi, 2009)” (in Nealy 2014).

Nealy (2014) suggests that the act of passing is very complicated because it is often seen as a form of deception.

“The very notion of passing implies that the transgender man is hiding a “true” identity that can be uncovered and revealed. This implies that he is not who he claims to be, and more specifically that he is “really” a woman pretending to be a man” (Nealy 2014, p.121).

Paradoxically, from the perspective of trans men, it is often the opposite. Nealy describes passing in terms of authenticity, whereby “passing means being read, or seen, for who you are: a man” and hence a potential source of pride. Passing leaves people open to confrontation and to being ‘discovered’, which may lead to accusations of being deceptive and for some trans people to violence. Consequently, it can be stressful to maintain over time, especially for people with dementia who are experiencing difficulties with memory, planning and concentration.

Recommendations

1. Health and social care professionals should:
 - provide opportunities and, if necessary, practical, emotional and administrative support for LGBT* people with dementia to manage effectively their gender identities (i.e. to present themselves as male, female or of non-binary expression, and to pass or to come out if and when they wish to do so),
 - strive to respect and validate the gender identity (including non-binary or gender fluid) that a person with dementia is seeking to communicate regardless of their voice, attire, physical appearance or attributes or identity documents,
 - ensure that LGBT* people have access to a person in whom they can confide (who affirms and is capable of communicating acceptance of their gender identities and sexual orientations) to represent their rights and wellbeing in the context of dementia care and support. This would most likely be a different person for people with different LGBT* identities,
 - protect the rights, promote the wellbeing and provide support to people with dementia and their partners, families and friends of all gender identities and sexual orientations at the end of life and during the bereavement process.
2. Health and social care service providers and commissioners should:
 - ensure that LGBT* people with dementia are not outed against their wishes or as a requirement to seek or accept services and support (which may be necessary to continue living in their own homes in the community),
 - educate professional and non-professional health and social care staff, as well as people in administrative roles, about gender issues with a focus on respecting the identities of the people in their care, living in their communities or participating in society, and reducing stigma,
 - provide medical, prosthetic and administrative support if and when required to enable intersex and trans people who have transitioned to manage their health and gender identities.
3. Governments should:
 - strive to ensure that educational materials, public health information, and messages and images in the media, portray ageing, sexuality and dementia in an inclusive way that does not perpetuate heteronormative assumptions.

Dementia, relationships and sexuality

About relationships and sexuality

Close meaningful relationships often provide a valuable source of support, a sense of security and a sense of wellbeing and connectedness, impacting on quality of life, life expectancy and mental and physical health (Holdsworth & McCabe 2018). They may also provide a means for people to express their identities. Sexual relationships and acts can, in addition, be a source of satisfaction, support, reassurance and a way for both people with dementia and their partners to cope, as well as a positive part of carers' lives (Simonelli et al. 2017) and something familiar or a 'safe harbour' amongst all the changes (Dow & Malta 2017, McParland & Camic 2018, Sandberg 2020). Sometimes, sex is one of the few things that partners feel they can still share. However, dementia can impact on relationships and on people's interest in sex and the satisfaction they gain from it. This applies to people who have dementia as well as their sexual partners. People with dementia nevertheless have a right to the enjoyment of sexuality, which is considered as a fundamental human

right and enshrined in several human rights frameworks (Peisah et al. 2021). Unfortunately, ignorance and prejudice, at the personal as well as institutional level, often serve to deny the basic human right of people with dementia to sexuality, as echoed in the following statements:

"Framing is everything. Ageism and ableism intersect to generate multiple disadvantages. Ageism frames them in a generalized way built on assumptions and stereotypes. And ableism discounts their humanity as well as abilities. As such, the intersection of ageism and ableism leads to age and disability discrimination and hinders older persons from the full enjoyment of their human rights" (Quinn & Mahler 2021, p.993).

"The right to a sexual life where there is true consent and mutual desire has been acknowledged by the courts as a fundamental human right. (.../...) However, proper enjoyment of the rights to sexuality of persons with dementia has been prevented by a range of ageist and mentalist stereotypes" (Peisah et al. 2021, p.1022).

Tarzia et al. (2012) describe ageism as operating at many levels, touching on fear of death, a deeply entrenched system which values productivity and the association in the media of youth and beauty with attractiveness. They point out that this positions older people as sexless and undesirable. This may further fuel stereotypes of older people with dementia as being asexual and contribute to their needs and rights being ignored or denied. In the residential care setting, rooms are usually designed and constructed for single people who are assumed to have no sexual desires. They incorporate technical constraints to sexual contact such as single beds, and contrary to usual societal expectations, being single is the accepted norm and being in a couple the exception or abnormality (Quentin 2012).

On the other hand, it should not be assumed that everyone has a long-term partner, or that the relationship involves sex. Some people do not have a long-term partner or do not live with their partner, and some have platonic relationships, characterised by closeness, honesty, acceptance and understanding, but with no sexual contact. Similarly, it should not be assumed, as is often the case, that partners are of the opposite sex and heterosexual. In addition, LGBT* people may have relationships with 'chosen' and 'found' families (Cousins et al. 2021) as well as or instead of relationships with their biological families. In this section, our main emphasis is on relationships between adults in which one person has dementia and the other is considered as their partner, irrespective of whether this includes sexual contact.

Many straight couples are either married or in civil partnerships, albeit less so than in the past. Being in a legally recognised couple is still largely taken as the norm. 'Gay marriage' was first legalised in the Netherlands in 2001 and many countries have since followed suit. 16 European countries currently legally recognise and perform same-sex marriages (soon to be 17 when Switzerland joins the list in 2022) and thirteen additional European countries legally recognise some form of civil union⁸. However, many LGBT* relationships have not been formalised in that way and many LGBT* people do not share the ideals or goals of marriage and formal civil unions (Cousins et al. 2021). For this reason, unless an issue is specifically related to the institution of marriage or to a civil partnership, we will refer broadly to relationships and partners. The following sections of this chapter focus on three broad aspects of relationships involving people with dementia and their partners:

1. Changes in the perceived nature and quality of relationships.
2. How dementia impacts on the sexual component of relationships.
3. The experience of being a carer and sexual partner.

These three broad aspects are of course not neatly separated in people's everyday lives. This approach is just to provide a structure to discuss different issues, and there will be some degree of overlap. One particular issue where there is considerable overlap is that of intimacy. Intimacy is often understood to mean close familiarity or warm friendship developed over years (which is often the case amongst couples) but is also used as a euphemism for sexual contact.

Changes in the perceived nature and quality of relationships

Dealing with changes in the couple and the partner

Dementia is frequently described as affecting the quality of people's relationships, resulting in a loss of companionship, of a trusted friend and lover, of reciprocity and of someone to talk to and confide in. It may also affect power relations and the fine balance that couples have established between dependence, independence and interdependence. This may involve subtle changes at first which become more pronounced as dementia progresses (Evans & Lee 2014, Egilstrod et al. 2019). However, the quality of the relationship, gender roles and the nature of the relationship prior to dementia clearly play a role in the further development of the relationship and in the impact on the couple (Harris et al. 2011, Egilstrod et al. 2019).

Whereas some theories of relationships suggest an interest in maintaining a balance between rewards and costs (e.g. in terms of commitment, satisfaction and personal investment), others suggest that some couples in which one person has dementia have other priorities and values. They may, for example, feel that the relationship *per se* is more important than what they get out of it personally and whether it represents a fair/balanced exchange (Baikie 2002). This is also related to the importance of timely diagnosis in that understanding cognitive difficulties that people with dementia are experiencing, and how these to some extent impact on what they say and do, may reduce some misunderstandings and hurt.

Dementia has an impact on the everyday lives of people with dementia and their partners. It is quite common for partners to notice changes in the behaviour and perceived character of the person with dementia. In a study carried out by Youell et al. (2016), two female spouses described this in terms of an 'absent presence' or 'ambiguous loss' (Boss 1999), which consisted of a lack of interaction, companionship and empathy, and a feeling of being with their partners and at the same time alone. This is an ambiguous loss within the relationship in the sense of being incomplete or unclear. The person with dementia is still a much-loved

⁸ For details, please see: https://en.wikipedia.org/wiki/Recognition_of_same-sex_unions_in_Europe

partner but one who may act or react out of character (not like their ‘old self’⁹) and, through their presence, remind their partners of the elements of the relationship that have been lost. Clearly, not all relationships are harmonious and whilst love and happy memories may help some partners to cope with the challenges of dementia, some couples’ earlier negative experiences within the relationship may render emotional connection difficult and lead to resentment. The quality of the relationship prior to dementia may help or hinder the maintenance of intimacy (Harris et al. 2011). The situation is not always so clear and there may be ambiguous feelings between partners which affect the quality of the relationship.

For married couples, the nature and status of marriage is sometimes called into question by the impact of dementia. Marriage status, and the associated vows, religious beliefs and shared expectations, may help some partners to cope with challenges to their relationships, but such challenges may for others cast doubts on the validity of their marriages. It can create instability and confusion as couples continue to live together as partners, whilst not relating to each other in the same way, with the partner without dementia sometimes supporting the spouse because of the marriage but no longer feeling part of a married couple. Kaplan (2001) describes them as the “unmarried-marrieds”, sometimes despite love and devotion, having stepped back from their marriage, shut off from their partners, and some contemplating a possible future relationship with someone else (Evans & Lee 2014).

The perceived changes in the marriage or relationship are experienced both by people with dementia and their partners, as demonstrated in the following quotes:

“I’m not who he married anymore. There’s pieces of me missing. There are little pieces of me sort of breaking away... little chunks..... I see so many changes this past month. I don’t recognise who I am right now.”

“It’s like the emotional part is just totally gone. It’s hard, any intimacy. We used to go to the movies a lot, hold hands, and do those kinds of things. Little by little, everything that we had done as a couple is just gone. But he still kisses me goodnight and tells me how much he loves me....”

“You become not just a role player; you go back to these vows you took. How you were standing up and how they tell, from death do us part, united for better or for worse” (Harris 2009, p.70–71).

“Love has lasted during the most beautiful years of our life and cannot be destroyed by this terrible disease in the last years of our life” (male carer from Spain).

“It is our last time together. It is positive and we are happy to be together, although the element of reciprocity is starting to fail (female carer from Denmark)” (Alzheimer Europe 2001, p.28).

The identity of the couple (e.g. based on opposing/complementary or supporting roles, attitudes and behaviours, also in relation to gender identity) is dependent on each person going along with the established script (using Goffman’s analogy). According to Molyneaux, Butchard, Simpson and Murray (2012), couples who encounter threats to that identity because of dementia use a variety of strategies to try to maintain it including normalising, externalising, sharing the experience and reframing the experience.

Partners sometimes find it strange and somewhat disconcerting to find that they are now considered as carers (at least by service providers). For many women, the role of being a carer is seen as an extension of their lifelong commitment to caring for their families (Alzheimer’s Disease International 2015) and they do not feel that they now have a different role. For some partners, people with dementia as well as ‘carers’, the term does not sit well. This is not just an issue for female partners of men with dementia but for partners in general although LGBT* partners are sometimes not considered as carers when it would often be helpful if they were. Also, the carer/cared for distinction is not always so clear within couples because the partner who does not have dementia may nevertheless need support and care for another condition.

The relationship between metaphors for dementia and gender identity

Metaphors are often used which reflect a perception of people with dementia being physically present but mentally absent or disconnected from the world around them. People with dementia have, for example, sometimes been described as being “away with the fairies”, an “empty shell”, “not there” (“lights on, no one at home”), “sitting there like vegetables”, or being “just a body”, a “speechless shadow” or a “zombie” (Swane 1996, Devlin et al. 2007, Dunham & Cannon 2008, Piehl 2009, Behuniak 2011 and Gove 2012). Not only are such metaphors demeaning and dehumanising but as Sandberg (2021) points out, they deny gendered subjectivity and embodiment, failing to recognise a person’s masculine and feminine status. Perceiving others in terms of objects (like an empty house or a vegetable) but

⁹ References to an ‘old self’ are intended to describe how a person was previously perceived by partners and not linked to discussions about personhood.

also as a zombie (which according to Behuniak is linked to appearance, loss of self and loss of the ability to recognise others) makes them genderless and, in the eyes of the partner, incapable of reflecting or validating the partner's own gender identity. The figure of the zombie may also be taken to represent one who consumes without producing, and therefore becomes a burden both on immediate caregivers and wider society. This is another way in which people with dementia are frequently stigmatised. The objectification of people with dementia through various metaphors also calls into question cognition and intellect. This is particularly threatening to masculinity which is constructed around such concepts (Sandberg 2021).

About new relationships

Aside from assumptions that older people are asexual, it is often assumed that people with dementia, being 'older', are either single and happy to be so or in long-term stable relationships. Less attention is given to people with dementia who are not in stable relationships or who are seeking either a new relationship or just a sexual partner. Anecdotal accounts have revealed the dilemma that some people face about whether to reveal straight away or in dating profiles that they have dementia or to do so later once they have got to know someone better, the dilemma being linked to the desire to attract a partner, to be honest, whether to 'pass' and what the implications are in relation to trust, honesty and support within relationships.

Changing gender roles and crossing gender boundaries

Couples often have specific roles in the relationship, covering the distribution of tasks and reflecting each person's interests, available time and abilities. These roles and responsibilities often reflect traditional gender roles (e.g. with women having main responsibility for household issues such as shopping and preparing meals, and men for household repairs and for the car) (Calasanti & Bowen 2006, Bamford & Walker 2012). Traditional female roles are generally unpaid, paid less or not as highly valued as those typically considered as masculine. They are also devalued because they are repeated endlessly without ever being finished once and for all. Simone de Beauvoir described this as follows:

"Few tasks are more like the torture of Sisyphus than housework, with its endless repetition: the clean becomes soiled, the soiled is made clean, over and over, day after day. The housewife wears herself out marking time: she makes nothing, simply perpetuates the present ..." (de Beauvoir 1949, pt5, ch. 1).

Traditional male gender roles are often associated with decision making and hence power. When a female partner

takes over the traditional male role, the man with dementia may be perceived as having lost not only tasks, but also power, with his partner now assuming that power, which O'Donnell (2000) described as a "couple of one". Nowadays, there is more overlap and couples are free to choose how to organise their daily lives outside of traditional gender roles, although there is little information on gender roles and responsibilities amongst LGBT* people with dementia. People fit into these socially constructed roles and responsibilities to a greater or lesser extent. They provide a structure and meaning to life, a sense of self and a shared identity. At the same time, regardless of how important they are and how long people have had them, they are not fixed. Indeed, gender itself has been described as something that is "done or accomplished in everyday life" (Connell 2005, p.6). On the other hand, that means that people need to constantly work on achieving and maintaining it, and complying with socially accepted gender roles is one way to do that.

Whatever relationship and roles a couple has, when one partner has dementia, there may be a gradual transition in which the person with dementia becomes more dependent on the partner and the latter helps or takes over some of the tasks and responsibilities that they previously had (Evans & Lee 2014). For example, a man who has always checked the tyre pressure on the car, and made sure it had petrol in it and was roadworthy may feel less of a man when he starts to have difficulty doing so. The issue is not that his partner is incapable of sorting out such matters but in the context of traditional gender roles, certain activities and responsibilities offer an opportunity for self-expression, a possibility to give something to and vice versa to receive something from the partner, and contribute towards maintaining self-esteem. A woman who previously cooked all the meals for her family and had pride and satisfaction in doing so, may experience the loss of this role as the loss of part of her identity, position in the family and sense of womanhood (Borley & Hardy 2017). Men for whom work and certain tasks are central to their self-identity and wellbeing are constantly 'doing' masculinity and recreating their masculine identity (Ritchie 2014).

People in LGBT* relationships have almost all grown up or live in predominantly heteronormative societies. Roles and responsibilities are often perceived in terms of the traditional male-female gender divide (i.e. male breadwinner, female homemaker), regardless of who carries them out, or as being egalitarian (equal sharing). One study found that female couples sometimes ask for help from men for certain 'male tasks' but male couples seldom ask for help for 'female tasks' (Martsenyuk 2013). Within LGBT* couples, difficulties managing certain tasks may also affect personal identity and the nature of the relationship but not necessarily the partner's gender identity. It has been suggested that LGBT* relationships are less based on power and inequality, and that same sex couples do not produce the same

gender inequalities within relationships as straight couples (Kimmel 2000). However, even when couples have always worked on household tasks together, no longer being able to accomplish those tasks together can result in a feeling of loneliness (Fjellström et al. 2010).

The continued harmony of the couple may be achieved by one partner stepping back from certain roles and responsibilities or reducing them and the other either stepping up to new roles, providing support to enable them to continue or finding an alternative solution (e.g. not having a car or seeking outside help). Couples who encounter threats to their identity because of dementia use a variety of strategies to try to maintain it including normalising, externalising, sharing and reframing the experience (Molyneux, Butchard, Simpson & Murray 2011). The relinquishment of old roles, and the acceptance of new ones, is not always part of a smooth transition as people cling onto their roles and reluctantly accept new ones. This can be stressful and partners may sometimes feel overwhelmed and strained as they struggle to take on new roles and responsibilities alongside those they have already (Holdsworth & McCabe 2018). Both partners often agree to try to maintain the situation as it has always been and many partners support the person with dementia to maintain their usual roles and responsibilities (Hellström et al. 2017). Surrendering roles can be difficult as they define people's place within the relationship and within the social group (Evans & Lee 2014). Roles and responsibilities also reflect continuity of personhood and personal integrity (Perry & O'Connor 2002).

Crossing gender boundaries in the context of care has implications for the partner with dementia as well as for the partner who has become a carer. Not everyone is willing to do this. Where one of the partners is not familiar with roles and responsibilities traditionally perceived as female, they may consider this as 'care work' rather than as something they would have been doing anyway. When men take on roles that are traditionally considered as 'female', they are sometimes complimented on their 'heroic' efforts and offered support to do so. In one small study, some female carers reported a lack of support for the 'male tasks' that they needed to take over, and men reported a more functional approach, merely aiming to accomplish their newly acquired tasks.

"For instance, husbands did not express concern about whether their wives were getting enough home cooked meals; rather they focused on making sure that they were fed" (Calasanti & Bowen 2015, p.261).

Whilst this might appear to be a masculine trait, it is possible that non-gender specific tasks do not serve to reinforce gender identity and therefore do not provide the same kind of incentive or satisfaction, other than simply managing and caring for or supporting the person with dementia. Adopting

a functional approach to managing care tasks (e.g. ordering meals-on-wheels, getting other people to provide meals or eating out more) may also enable men to detach from the task and see themselves as organisers rather than identifying with a 'female role'. Others may have no problem doing so or not consider tasks as male or female.

Women may sometimes hesitate to take over some aspects of care for male partners based on concerns about violating their partner's masculinity by drawing attention to their reduced ability to be independent (a characteristic feature of traditional perceptions of masculinity). Sandberg (2021) suggests that men may be more preoccupied with upholding their gendered identity and to having it upheld by others because the male identity is privileged and taken as the norm, whereas the female identity is already considered as "other". In her influential book "The Second Sex", Simone de Beauvoir described women as "other" as follows:

"She [woman] is defined and differentiated with reference to man and not he with reference to her; she is the incidental, the inessential as opposed to the essential. He is the Subject, he is the Absolute – she is the Other" (de Beauvoir 1949, vol. 1).

As masculine roles are seen as reflecting the norm and feminine ones as being 'other', the masculine roles tend to be considered as more important. This is linked to the concept of hegemonic masculinity (see page 14), which is powerful in the context of crossing gender boundaries as it renders femininity and other masculinities (together with their associated gender roles) subservient and undesirable.

The role of gender and sexuality in the context of intergenerational caring

Different families organise the care of their older relatives and friends with dementia in different ways. Women are, nevertheless, usually the ones who assume the main responsibility for care. Very often, this is linked to social pressure and expectations based on gender stereotypes. Innes, Abela and Scerri (2011) describe the situation in Malta, for example, as being particularly influenced by gendered expectations (often imposed on daughters and daughters-in-law), but also accompanied by a lack of adequate formal care provisions and issues related to the geographical proximity of the different members of the family to the person needing care or support. Caring in Malta is also often based on the concept of shared filial obligation whereby daughters and sons rotate the care of their mothers and fathers in their homes on a week-by-week basis. This is engrained in Maltese cultural and social norms, and partly responds to the increasing acknowledgement of women's right to engage equally in the public sphere and not to be confined to the home. This approach has also been reported in Spain. However, in practice, responsibilities are not always equally

shared and women in this Maltese study expressed their disappointment in the lack of support from other family members and resentment that men made the decisions but did not play an active role in providing hands-on care.

In the context of intergenerational caring (e.g. for a parent with dementia), people may experience caring differently and be subject to different expectations not only in relation to their gender but also to their sexual identity. Reczek and Umberson (2016) found that whereas in heterosexual couples, the female partner often cares for both sets of parents, with little support from the male partner, same sex couples often share caring responsibilities more equally and also support each other. They often describe a situation of being interchangeable carers.

The expectation that women will care for parents with dementia often transcends traditional stereotypes in that even lesbian women in families where there was previously tensions around their sexual orientation are often expected to provide care. The sexuality of women is, on the one hand, “only a peripheral consideration” (Manthorpe 2003) and, on the other hand, for lesbian women, overlooked in terms of relevance. Price (2011) suggests that single, lesbian women with no children are often not considered as having any other more pressing responsibilities and that this represents a blanket negation of their own lifestyles and commitments.

Gendered care roles within minority cultural groups

There are also gender differences in and between some minority ethnic groups with regard to who should provide care. In some minority ethnic groups, men play a key role in the organisation of care. In some African, Middle Eastern and South Asian communities, for example, male relatives are considered as the decision-makers and ‘spokesmen’ for the family and therefore decide whether and how to access support services. However, the actual physical/hands-on care is provided by women, usually wives, daughters-in-law and daughters (Rauf 2011, APPGD 2013), sometimes the oldest, youngest or an unmarried daughter. Female members of the household may nevertheless make a lot of the decisions which precede the involvement of the male members of the household (Rauf 2011).

Women from minority ethnic groups who have been given sole responsibility for the care of a person with dementia often struggle to cope. Some may be angry about having been given this responsibility (Ar & Karanci 2017). They may, however, hesitate to ask for professional help for fear of criticism that they are unable to fulfil their role, of angering other members of the family or of being excluded because “only bad women complain” (Tonkens, Verplanke & De Vries 2011). This may sometimes be balanced to some extent by

the satisfaction that providing care brings in terms of recognition and praise from other members of the family (Watt et al. 2014, Van Wezel et al 2016). However, cultural perceptions of care responsibilities often result in women from minority ethnic groups caring for people with very advanced dementia with little or no support, and waiting until a crisis occurs or terminal care is required before seeking help (Mukadam et al. 2011 and 2015).

The gender-based power relations in families may also be based on or accompanied by religious beliefs about relatives having a duty to care for their dependent relatives (e.g. within Hinduism, Islam and Sikhism), especially within the South Asian communities in the UK (Rauf 2011) but also amongst Turkish and Moroccan groups in the Netherlands (van Wezel et al. 2016). Some studies have also reported Christian beliefs about caring for older dependent relatives (van Wezel et al. 2016). The duty to care is in some cultures accompanied by the belief that someone has done something wrong and is being punished (this could be the person with dementia or someone else in the family) or that they are being tested. The person or family concerned may wish to show acceptance of the test (by being patient and providing the care needed) rather than evidence of failure (by accepting outside help) which would put them at risk of criticism (Rauf 2011). In the ultra-orthodox Jewish community in Israel, there is a strict separation between men and women. The primary care is mainly carried out by female members of the family, but male members of the family often provide personal/intimate care for male relatives and take them to the synagogue. Similarly, in the Druze community, women also have main responsibility for care but with some gendered division of responsibilities in that daughters care for their mothers, whereas sons may provide some care to their fathers (intimate care and helping the relative to fulfil his religious duties) (Golan-Shemesh & Lahav 2018).

Criticism or pressure on the female carer often comes from outside the immediate family (e.g. from the in-laws, the extended family and neighbours as well as spiritual leaders). In some cases, relatives who are not responsible for providing care interpret the need for support not as being related to a person’s increased cognitive deterioration but as the carer’s inability to manage (Sagbakken et al. 2018). Spiritual leaders in some religions may play a decisive role in care decisions. In Islam, for example, Muftis (senior Muslim scholars) can be asked to provide an Islamic ruling on whether it would be acceptable to accept certain support or place a relative in residential care (Mohammed 2017). Whilst women are not necessarily excluded from being religious scholars or spiritual guides, their authority to act is often restricted to certain situations or areas. Consequently, female carers may find men making decisions or dictating what is allowed or acceptable with regard to some care decisions.

Practices linked to the provision of care within the family and the use of outside support may be gradually changing as a result of changing family structures, more women taking up paid employment outside the home and different perspectives on care especially amongst second and third generation groups (Lawrence et al. 2008, Bhattacharyya & Benbow 2013, Golan-Shemesh & Lahav 2018). However, changing attitudes towards the use of services may sometimes lead to conflict within families, especially between younger and older generations and between male and female relatives.

Several studies report positive attitudes towards caring for older relatives with dementia. A recurring theme in the literature on responsibility for care is that of reciprocity. In one study (Mackenzie 2006), some Sikh and Hindu carers described care as a way to repay parents for their previous acts of kindness and in two other studies involving carers having migrated to Norway from Pakistan, Afghanistan, China, Vietnam, Turkey, Lebanon, Sri Lanka and Chile (Næss & Moen 2015, Sagbakken et al. 2018), carers described the care as a moral question and, again, a matter of reciprocating the care they had received as children. The theme of reciprocity is also linked to a sense of duty for caring for one's elders inherent in many cultures, such as reported in this study with Sri Lankan families (Watt et al. 2014). This study also observed that daughters and daughters-in-law had the main responsibility for caring for older relatives, thus perpetuating the traditional female stereotypes and undermining efforts to promote gender equality. It is important to avoid stereotyping women within minority ethnic groups as having no choice with regard to care responsibilities, and placing the blame on culture or religion, and ignoring the pressure on women within majority ethnic groups in Europe to provide care based on heteronormative assumptions.

How dementia impacts on the sexual component of relationships

About sexuality and dementia

Sexuality covers a range of needs and interests, which continue to be important for straight and LGBT* people with dementia (Benbow & Beeston 2012). Dementia often has an impact on sexuality and sexual relationships but every couple and every relationship is unique. Whilst people with dementia and carers may encounter similar issues and sometimes react in similar ways, it is difficult to generalise. Also, what we know about sexuality and dementia is largely based on self-reporting by carers (rather than by people with dementia), many of whom are female, and by people who are heterosexual (or are assumed to be heterosexual), many of whom are married. As sexuality is still a fairly taboo subject, not everyone is willing to share information about it. Those who are willing and comfortable to talk about sexuality do not necessarily have the

same or similar experiences to those who are not. It is also not clear what people understand by the term 'sexuality' which affects the conclusions that are drawn from some research on this topic (Nogueira et al. 2017). Some groups of people, such as LGBT* people and people from ethnic minority and other marginalised groups, are under-represented in research about dementia and sexuality, so their perspectives are also missing from the picture. When the sexuality of people with dementia is addressed directly, it is often limited to the residential care context and framed as problematic.

Problematization/pathologisation of sexuality

Sexuality touches on several issues such as the rights to sexuality, wellbeing, capacity to consent, the impact on other people and criminal offences, but discussions about sexuality and dementia often focus on sex as a problem or abnormal. Terms such as 'inappropriate', 'improper', 'sexually ambiguous', 'hypersexual' and 'sexual dysfunction' are often used (Sandberg 2020). Sexuality is often seen as a challenge, inappropriate, or a medical issue to be controlled, especially in the case of men with dementia. The main focus is on coping with the sexual 'demands' of people with dementia and the sexual 'needs' of their partners. Displays of affection or courtship towards other residents in care homes or towards carers may be interpreted as misplaced or inappropriately voiced expressions of a human need for intimacy (Youell et al. 2016, Kontos et al. 2017). It may also be the case that it is the place rather than the act that is inappropriate and if people with dementia had the privacy they are entitled to, their sexuality would not become a matter of concern debated by outsiders. The consequences of labelling the expression of sexuality as inappropriate can be considerable resulting, for example, in loss of the right to sexuality and to family, the person having to move into residential care or to a specialised unit and in some cases even the loss of a loved person (due to one of the partners being moved to a different facility).

In 1973, Gagnon and Simon introduced the concept of Sexual Script Theory (SST) in their book 'Sexual Conduct'. As with Goffman's dramaturgical theory, SST makes an analogy between people's behaviour (in this case being engaged in consensual sexual acts or relationships) and actors in a play or film following a script. These scripts dictate what and when people should be doing something if complying with the role associated with that script. Drawing on SST, Sandberg (2020) emphasises sexuality as being linked to societal and cultural expectations. She points out that sexual scripts are often ageist in that they frame sexuality amongst older people as inappropriate, dysfunctional or non-existent, thereby deterring older people from engaging in sexual relationships.

Sandberg, Bertilsdotter Rosqvist and Grigorovich (2020) identified three interrelated discourses¹⁰ on sexuality, namely regulating, fostering and preserving sexuality. Two of these (i.e. regulating sexuality and preserving sexuality) are particularly relevant to people with dementia. They focus on perceptions of ‘normality’, stability and continuity, and reflect ableist and ageist assumptions. The first reflects a pathologisation of sexuality (i.e. considering it abnormal) and the second promotes sexuality provided that it is consistent with what was considered as ‘genuine’ or ‘authentic’ in the past (i.e. what was ‘normal’ for the person prior to dementia) (Sandberg 2020). Such assumptions/perceptions reinforce the cultural ideal of only rational, autonomous and ‘able-bodied’ adults with decision-making capacity engaging in “healthy, good sex” (Sandberg, Bertilsdotter Rosqvist & Grigorovich 2020). The idea of positive or healthy ageing¹¹ doesn’t sit well with perceptions of ageing involving negative decline, cognitive deterioration and the prospect/existence of unsuccessful ageing (Sandberg 2008 & 2017). Most people with dementia are older, have, by definition, some degree of cognitive deterioration and dementia counts as a disability. Stereotypes of dementia often focus on advanced dementia and together with ageism, ableism and mentalism combine to create and perpetuate particularly negative perceptions of and attitudes towards the sexuality of people with dementia. Homophobia and transphobia add additional layers of complexity to issues surrounding the acceptability of sexuality amongst people with dementia.

Inappropriate sexual behaviour is one of the symptoms mentioned in the BPSD (Behavioural and Psychological Symptoms of Dementia) scale but has been defined in different ways. Sometimes it is based on a distinction between conventional and unconventional behaviours, which is clearly value-laden and discriminatory against people with marginalised sexual practices. Typically, inappropriate sexual behaviours include sexual talk, sexual touching, sexual acting out, sexual practices and viewing of pornography which are considered inappropriate by other people, as well as sexual assault, rape and ‘false sexual allegations’ (which might not be false at all).

Acts may sometimes be misinterpreted as being sexually inappropriate because of the values, assumptions and prejudice of the people assessing the acts, as well as the difficulties of the people with dementia to explain their perception of the situation. In the context of residential care, people with dementia often have to abide by the regulations of the home which impacts on their freedom of movement, autonomy and privacy, and may influence how, when and with whom they express their sexuality and how

others (e.g. staff, residents and visitors) perceive it. It has been suggested that the term ‘inappropriate sexual behaviour’ should be reserved for disinhibited sexual behaviour or hypersexuality that is beyond the person’s control. This would also exclude wilful behaviour and personal preferences that just don’t comply with the values and social expectations of the people judging the behaviour, as well as intimacy seeking behaviour and behaviour that is not actually sexual by intention (Guay 2008, Medeiros et al. 2008, Mahieu et al. 2017). A person might, for example, be trying to adjust a continence pad that is uncomfortable or out of place, or be itching because of a urinary tract infection, which is then perceived by care staff as sexually inappropriate behaviour. Often, it is people in positions of power who determine what is appropriate and inappropriate with regard to the behaviour of other people who lack the ability to defend or explain their behaviour. This is particularly problematic for men who are typically stereotyped as perpetrators of sexual assault and for people who have marginalised gender identities or sexual orientations.

Interestingly, boys are traditionally socialised to have a different, more direct relationship to their bodies (involving handling their genitals, which are visible to them, when urinating and washing) and the traditional heterosexual sexual script is more supportive of them exercising their sexuality more freely. Women’s relationships to their bodies are more complex and problematised, and they are traditionally expected to confine sexual behaviour to the context of a committed relationship (Wiederman 2005, Ward et al. 2005). At the same time, although men’s sexualities are often regarded as natural and matter of fact, they are also regarded as dangerous and this is exacerbated in the case of dementia. There is thus a greater tendency to view male sexuality as pathological and female sexuality in terms of vulnerability and abuse when involving people with dementia. These gendered sexual scripts were also observed in Ward et al.’s (2005) study where transgressions by male care home residents were more likely to elicit a punishing response, such as discharge from the care home, while reactions to female residents tended to be more protective.

“Women with dementia often attract a protective response, underpinned by an assumption that they would neither welcome nor benefit from sexual relations” (Ward et al. 2005, p.68).

Often, the sexual acts or the sexuality of the people with dementia concerned were not mentioned or discussed with them, which suggests that decisions and reactions were based on assumptions and stereotypes.

¹⁰ Ways of thinking about, communicating and giving meaning to things.

¹¹ See also earlier section on living and ageing well with dementia on page 17.

People with Alzheimer's dementia are less frequently described as engaging in sexually inappropriate behaviour compared to people with other forms of dementia. Whereas it is often assumed that such behaviour is common amongst people with fronto-temporal dementia, apathy and loss of interest in sex are more common. There are more reports of people with vascular dementia having inappropriate sexual behaviour (D'Cruz et al. 2020). However, research does not support the assumption that is sometimes made that people with dementia exhibit sexually inappropriate behaviour (Kuppuswamy et al. 2007) and statistics on this issue need to be considered in the light of the problematisation of sexuality in people with dementia in general.

Impact of dementia on frequency, willingness and satisfaction with sexual intercourse

Although older people are often portrayed as being asexual (Youell 2015), there is ample research to suggest that they remain sexually active, regardless of their gender and sexual identities. Most older people are sexually active and engage in regular sexual activity well into their eighties (Abdo 2013) even if sexual activity decreases in frequency with increasing age (Benbow & Beeston 2012). There is some evidence to suggest that men remain sexually active for longer than women but as Mahieu, Anckaert and Gastmans (2017) point out, this may be partly due to fewer of them being widowers. Over half of LGBT* and heterosexual 65-to-74-year-olds and over a quarter of 75-to-85-year-olds, in one study, reported being sexually active with one or more partners (Lindau et al. 2007, Alzheimer's Association & SAGE 2018).

Some studies report no significant gender differences in terms of interest and engagement in sexual activities in couples in which one of the partners has dementia. Others have found an increase or decrease in sexual interest amongst men (increased interest sometimes being linked to forgetting having just had sex), less sexual satisfaction amongst female carers and uncertainty between couples about the partner's willingness to engage in sex (Baikie 2002, Zeiss & Kasl-Godley 2001, Davies et al. 1998, Davies et al. 2012). Nogueira et al. 2017 found no significant gender differences in levels of sexual satisfaction amongst people with dementia but greater dissatisfaction amongst female carers. Not being recognised as the spouse (e.g. being perceived as a daughter or mother) can also be an obstacle to sexual relations (Davies et al. 2010).

In one study, sexual activity and willingness were already found to be decreased in people with Mild Cognitive Impairment (which often but not always leads to dementia) as well as in people with mild dementia (Tsatali & Tsolaki 2014). The authors cautioned against generalising their findings, pointing out that responses were personal and could not be verified, which applies to a lot of research on very sensitive issues. It is notable that many studies about sexuality

in men and women with dementia reflect heteronormative assumptions in the sense that participants are described as male or female, married or unmarried (sometimes non-married partners are included) and assumed to be heterosexual and cisgender (that their stated gender corresponds to the sex assigned to them at birth). This is important to bear in mind also when reading this section.

Men are less likely to find changes in character an obstacle to sex, but concerns about sex not being engaged in freely or wanted can be an obstacle (Davies et al. 1998, Evans & Lee 2014, Nogueira et al. 2017). Sometimes, consent is perceived through the level of interest shown (Hayes et al. 2009). For women with dementia, increased interest in sex may be partly explained by loss of inhibitions (linked to upbringing and religious attitudes) and decreased interest to earlier memories of sex not being allowed (Baikie 2002). For female carers, a lack of emotional closeness and failure of men with dementia to initiate sex have been mentioned as contributing towards a lack of interest in sexual contact and to feeling rejected (Hayes et al. 2009). Some women have described continued sexual contact with their husbands who have dementia solely in terms of the comfort that it provides to their husbands, as a means to hold on to the last remnants of their relationship and to support their husbands' gender identities (to enable them 'to feel like a man'), reflecting a somewhat blurred distinction between being a spouse and being a carer (Youell et al. 2016). This perception of 'being a man' is reflected in the following quote:

"I can no longer provide an income, make decisions or take care of things; this is the only thing that I still have that I can give to my wife" (Davies et al. 1998, p.195).

There are a few reasons why interest in and frequency of sex sometimes diminishes. Some medication for dementia, for example, may affect the person's character and sex drive (Youell 2015). Also, changes in the couple's relationship and its dynamics have an impact on how they experience sexuality. Egilstrod et al. (2019) identified changes in the marital relationship and roles as one of the main themes for couples when one partner is diagnosed with dementia. These changes may also impact negatively on the sexual relationship, as seen for example in Sandberg (2020). This study shows that increasing conflicts in the relationship and exhaustion due to increasing responsibilities for the partner led to loss of intimacy and sexual desire in couples.

Many people with dementia, especially those who are older, have other medical conditions and medication which impact on their ability or desire to have sex such as heart disease, diabetes and prostate problems (Harris 2009). Having dementia may make it more difficult for partners to communicate with each other about the problem and to find a solution. A high percentage of men with Alzheimer's

dementia experience erectile dysfunction that is due to physical problems or medication, and people with dementia may have difficulty remembering sequencing and what is appropriate in their relationship (Davies et al. 1998, Davies et al. 2010). Problems with memory may also affect the ability to attend to respond with sensitivity and in whatever way is appropriate in the context of their relationship, knowledge and understanding of the partner. Carers often complain that their partner with dementia is not paying attention to their sexual feelings and needs (Eloniemi-Sulkava 2002) and some feel that their partner is no longer the same person and that it is like having sex with a stranger (or at least not with the person they married or have a relationship with) (Evans & Lee 2014, Youell et al. 2016, Sandberg 2020).

Differences in the level of interest in sex, difficulties having sex and possible sexual dissatisfaction may take a toll on relationships and affect other aspects of the relationship as well as the overall wellbeing of the partners. In the worst-case scenario, they could contribute towards a breakdown in the relationship, thereby jeopardising the support and care that the person with dementia needs from a close and trusted person. However, sex is not everything and is not an essential part of long-term relationships. In one study, most couples indicated no change in the level of commitment to each other and that they were still appreciating each other regardless of changes in their relationship (Davies 2011).

Sexuality can also be an important part of people's lives outside of stable or indeed any relationship. It does not always involve sexual intercourse and for many people is closely related to love, tenderness and affection and to other

activities such as kissing, touching, hugging and cuddling (Grigorovich & Kontos 2016, Youell 2015, Hayes 2009, Nogueira et al. 2017), as well as masturbating, flirting and feeling 'masculine' or 'feminine' (Tarzia, Fetherstonhaugh & Bauer 2012). One study found that most people with dementia and their spouses associated sexual satisfaction with sexual intercourse but that some (a quarter of the women) associated sex with affection (Dourado et al. 2010). According to Kuppaswamy et al. (2007, p.80),

"To know that one partner in a couple has dementia does not allow the clinician to predict with any accuracy how that will affect the couples' sex life and physical intimacy. (.../...) It is essential that assumptions, implicit or explicit, about "typical" reactions of patients and their partners as dementia progresses be challenged."

Consent to sexual acts and relationships

It is always essential for anyone engaging in a sexual relationship to have the capacity to consent to it. In most cases, it is assumed that people involved in a sexual relationship have such capacity but certain circumstances or signs might lead to concerns that this is not the case. It becomes a particular issue where health and social care professionals have a duty of care towards their patients or residents, especially when there are doubts or it is known that at least one of the people in the relationship (or engaging in a sexual act) might lack that capacity. Having dementia does not equate with lack of capacity to consent to a sexual act but may justify possible concerns

Figure 6: Examples of changes in sexual relationships where one partner has dementia

- loss of interest/apathy,
- decreased or increased sexual desire,
- forgetting having had sex and repeatedly initiating sex,
- difficulties with erection or ejaculation,
- changes in the usual repertoire (which might not be appreciated),
- acting out of character (in general, not just during sex),
- apparent lack of consideration for or sensitivity towards the partner,
- 'inappropriate' sexual behaviour,
- moving from sexual intercourse to other ways of displaying affection such as holding hands, kissing and cuddling,
- not recognising the partner or mistaking them for someone else,
- combining the role of partner and carer,
- one-sided initiation of affection and needing to prompt the person to respond appropriately,
- partners not feeling 'in love' or not finding the person with dementia sexually attractive,
- partners feeling that they are a carer more than a partner (and sometimes that it feels like a parent-child relationship),
- uncertainty about the willingness of the person with dementia to engage in sexual activity (consent issues),
- changes in the expression of intimacy due to the added tasks of keeping the partner with dementia clean and continent.

about whether this is the case. The list in Figure 7 below has been adapted from criteria for assessing the capacity of people with dementia in care homes to consent to sexual relationships developed by Lichtenberg and Strzepek (1990, in Lightbody 2014, p.3).

Some of the points in Figure 7 might not spring to mind in relation to people with dementia because of stereotypes surrounding childbearing and sexually transmitted diseases linked to assumptions and stereotypes about older people. However, men are capable of becoming fathers at an advanced age, women up to about 56 years of age may bear children, some groups of people develop dementia at an earlier age and sexually transmitted diseases are steadily increasing amongst older people (Duffin 2008). Moreover, many older people with dementia did not receive formal sex education and may believe that they are not at risk (Lightbody 2014).

Consent involves the ability and right to make decisions about one's own life and behaviour. It therefore requires decision-making capacity and legal capacity (in both cases insofar as this relates to engaging in a sexual act, and not assuming that legal guardianship measures necessarily restrict a person's sexual rights). In the case of supported decision making, which means providing whatever support is necessary for a person to make a decision, it is important to ensure that such support is not biased. It could, for

example, be linked to issues surrounding future inheritances (i.e. on supporters' fears of losing out on their inheritance, or part of it, should the person with dementia establish a stable relationship). This point has also been raised in connection with relatives acting as 'moral guardians' or 'guardians of past identity' (Quentin 2012). Support could also be biased because of stereotypes about older people and sexuality, or because the supporter is homo/trans-phobic. In some cases, staff and supporters may be more concerned about the assumed moral standards and views of other residents and visitors. It is important, also in the context of person-centred care, to consider the possible impact of people's behaviour and needs on others.

Whilst there is often a great emphasis on the capacity to consent to sexual relationships and acts in residential care settings, people are often deprived of their right to express their sexuality by informal restrictions of legal capacity. Informal restrictions are not based on a legal or even administrative process to assess capacity but on assumptions, paternalistic attitudes, ignorance, a culture of oversight and institutional procedures (Tarzia et al. 2012, European Union Agency for Fundamental Rights 2020). In the context of sexuality, they could, for example, consist of:

- internal rules of the care facility,
- lack of double rooms (for couples),
- lack of possibilities for privacy,

Figure 7: Issues to consider in relation to the ability to consent to sexual relationships

Awareness of the relationship

- Does the person know who is initiating the sexual contact?
- Does the person (if involved in a monogamous, long-term relationship) believe the other person is their spouse/partner? And is this the case?
- Can the person express the level of intimacy that they would be comfortable with?

Ability to avoid exploitation

- Would the person wish to engage in the relationship if they understood that the other person involved was not their spouse/partner?
- Is the behaviour consistent with the person's former values, practices and beliefs?
- Does the person understand that they are free to choose whether or not to engage in the relationship and with whom?
- Does the person have all the information needed to make a decision?
- Does the person have a guardian or the appropriate support to make an informed decision?

Awareness of possible risks

- Does the person realise that the sexual relationship may be time-limited (if that is the case)?
- Is the person aware of possible risks (e.g. of pregnancy or linked to conditions they or their partner may have)?
- Can the person take precautions against risks?
- Can the person assert their wishes and reject any unwanted sexual advances?

- failure to give double rooms to same sex or unmarried couples,
- separation of couples on entry into residential care,
- sending people who engage in sexual relationships to other care facilities,
- shaming residents who engage in sexual activities or declaring their behaviour inappropriate and
- having a clear ethos of disapproval of sexual relationships.

These measures are a far cry from the acceptance/support of sexuality for people with dementia at home and in care facilities, and from the principles of non-discrimination and reasonable accommodation.¹²

Paternalism versus empowerment and other ethical principles and values

Paternalistic and inhuman approaches to sexuality amongst older people and people with dementia deny people in those groups their right to sexual expression and their right to take a certain degree of risk. It is important to bear in mind that nobody is guaranteed protection from manipulation, lack of sincerity and emotional distress that might result from a sexual relationship. Tarzia et al. (2012) argue that people with dementia should not have to prove that they have capacity to make decisions about sexual relationships but rather that care professionals, if responsible for their well-being, should have to prove beyond dispute or doubt that they do not. Moreover, sexual abuse of people with dementia of all sexes, genders and sexual orientations may also be inflicted by care visitors and care staff. The relationship of dependency by people with dementia in residential care on care staff calls for particular vigilance.

Whilst it is often assumed that the key concern of carers is to protect people with dementia from sexual abuse (i.e. in keeping with the principle of non-maleficence), discussions about sexuality and consent often also reflect other ethical principles and values such as autonomy, beneficence (doing good), justice, care and dignity (Mahieu & Gastmans 2012). For many people, with and without dementia, sexuality is very private. Mahieu et al. (2017) point out that nursing home residents often do not appreciate outsiders meddling in such matters. There are three forms of privacy, namely physical privacy, privacy of information and privacy of association, that are often threatened in residential care settings for people with dementia (Mahieu & Gastmans 2012).

Staff may sometimes feel obliged to raise the issue of sexuality as a result of pressure from other residents, visitors and relatives. Indeed, relatives may try to impose their

values and beliefs, seek restrictions on the sexual life of the person with dementia and discuss the sexuality of the latter with residential care staff and healthcare professionals. The belief that they have an automatic right to do so reflects to some extent the tendency to infantilise people with dementia and failure to respect their privacy and confidentiality of information about them. Some degree of discussion with relatives, partners and close friends may sometimes be justified, within the context of trying to understand the needs of the person with dementia. However, such information should not be shared unnecessarily. Hughes, Beatty and Shippen (2014) emphasise the fine line between families needing to know what is going on and needing to control what is going on, under the guise of best interests (with the further question being whether either of these needs is justified).

When considering the current sexual activity or relationship in the light of the people's former values, practices and beliefs, it is important to bear in mind that people with dementia, like anyone else, can change but also that people do not always know what a person's sexual orientation is or was. A married woman, who develops a lesbian relationship with another resident, might be considered by staff and family to be acting out of character (based on their knowledge or assumptions about her values, beliefs or practices) and perhaps that the other woman is taking advantage of her. However, she may have always been lesbian, she may have had lesbian relationships in the past, is or was bisexual or this may be a completely new development in terms of her sexual orientation. Hughes, Beatty and Shippen (2014) emphasise the need to consider each case separately, rather than trying to make hard and fast rules in anticipation of situations that might arise. As Sandberg (2021) eloquently describes in 'I was the Woman, he was the Man', the consideration of the person with dementia, not only as a subject but as a 'gendered subject', is essential for intersubjective recognition.

Hughes, Beatty and Shippen (2014) also emphasise the importance of values in discussions and decision making linked to the right to and expression of sexuality. Drawing on the work of Fulford (2004), they highlight the importance of looking at both facts and values, keeping the perspectives of the person with dementia centre-stage, not assuming that other people share the same values, exploring differences in value judgements and giving them legitimacy even if later rejected, involving all relevant partners in decisions that need to be made and ensuring good communication and a willingness to compromise.

¹² Reasonable accommodation is a term used in the United Nations Convention on the Rights of Persons with Disabilities (2006, §5.3) denoting: "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others all human rights and fundamental freedoms."

The experience of being a carer and a sexual partner

As people with dementia become more dependent on their partners for care, especially intimate care, this can be tiring for the partner, who might also feel that they are more a carer than a partner.

“When you’re a caretaker, the sexual intimacy that we had as husbands just isn’t there anymore. But we can still love them, REALLY love them, probably even more so than before” (Harris 2009, p.70–71).

Also, the extent to which couples are at ease with nudity, non-sexual bodily contact and privacy surrounding toileting is likely to vary considerably. This can be further exacerbated if the relationship is perceived as asymmetrical with the behaviour of the person with dementia being perceived as child-like or if the partner feels that their role in the relationship resembles that of a parent (Hayes et al. 2009, Davies et al. 2010, Evans & Lee 2014, Holdsworth & McCabe 2018, Sandberg 2020, Sandberg 2021). This may result in spouses resenting the ‘new’ partner who is perceived as child-like (Hayes et al. 2009). It may also lead to sexual intimacy being perceived as somewhat incestuous (Dow & Malta 2017), and thus inappropriate and destabilising.

The potential conflict between being a carer and being a sexual partner is quite gendered (in the context of traditional gender roles). Many women have had the main responsibility for the care of children and other dependent relatives, prior to becoming the carer of a partner with dementia. This means that the caring role, even if not always chosen freely, is familiar to them and may be associated with parenthood. This is less common in the case of men. The impact of caring on sexual interest and satisfaction of partners of people with dementia is therefore quite complex for many women. Another issue which is gender-based is that male carers are more likely to get help with caring, not provide intimate care themselves and consequently not have the same issues (Simonelli et al. 2007).

We discussed earlier how couples often support each other by taking over gender-based roles if and when necessary. This can be understood as a flexible and pragmatic approach to coping but the change in gender roles and the perceived child-like transition of one of the partners may also impact on gender identity (Quinn et al. 2009, Harris 2009). The traditional/stereotypical masculine role (usually held by a man)

is associated with decision making and power, sometimes described in terms of being the dominant partner in the relationship. If this role is gradually lost, the partner with dementia may come to be perceived as having female characteristics through the association to child-status. Sandberg (2021) describes this as follows:

“The narrative of the husband versus child subjectivity has evident gendered connotations when the role of the husband is that of a man “to lean on”, to depend on and be weak and vulnerable with, whereas the child is dependent and vulnerable and as such occupies a feminised position.”

Cultural conceptions of femininity in relation to sex and caring, especially in older generations, may also make it difficult for women to talk about their sexual needs (Youell et al. 2016). They may feel that it is simply their duty and role to care for others, adults and children alike. Not considering such needs and related difficulties as legitimate may make it more difficult for women to seek help in relation to difficulties with the combined role of carer and sexual partner.

Couples’ reactions to being both a carer and a sexual partner may be different for older and younger couples. Interviews with couples of different ages, in which one person had dementia, revealed the importance of age and life course. Sandberg (2020) found that older couples understood changes in their sexual relationships as consequences of the physical ageing process and other health issues and attached much less importance to dementia. Younger couples saw dementia as having a broad impact on satisfaction with life, creating dependency, halting a previously passionate and intimate sexual relationship and being in conflict with their perceptions and expectations for being part of a happy couple. The younger couples experienced dementia as “out of place” and a sign of premature ageing. For older couples, dementia was not totally unexpected and often perceived as a more common later-life illness, resulting in less difficulty moving between the roles of carer and sexual partner.

Finally, Mahieu and Gastmans (2012) suggest that older people living in residential care facilities (as many people with dementia do) are often infantilised by care staff. Perceiving people with dementia as child-like, therefore, not only impacts on relationships between couples but also on people with dementia expressing their sexuality, increasing the likelihood of sexual acts being labelled as inappropriate or abusive.

Recommendations

1. Health and social care professionals should:
 - challenge heteronormative assumptions, attitudes and practices related to sexuality and relationships involving or between people with dementia,
 - reflect on their own attitudes, assumptions and beliefs about relationships and sexuality of people with dementia of different sexes, gender identities and sexual orientations, and how this might affect the support and care that they provide to their patients and clients,
 - reflect on the implications of using terms which pathologise the sexuality of older people and people with dementia,
 - adopt a proactive and sensitive approach to discussing issues related to relationships and sexuality,
 - avoid, and challenge if encountered, any demeaning or dehumanising metaphors used to refer to people with dementia, as well as to the portrayal of people with dementia as being like children,
 - ensure that people with dementia are involved in all decisions about their own sexuality,
 - assume that people with dementia have the capacity to engage in sexual acts or relationships and prove beyond any reasonable doubt that this is not the case before making any decision to deprive them of that right,
 - ensure that people with dementia have access to appropriate and unbiased support for all discussions surrounding their capacity to consent to sexual activities or relationships,
 - take into consideration the prior values, beliefs and experience of people with dementia in order to understand their personal history but not rule out currently expressed interests or sexual orientation that may be different to those of the past,
 - give people a 'do not disturb' sign to put on the door, or a key, and tactfully withdraw and come back later if the person is engaging in sexual activity or sharing a private moment with someone.
2. Health and social care professionals should not:
 - assume that people with dementia are all male or female, heterosexual and asexual,
 - frame issues surrounding sexual activities or relationships involving people with dementia in terms of victims and perpetrators,
 - stereotype women as vulnerable or victims and men as predators,
 - involve or consult someone about the support and care of a person with dementia solely on the grounds of them being married or biologically related to that person,
 - shame, draw attention to, talk about or ridicule displays of affection or knowledge about the sexual activities of people with dementia,
 - debate or intervene in emotional relationships unless one of the two people concerned demonstrates, a categorical refusal or simply disapproval of that relationship.
3. Health and social care service providers and commissioners should:
 - provide training, support and opportunities for reflection for health and social care professionals, as well as auxiliary and support staff, on the topic of gender and sexuality in relation to dementia,
 - take into consideration, when developing services for people with dementia, their affective and sexual needs and rights, and those of their partners, with regard to the preservation of their relationships and sexuality,
 - ensure that people with dementia and/or their partners have access to sexual counsellors or therapists if needed at any time,
 - have at least one sexologist in each establishment or access to one periodically in smaller homes and institutions to provide advice, raise awareness and demystify issues surrounding relationships and sexuality involving people with dementia,
 - take into account the geographical distance and accessibility of residential care homes, as well as issues related to the continuation of relationships, when proposing care and accommodation to people with dementia who have a partner.
4. Governments should:
 - establish a requirement for all rooms in newly constructed or approved residential care establishments to be individual (i.e. for one person) or for established couples and for the gradual phasing out of multiple/shared rooms (unless explicitly requested),
 - during the period of transition, and for people who prefer to share a room, ensure that every resident has access to a room where they can spend time with a person of their choice in complete privacy,
 - set clear guidelines and operational policies regarding sexual abuse in long-term care settings and provide counselling and support to the victims.

4. Accessing and using professional services, support and care

Inequity in the need for and dependency on professional care

Gender, isolation and non-mainstream support networks

In Western European societies, independence tends to be highly rated despite a growing awareness and recognition of the many ways that people are dependent on each other throughout their whole lives. Having dementia may be accompanied by concerns about becoming dependent on other people for support and care. This may be heightened by the increased geographical dispersion of nuclear families and frequent media reports of inadequate funding of social care, as well as poor quality care in nursing homes. As mentioned earlier, higher numbers of women live in residential care, partly because they have higher life expectancies and they outlive the partner who might otherwise have cared for them at home. Heterosexual men and women are nevertheless more likely to have a network of relatives who are able and willing to support them (often consisting of daughters, daughters-in-law, nieces and sisters).

Older LGBT* people tend to be more socially isolated because of declining friendship networks (Barrett et al. 2015) and more dependent on professional carers. This has been linked to higher levels of depression, lower quality of life, mental and physical abuse in residential care settings (Haber 2009) and a faster progression of dementia symptoms (McGovern 2014). This may be a daunting prospect for people who have no one to turn to (Ward et al. 2005, Price 2008). An American study of LGBT* older people revealed that many had concerns about who would care for them if they had dementia, whether they would be alone and how they would afford residential care. Many had no plan in place, no support system to help them remain at home and insufficient means to move into a retirement home (Putney et al. 2018). One person stated,

“It’s so terribly complicated for a person who’s alone. And, I could be that person, and it’s scary. It’s very scary” (Putney et al. 2018, p.896).

LGBT* people do not all have the same experience and some studies suggest that bisexual older adults, in particular, have lower levels of social support and sense of belonging

to a community compared to lesbian and gay older people. Together with transgender people, they are also less likely to have supporting biological families. Putney et al. (2018) suggests that whilst families of choice may provide valuable emotional support, LGBT* people may have lower expectations of them in terms of providing long-term care. The following testimonials from lesbian women with dementia in Germany highlight a mixture of positive and negative experiences of support, economic restrictions and concerns about future care.

“Dementia has affected my social life like it affects everybody else’s: social isolation – my friends disappeared as they were frightened of my diagnosis. Too little support from friends. I joined the tea club for people with dementia organised by the church. Since being diagnosed my sense of orientation has diminished a lot. I mainly stay at home. Even for a short walk somewhere, I need somebody to accompany me. I am particularly concerned about what kind of care home I could afford. It is important that it is one with a garden and pets/birds” (Brigitte, 73).

“Dementia changed my life since I have problems speaking. In social life, my colleagues are very patient; the same when I go to my bakery store or people who know me as: lesbian and now diagnosed. I feel well supported. I am in touch with friends globally (since I can write in English too). The groups and zooms are valuable” (Martina, 51).

“My quality of life has been impacted. Since being diagnosed, I have been in a different department in my office job (simpler but also less paid). My social outings are reduced (I cannot afford many of the hobbies I had before getting diagnosed)” (Daniela, 38).

Economic disadvantage

LGBT* people often have a higher need for formal care and support but are economically disadvantaged. Unmarried couples and single people usually pay the highest percentage of tax on their salaries. In some countries, LGBT* couples are still barred from adopting children, and lesbian or single women from accessing in vitro fertilisation. According to Savage (2021), 21 countries in Europe allow a member of a

same-sex couple to adopt their partner's child and 17 allow joint adoption. The European Atlas of Fertility Treatments (Fertility Europe 2021) reveals that it is possible for female couples and/or single women in 14 to 17 countries (depending on whether it involves donated sperm or donated eggs) to access in vitro fertilization (IVF). In some countries, it is possible for single women but not female couples, sometimes vice versa and in some countries, it is possible for both groups or for neither. Single people, especially women, often find it more difficult to take out mortgages and are therefore denied the opportunity to plan for lower living costs when they are older. These are all forms of structural discrimination which result in LGBT* and single people lacking the financial security that other members of society have. Same-sex couples tend to lag behind straight couples in terms of income, assets and home ownership (Alzheimer's Association & SAGE 2018).

Many women have not been in paid employment at various times in their adult lives (often because they have been caring for children or taking care of the home) and for many, this has resulted in them having a very limited pension to live off in later life (when they may need care themselves). In some countries, pension fund contributions for periods spent caring for others are covered by the state but women's pensions are often still comparatively smaller than men's. Many accepted work contracts and part-time work which did not cover such contributions, or for which pension contributions were not obligatory for employers and/or employees (e.g. the EUR 450 jobs in Germany prior to 2013¹³).

“One-third of employed women were working part time (30%) in the EU in 2018, nearly four times the rate for men (8%). A similar pattern was observed across all Member States. The highest share of employed women working part-time was recorded in the Netherlands (74%), while the lowest share was in Bulgaria (2%)” (EUROSTAT 2018).¹⁴

These may be personal choices to some extent, but it is important to recognise that they are decisions that are often taken jointly with partners, within societies which have certain traditions and structures that are inherently sexist (e.g. unequal pay, assumptions about gendered roles related to care and social pressure). Moreover, as pointed out by the European Women's Lobby (2000), part-time posts, which are predominantly occupied by women and often believed to help people to combine employment and family life, do not challenge the unequal sharing of family responsibilities between men and women.

Older LGBT* people often lack support from biological families, have no children and have higher costs for formal care and support and less money at their disposal to pay for it. Many older women and LGBT* people with dementia live in fear of becoming dependent on others, of not being able to afford adequate and good quality care and of experiencing discrimination and mistreatment. These are existential fears and reflect sex/gender discrimination and injustice, which may impact on the quality of life of some groups of men and women with dementia.

Complex care needs

As mentioned earlier, some medical conditions are more common amongst people with certain gender identities than others. These include, for example, diabetes, hypercholesterolemia, hypertension, and renal and liver diseases (Vance et al. 2010). People with these conditions have a higher risk of developing dementia but also a higher risk of eventually needing care and support for those conditions and for dementia. In the case of LGBT* people, this increased risk and for many the experience of such conditions alongside dementia can be particularly challenging, especially when combined with a lack of informal support from a biological family. Gay and bisexual men are more likely than straight men or women to contract HIV and transgender people are 49 times more likely to contract HIV than the general population (UNAIDS 2016 in Alzheimer's Association & SAGE 2018). People with HIV may develop HIV-associated dementia (HAD), and about 50% will experience cognitive impairment. The term 'HIV associated neurocognitive disorder' (HAND) describes the whole spectrum of cognitive impairment but people who receive treatment for HIV are less likely to develop HAND (Pebody 2021).

The stigma associated with some medical conditions is closely linked to perceptions of personal responsibility. Perceptions of the origin, cause or onset of a particular condition as having been avoidable by the person with the condition tend to elicit anger and negative judgements rather than pity (Weiner, Perry & Magnusson 1998, Jones et al. 1984). This may result in isolation, mental health problems, lack of support and in some cases passing (as straight or as a person without that condition). This is not conducive to people with dementia living out their gender/sexual identities within a supportive and accepting environment in the same way as other people.

Intersex and trans people may also have complex care needs. There is a lack of data on the long-term use of hormonal drugs and trans people with dementia often have advanced care needs linked to managing hormone medication as well

¹³ <https://www.steuerklassen.com/minijob/450-euro-job/>

¹⁴ <https://ec.europa.eu/eurostat/web/products-eurostat-news/-/EDN-20200306-1#:text=One-third%20of%20employed%20women%20were%20working%20part%20time,while%20the%20lowest%20share%20was%20in%20Bulgaria%20%28%25%29>

Recommendations

1. Health and social care professionals should:
 - ensure that they have the necessary skills and knowledge to provide good quality care and promote the quality of life of people who are socially isolated or have special needs linked to their sex, gender identity or sexual orientation,
 - be led by the expressed wishes of the person living with dementia at the current moment in time.
2. Governments should:
 - address structural discrimination against women (e.g. in the field of wages, taxation, working hours, parental leave, reproductive and adoption rights and childcare responsibilities), which directly or indirectly contributes towards economic disadvantage and in some cases the need for women with dementia to move into residential care,
 - valorise the achievements of women who now have dementia in terms of their lifetime contribution to society,
 - recognise the right to try to have a child as a universal right, and guarantee equal access to fertility treatments,
 - ensure that people with dementia have appropriate, affordable and good quality care services to enable them to live in their own homes and communities for as long as they wish,
 - provide or promote alternative living arrangements (i.e. other than living alone or in residential care) such as living on a rota basis with relatives or friends, or in houses in multiple occupation,
 - address homo/transphobia in the field of health and social care, and develop a system specifically to protect the rights, wellbeing and safety of LGBT* people within the health and social care system (including in all types of residential care facilities),
 - ensure that intersex and trans people's access to social and medical care and treatment is recognised, respected and properly followed up by health and social care professionals with the appropriate skills and knowledge,
 - ensure that health and social care professionals have access to initial professional or ongoing training to meet the needs and respect the rights of people with complex care needs.

as dementia drugs (especially with regard to drug interactions, contraindications and polypharmacy) (Cousins et al. 2021). Things may change over time. There are instances, for example of men and women with dementia coming out as gay or lesbian for the first time following a diagnosis of dementia, and there are also instances of trans women and men with dementia reverting to their gender at birth and of some lesbian, gay and bisexual people returning to a time in the past before they came out. This may be emotionally challenging for them and their partners, and a practical challenge for professional carers seeking to support them (Cousins et al. 2021). It is important not to confuse expressed wishes with changes in behaviour that are more likely to be related to procedural memory, such as, for example, the position adopted when urinating (Baril & Silverman 2019).

Issues related to the nature and quality of services, support and care

Person-centred care

It is widely accepted that care and support for people with dementia should be person-centred. Within this approach, the focus is on supporting the wellbeing, dignity and autonomy of the whole, unique person regardless of the extent

of their cognitive impairment rather than on a collection of symptoms or behaviours to be controlled. A person-centred approach therefore benefits people with dementia by respecting their human rights and individuality, and by contributing towards quality of life and wellbeing. However, the actual practice of person-centred care varies considerably. The provision of services that are adapted to the needs and wishes of each person with dementia should take into consideration their cultural, religious and linguistic backgrounds but should also acknowledge and respect other aspects of their identity, such as their gender and sexual orientation. These are core aspects of people's identities and should be recognised as such. People, including those who reject the binary (male/female) classification or do not label themselves as having a particular form of sexuality, are not neutral beings. However, for some people, being recognised as a man, woman, male, female or other non-binary identity, straight or LGBT* is an essential part of being recognised as a person, whereas for other people, other aspects of their identity might be more important. Often, their sex, gender and sexuality are indivisible from other aspects of who they are e.g. an intersex person from the traveller community, a pansexual woman with an intellectual disability or a male, straight Muslim. Person-centred care must recognise the whole and unique person.

Attempts to provide person-centred care all too often occur within a framework which reflects the cultural traditions, norms and awareness of heteronormative societies. People tend to be influenced by things that they learnt from other significant people in their lives, from beliefs shared by some religious communities and from their earlier education. Prior and current experience and the influence of other people sometimes result in negative attitudes and behaviour towards people with dementia in relation to their sex, gender and sexuality. Such attitudes and behaviour are not necessarily intentional. For this reason, a framework for guidance and support is important. At the same time, person-centred care relies on the availability of formal services and support that respond to the collective needs and interests of different groups in society (as well as at the individual level), taking care to avoid stereotyping. If these are lacking or heavily reflect heteronormative assumptions, it may be more difficult for health and social care staff to provide person-centred care. For example, some men may love knitting, yoga and flower arranging (and some women may not) but if that is the sum total of social activities on offer in a care home, there are likely to be many bored men, lacking opportunities for social interaction and cognitive stimulation. On the other hand, this doesn't necessarily imply the need for gender-specific support for people with dementia or carers. In countries which have support groups for male carers, for example, it has been found that men do not always want to be in a male support group and those who do, sometimes like to attend a group for female carers or a mixed group (Alzheimer Europe 2001).

There is often a lack of formal services and support that reflect the needs and interests of LGBT* people with dementia, resulting in LGBT* people feeling the need to develop their own informal support networks. In a talk given by Roger Newman (a gay carer who set up the Gay Carers Network in the UK and was a member of Alzheimer Europe's EPOCH¹⁵ working group), he emphasised that there is an added dimension to caring for a gay man or woman that an ordinary helpline/network does not cater for. The persistence of discrimination, prejudice and lack of sensitivity in most communities, he felt, means that there is a need for support and solidarity from the gay 'family' and also that gay carers often prefer to talk about sexual and emotional needs with their own community (Alzheimer Europe 2001). In the following testimonial, a non-binary person with dementia shares their perception/opinion about the situation in Ireland with regard to support for LGBT* people with dementia.

"Irish culture is too often infected by toxic positivity. 'Everything's grand!' when it most certainly is not. And

Irish queer leadership is failing to address healthcare and housing inequities, particularly as it impacts older Irish queer folk with ageing brain issues.

I know some other folks dealing with dementia and we have managed to stitch together an informal network of support. And there are a few Irish dementia researchers trying to shine a light on intersectionality, but they are WAY behind schedule, especially compared to the UK, US, and a few other EU states" (David, a non-binary person with dementia).

The term 'person-centred' is increasingly being extended to take into consideration everyone involved in the act of giving and receiving care and support. Nolan et al. (2004) have proposed a shift from individualistic notions of person-centredness to relationship-centredness. A relationship-centred approach reflects the interdependence between carer and care receiver and the importance of interpersonal interactions in creating a basis for care and support (Walsh & Shutes 2013). According to the 'senses framework' developed by Ryan, Nolan, Reid and Enderby (2008), good care can only be delivered when all the parties concerned (i.e. people with dementia, care and support staff, and families) experience a sense of security, continuity, belonging, purpose, achievement and significance¹⁶. Taking the example of a sense of significance, this is described as people with dementia feeling "recognised and valued as a person of worth", that their actions and existence are of importance, that they 'matter', and carers as feeling that their "caring efforts are valued and appreciated" and that they experience an enhanced sense of self.

LGBT* people with dementia and carers do not always feel recognised and valued or that they matter. They may sometimes not even be recognised as partners or carers, or, as stated earlier, it might be assumed that they can just get on with caring as their lives and personal commitments are not considered valid. If healthcare professionals simply assume, for example, that a gay man's partner is his brother or a friend, the partner may feel distressed and that their identity is not being acknowledged (Alzheimer's Society 2021). Roger Newman explained that some gay carers in the Gay Carers Network had described how they wanted recognition of the fact that they were providing care out of love and not merely because they were a good friend of the person with dementia (Alzheimer Europe 2001). The Canadian National Ethics Committee on Ageing (CNEV 2021) suggests the need to introduce the principles of beneficence and non-maleficence into the debate in order to avoid increasing the vulnerability of two people by not considering their relationship (the relational dimension), and by extension, their emotional needs.

¹⁵ EPOCH stands for Equality in the Provision of Care at Home.

¹⁶ For a concise summary of the senses framework, please see the poster produced by the University of Sheffield at: https://www.sheffield.ac.uk/polopoly_fs/1.8113791/file/Senses_Framework_Posters.pdf

For LGBT* people and people who don't have a biological family or partner, recognition of the importance of interpersonal interactions should be extended to any person of their choice. However, society is not particularly well-equipped to deal with relationships and informal care networks that fall outside the typical heterosexual, biological family-related framework. This leaves families of choice and other people in the social network of LGBT* people with dementia outside the framework, ignored or excluded from taking part in social activities, administrative and legal matters or decision making about care, support and treatment. People with dementia may experience shame and embarrassment when their partners and close friends are treated with disrespect and not recognised as legitimate partners (Peel & McDaid 2015 in Cousins et al. 2021). Living arrangements and staff providing care and support are not always inclusive and respectful towards LGBT* people with dementia. Some people prefer services and support, including residential care homes, that are specifically for LGBT* people. Such services are not yet widespread and there are differences of opinion amongst policy makers and services providers as to whether separate/dedicated services are the solution (as opposed to improving mainstream care and support). It is also a personal matter as can be seen from the testimonials below from three lesbian women and a non-binary person with dementia.

"I do not need a home specifically for lesbians Nobody ever knew about my inclination. My girlfriend died. Even when we were together, people thought we were just friends who shared an apartment. If I have to go into a care home, I will definitely choose an ordinary one, also because being a lesbian is my private affair" (Brigitte, 73).

"I would only choose a home for lesbians (which I hope we will have a wide selection of here in Germany). Everyone knows about my marriage to a woman (even at my working place). A care home for lesbians should have a very open and clear announcement: 'Our personnel is trained to deal with lesbian women and has a good knowledge in the validation of biographies'. I would prefer it if carers working in the nursing home were lesbian too. They would understand best my inclination and be easy going" (Martina, 51).

"I do not really need a specific care home for lesbians. I have always been a very open-minded person. We are all equal despite dementia! Definitely, if ever I need day care or whatever, I will frankly tell them that I am lesbian and I will be very clear and objective about what I cannot accept: no male carers and no discrimination in language or any other way about lesbians. There is no need for any special difference between homes. The important thing is the quality

of care and what is in the documents referring to me. The biography page should be very 'open' and clear. I do not hide this side of my personality" (Daniela, 38).

"Inclusion and diversity matter. And LGBT care homes start with the notion that sexual/gender identity is in no way pathological, but something to be celebrated, in ways large and small. And there are numerous LGBT* care homes with a proven track record of success: the Rainbow House in Stockholm; the ones in Germany, the Pink Passkey homes in the Netherlands, the ones in the US, Canada, Denmark, France and Italy... I acknowledge my heterophobia and I don't want to sit around with a bunch of old fuckers, listening to them drone on about their children and grandchildren. I want drag queen bingo!" (David, a non-binary person with dementia).*

Fear of discrimination and abuse may lead to many LGBT* people hiding their gender and sexual identities. This in turn renders them invisible within the health and social care system and contributes toward the belief that everyone is cisgender (identifying with the gender attributed to them at birth) and heterosexual, which is clearly not the case or compatible with person-centred care. In the light of the estimated proportion of the population that is LGBT*, claims that "We treat them all the same" or that "we don't have any where I work" are testimony to this (Simpson, Almack & Walthery 2018).

[Health and social care professionals need to] "start by acknowledging the absolute failure of the health-care system to adequately train healthcare providers in delivering holistic, integrated care to older queer folk that does not erase their sexual and gender identity. The 'we treat everyone the same' model is bullshit" (testimonial from David, a non-binary person with dementia).

Some approaches have been developed to help professional carers to learn about people's identities and backgrounds, and to stimulate people's memory and promote social interaction. Reminiscence work is one example of this. Sensitivity is needed when doing this kind of work because it may uncover certain traumatic memories (e.g. of abuse, neglect, discrimination or hardship), some of which may have been suppressed or are unknown to the family or friends of the people with dementia concerned. With regard to sex, gender and sexuality, some people may have memories of difficult periods in their lives, difficult decisions that they had to make (e.g. coming out, passing and transitioning), and hostility, rejection and discrimination (from the general public, relatives and colleagues). Some may have moved on, gone in different directions in life, and find it unpleasant or traumatic to relive earlier experiences (Cousins et al. 2020). This does not mean to say that all topics should be avoided which might be psychologically or emotionally challenging

as that would create a kind of taboo and deny certain groups from benefiting from such approaches.

Figure 8 below is an adaptation (by Townsend 2020) of a scale produced by the World Health Organization (2011)¹⁷, which may be helpful for health and social care professionals, as well as policy makers, to reflect on whether, how and to what extent interactions, procedures, services and support at the individual or societal level respond to the needs and interests of people with different gender identities.

Discrimination and micro-aggressions against LGBT* people

LGBT* people and couples do not always have the same rights as other people and their specific needs and wishes are not always given equal importance. Moreover, there are not many LGBT* services outside of big cities. LGBT* people often fear being exposed to homophobia and transphobia within the context of care and support (e.g. from service providers, health and social care professionals, as well as from other residents and staff in care homes) (Fredriksen-Goldsen et al. 2018, Siverskog 2016). The following testimonials from a lesbian woman and a non-binary person with dementia emphasise concerns about discrimination and homophobia/transphobia, as well as the impact of heteronormativity on the lives of LGBT* people receiving support and care.

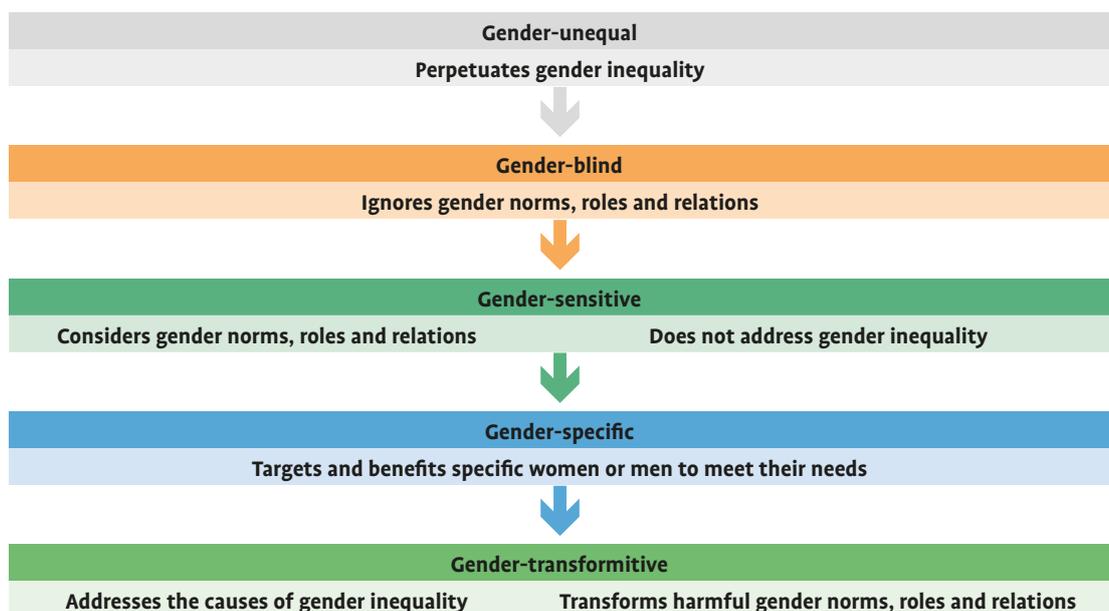
“There should be no difference in how LGBT people are treated compared to other residents. We are all equal in a modern society” (Daniela, 38).*

“I am VERY concerned about not only homophobia/transphobia in eldercare, but also heteronormativity that is pervasive and is every bit as harmful. I want care services that acknowledge my sexual and gender identity as a central component, not as some sort of afterthought, or worse, totally ignored” (David, a non-binary person who has dementia).

The fear of discrimination can sometimes be just as damaging as actual discrimination, leading to lower self-esteem, isolation, withdrawal, fear and lower quality of life. One survey, carried out in 2011, found that 89% of LGBT* and non-LGBT* older adults felt that staff in long-term care settings would discriminate against LGBT* residents. A more recent study in 2018 found that over 60% of LGBT* adults expressed concerns about neglect, abuse, limited access to services and verbal and physical harassment in long-term care. These were American studies (see Putney et al. 2018) but there is also evidence of similar expectations and concerns amongst LGBT* people in Europe. This may lead to anticipatory stress linked to concealed gender identities and sexual orientations becoming known. In some cases, discrimination and hostility are openly expressed but often, negative or discriminatory attitudes and behaviour are quite subtle and even unintentional (see Figure 9 on the next page). This does not excuse them but calls for greater awareness of the powerful and negative impact of heteronormativity and for greater awareness of the challenges faced by LGBT* people with dementia and their supporters.

Much of the behaviour and attitudes described above reflect a lack of respect for people from LGBT* communities and lack

Figure 8: Gender Responsive Assessment Scale



¹⁷ See also: https://www.who.int/gender/mainstreaming/GMH_Participant_GenderAssessmentScale.pdf

Figure 9: Examples of discrimination and micro-aggressions

- hostility, stigmatisation, ridicule and harassment of LGBT* people, especially trans people,
- snide remarks and insinuations,
- failure to acknowledge a person’s gender (in the social context or on medical, administrative or other documents),
- mis-gendering (e.g. not using the correct gender when talking to or about someone such as referring to a trans person with a female gender identity as ‘him’ and ‘he’),
- considering people identifying with different groups as being the same (e.g. assuming that trans people have the same needs and experiences as people in same-gender relationships or that people of non-binary experience who are lesbian or gay have the same needs and experiences as other lesbian and gay people) (Ansara 2015),
- marginalising (e.g. emphasising that someone is trans when they would just like to be considered and live their lives unobtrusively as a man or woman),
- not respecting confidentiality where a person’s sexual identity is recorded,
- broaching topics that would not be broached with non-LGBT* people (e.g. referring to genitalia or assuming that it is OK to talk openly about the person’s sexuality),
- assumptions that exclude many or all LGBT* people and their needs,
- ignoring the interests of LGBT* people (e.g. hobbies, TV programmes and events),
- organising activities and services in accordance with assumed male/female needs and interests, thereby overlooking non-binary gender identities, focusing on traditional gender roles and undermining personhood,
- failing to help people who have transitioned to manage their gender identities (e.g. shaving, dressing appropriately, putting on make-up, getting their hair done etc.),
- not allowing visitors who are not biologically related or linked through marriage,
- being unfriendly to friends and ‘family’ of LGBT* people,
- not supporting (or allowing) people to wear clothes which correspond to their known or supposed biological sex (thus denying them the possibility to express their gender identity and for this to be recognised and validated by other people).

of consideration for their needs and interests. Some of these issues also apply to other people. As mentioned earlier, heteronormativity reflects a certain kind of heterosexuality, namely linked to the nuclear family and reproduction. People who find themselves outside of that framework (e.g. people who are not in a couple or who have no children) may also experience inconsideration or be considered and treated as ‘other’. This could, for example, include unnecessarily drawing attention to or emphasising their marital status (e.g. Miss Brown unless the person in question prefers to be referred to as such), organising events with an emphasis on the family and endless conversations about children and grand-children (i.e. assuming everyone has some). A lack of sensitivity or intentional disregard for the needs of LGBT* people amounts to discrimination in that it results in a qualitatively different and negative outcome for people in that group, which for some may lead to shame, depression, isolation and existential fear. The following quotes are taken from a study into the experiences and needs of an international group of trans people.

“I am a woman with a penis. What will they do to me in a nursing home? What will happen if I cannot defend myself because of dementia?”

“If I have to go into a home, as a tall non-op who might have thinning hair by then, I might be treated as male. I worry I might be socially isolated.”

“I need to wear a wig. If I am in a retirement home or nursing home, I am unlikely to be able to maintain a feminine appearance. If I can’t continue to take hormones, I may get hairy again” (Witten 2015, p.79).

Some discrimination and many micro-aggressions are unintentional. They may be based on ignorance, fuelled by heteronormative assumptions (i.e. that everyone is straight, that their gender corresponds to the sex attributed to them at birth and that they have children). Many people have grown up in societies in which such assumptions guide expectations and beliefs about how people should be and should act. This limits their ability to meet the needs of older LGBT* people, especially of trans people and people with non-binary identities (Ansara 2015). It is therefore important to avoid assuming the intentions behind discriminatory behaviour and micro-aggressions and rather, to try to raise awareness about the experiences, rights and needs of LGBT* people. There are a few good examples of this. The Lancashire County Council, for example, in the north-west of England, recognised that there was a large community

of older trans people in the county who were facing such discriminatory and negative treatment, and brought in an organisation supporting transgender people to train staff across the county, to bust myths and raise awareness about transgender people using their services. This, it is claimed, resulted in greater respect for older transgender people using services (Scie 2011). People with dementia with marginalised gender and sexual identities should be able to benefit from positive action to promote their wellbeing.

“With cognitive decline comes a loss of sense of self, lack of control, and powerlessness, which may be particularly terrifying for people who have bravely forged their authentic identities in the midst of multiple oppressive forces that dehumanized, stigmatized, pathologized, and criminalized them. Such individuals need providers who can affirm their humanity, preserve their dignity, create opportunities to feel a sense of belonging, include them in meaningful ways in their community, and maximise their autonomy to the greatest extent possible” (Putney et al. 2018, p.900).

Dementia in the context of sex work

As among the general population, there will be older people with dementia who have at one time or another accepted payment for sex. Similarly, there will be people with dementia who have relied on sex workers in place of, or in addition to, forms of relationship that are more readily condoned by society. Opinions about sex work and payment for sexual intimacy or favours are often coloured by social mores (i.e. they are influenced by cultural values, ethics and sometimes religion). There is little if any literature on the subject of women with dementia and sex work but sex work has historically often been a means for women who were living in poverty and unable to find other work to support their families. For a woman now living with dementia, this may lead to renewed shame and fear of disclosure, particularly in care environments that may be shared with former clients. Very little information is available about the situation for male sex workers and more specifically for LGBT* sex workers. Slightly more has been said

about enabling men with dementia who wish to access the services of sex workers to continue to do so, including in the context of long-term care (e.g. <https://www.theatlantic.com/health/archive/2013/06/sex-after-dementia/276489/>) but these are still currently under-researched areas and issues that are rarely adequately addressed in guidelines and policies in care homes and in relation to supporting people with dementia living at home.

Cultural and gendered traditions regarding responsibility for decision making

We mentioned earlier that in some cultures, men are officially responsible for care, even though women tend to actually provide the care. This is also relevant to decision making in the context of professional care. In Western culture, autonomy is very much focused on each person's right to make decisions about their own life (to the extent that they are able). This stands in stark contrast to traditions that are more common in collectivist or interdependent societies where decisions are often made collectively or deferred to others. Husbands may, for example, make decisions on behalf of their wives, and parents or brothers on behalf of unmarried women (Hanssen 2004).

It could be questioned whether handing over decision-making power to others (e.g. to fathers, husbands or brothers) is really an autonomous decision, given that those who do so did not choose their social position within society or the cultural traditions surrounding decision making (Alzheimer Europe 2020). In some contexts, the Western/individualist approach to autonomy is so deeply ingrained that there is a risk of healthcare professionals putting pressure on people to take decisions that they would rather defer to others or make with others. At the other extreme, professionals may sometimes be so keen to respect cultural traditions that they fail to uphold ethical principles and legal rights with regard to women with dementia from minority ethnic groups. There is a need to be sensitive to cultural traditions, whilst avoiding leaving the door wide open to paternalism or to failure to respect women's rights.

Recommendations

1. Health and social care professionals should:
 - seek the views and preferences of everyone with dementia in group living situations and when developing services and support in the community, taking care not to leave out people with minority or marginalised genders and sexual orientations,
 - ensure that everyone with dementia is safe from violence, micro-aggressions, harassment and discrimination from service providers, fellow residents (in residential or day care facilities) and visitors or other service users,
 - encourage respectful inquiries about a person's wishes with regard to how they would like to look, be addressed and treated in terms of their sex, gender identity and sexual orientation,

- ask which pronouns people would like to be known by (e.g. 'he', 'she', 'they' or another term) and which title to use before their surname (avoid using terms like Mr, Mrs, Miss or Ms unless they know which, if any, they use),
 - try to get to know the likes, dislikes and life histories of LGBT* people with dementia and not solely factors related to their LGBT* identities,
 - strive for a good balance between awareness of specific needs of LGBT* people with dementia and awareness of the things that they have in common with non-LGBT* people with dementia,
 - ensure that documentation, forms and databases have options which allow for people to express their gender identity (including non-binary and non-gendered options) and for this choice to be recognised and recorded,
 - when people use terms that are unfamiliar, use the opportunity to talk to the person and find out what they mean (if they seem happy to discuss this), ask colleagues or friends or look up the term on the Internet,
 - include sexuality in discussions linked to advance care planning and include, where appropriate, specific needs linked to the maintenance of gender and sexual identities,
 - give partners, chosen family and close friends of LGBT* and single, unmarried people with dementia, subject to the approval of the latter, the same rights in relation to involvement in their support and care as would be given to their biological family or family through marriage,
 - respect people's privacy and private space (e.g. knock before entering someone's room).
2. Health and social care professionals should not:
- assume that people with dementia are all male or female, heterosexual and asexual,
 - frame issues surrounding sexual activities or relationships involving people with dementia in terms of victims and perpetrators,
 - stereotype women as vulnerable or victims and men as predators,
 - involve or consult someone about the support and care of a person with dementia solely on the grounds of them being married or biologically related to that person,
 - shame, draw attention to, talk about or ridicule displays of affection or knowledge about the sexual activities of people with dementia,
 - debate or intervene in emotional relationships unless one of the two people concerned demonstrates, a categorical refusal or simply disapproval of that relationship.
3. Health and social care service providers should:
- recognise and incorporate into their policies and procedures the importance of relationships and of the affective and sexual needs and rights of residents or clients with dementia,
 - take into account the geographical distance and accessibility of residential care homes, as well as issues related to the continuation of relationships, when proposing care and accommodation to people with dementia who have a partner,
 - provide different options for dementia support and care, including ones that are mainstream but inclusive and ones that are specialised or specifically geared towards the needs of people with certain gender identities or sexual orientations,
 - ensure that people of all sexes, genders and sexual orientations have access to good quality dementia care and support, taking into consideration inequity and structural discrimination faced by some sub-groups of the population,
 - have clear and concrete guidelines on how to incorporate not only respect and acceptance but also support for the sex and gender identity and sexuality of people with dementia into person-centred care,
 - take measures to ensure that staff recognise every person's unique relationship to their own sex, gender and sexuality, their right to express these, to share them with or conceal them from other people and to be respected for, and irrespective of, these,
 - take concrete actions to demonstrate such respect and acceptance, and to enable people to live out their sex, gender and sexualities,
 - provide training incorporating self-reflection, accepting and valuing difference and negotiating between competing needs and interests (e.g. of partners, families, friends, auxiliary staff and other health and social care professionals), whilst focusing on the person with dementia and their rights and wellbeing,
 - develop materials and tools to help health and social care professionals:

- to broach the topics of sex, gender and sexuality with people with dementia (and their partners, families and close friends if appropriate) in a sensitive and culturally appropriate manner,
 - to identify and minimise present day triggers which may reactivate traumatic memories related to gender identity or sexual expression.
 - have at least one sexologist in each establishment or access to one periodically in smaller homes and institutions to provide advice, raise awareness and demystify issues surrounding relationships and sexuality involving people with dementia,
 - provide opportunities within a safe environment for health and social care professionals to explore their assumptions and beliefs about sex, gender and sexuality, as well as their own gender identities and sexual orientations,
 - involve LGBT* people with dementia and their carers/supporters in LGBT* cultural competency training and awareness raising activities for staff and service providers,
 - ensure that people who have changed their gender or sex on official documents have the right not to disclose (or to have other people disclose) their previous sex/gender identity,
 - ensure that documents and visual information aimed at welcoming people of trans and non-binary expression are not limited to images and accounts of gay, lesbian and bisexual couples,
 - ensure that declarations about welcoming LGBT* people are not empty words, but actually supported by positive and welcoming acts and attitudes towards people from those groups,
 - find out about possible services and support from local LGBT* associations,
 - ensure that when the term 'family' is used, it is acknowledged at some point (or somewhere in the text) that this is not limited to biological relatives and extends to all close relationships with people of any sex, gender identity or sexual orientation,
 - develop guidelines and procedures on the correct approach to the recognition and affirmation of people's gender identities and sexual orientations (including disciplinary measures in case of non-respect of procedures and support/guidance on how to deal with biological relatives who disrespect the gender of people with dementia receiving services or support),
 - examine organisational procedures and structures with the aim of tackling structural discrimination and creating more inclusive services and support.
4. Governments should:
- take measures to ensure that partners who are neither married nor in recognised civil unions can also be formally recognised (e.g. subject to a straightforward/free administrative procedure with the consent of the person needing support or care) as the partner of a person with dementia for matters relating to their support and care within the community, hospitals and residential care context,
 - promote a positive image of male carers and seek to redress the devaluation of informal care (e.g. in official documents, visual representations and in educational materials).

Issues related to gender and sexual identities of professional carers

Health and social care staff/workers

The gender imbalance in people with dementia in need of support and care from professional carers is matched by a similar gender imbalance in the health and social care profession itself. Zhelyazkova (2018) also points out the gender imbalance in the field of global healthcare policy making, "where a majority of both patients and healthcare providers are female, yet the policy makers instituting legislation on healthcare are not". In the UK, for example, one report estimates that over 80% of posts in the social care sector are occupied by women (Shepherd 2018) and in some countries women occupy over 75% of posts in the healthcare sector (Zhelyazkova 2018). However, women in

these posts are not represented to the same degree in the higher decision-making posts.

This pattern is reported consistently across countries and cultures, as presented in the World Health Organization's 2019 report "Delivered by women, led by men: a gender and equity analysis of the global health and social workforce". Four key findings are presented in this report including a universal occupational segregation by gender, a gender leadership gap with the majority of leadership roles being held by men, a majority of female healthcare workers facing bias, discrimination and sexual harassment and a global gender pay gap (please see Figure 10 on the next page).

Social care is marked by gender stereotypes which lead to discrimination against men wishing to enter the profession, whilst simultaneously discriminating against women

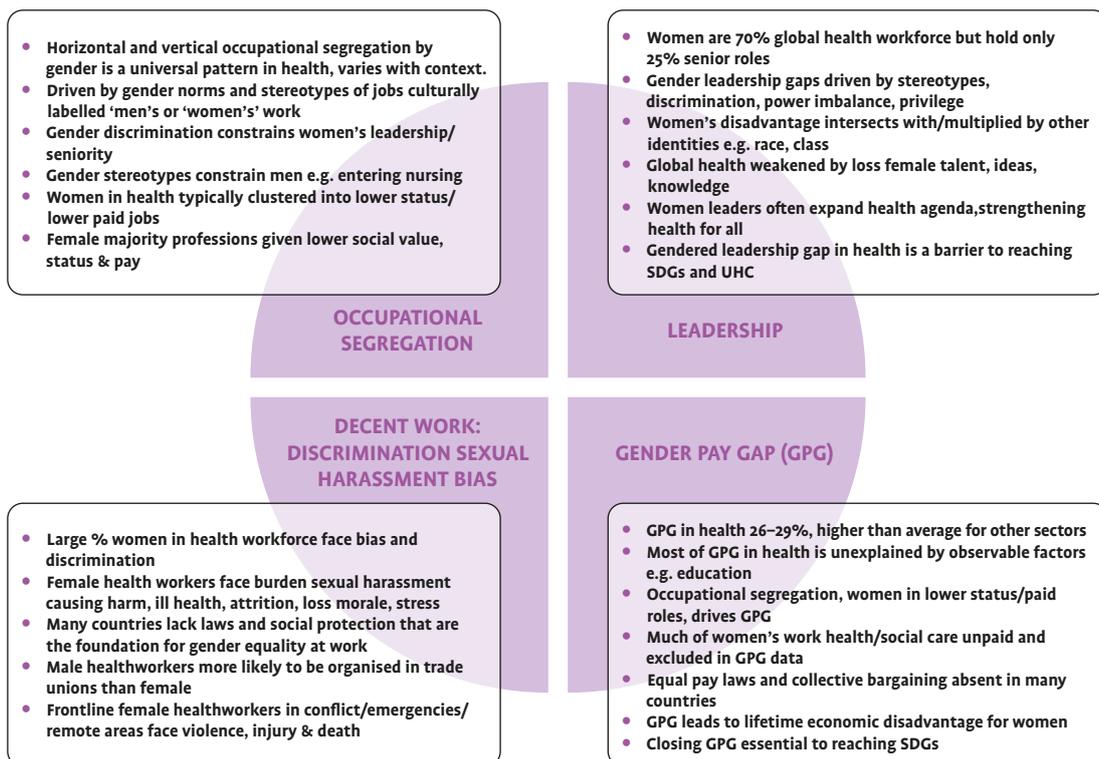
in those posts by underpaying them. The gender-based stigma is difficult to address as it reflects a power imbalance that creates and perpetuates structural injustice against women. This includes poor working conditions, lack of prestige, unstable contracts, low wages and poor career prospects, all of which does little to attract men to the profession or to allow women to build careers. Moreover, the clustering of female health and social care professionals into lower-status and underpaid (or unpaid) jobs results in a loss of female talent, perspectives and morale (World Health Organization 2019). This situation represents a lack of equity amongst health and social care professionals and is detrimental to the wellbeing of male and female professional carers alike.

The lack of male social carers, providing hands on care, may also impact on the quality of care provided to people with dementia. Whilst women from some ethnic groups tend to prefer to be cared for by female carers, it is also the case that in some ethnic groups, the intimate care of men is traditionally carried out by men (Alzheimer Europe 2018). According to the charity 'Care England', overall, the number of men living well into old age is growing, some older men prefer to be looked after by men rather than by women (especially when it comes to personal care) and more male care workers are therefore needed. The charity highlights the problem that caring roles are seen as female roles and emphasises the need "to make society understand that everyone has the potential to be a carer" (Doughty 2015).

Although women tend to be considered more empathic, there is still limited evidence about this difference, which could be attributed to gender-related stereotypes (Baez et al. 2017). Savitch, Abbott and Parker (2015) found in their exploration of the views and experiences of women with dementia, and informal and professional female carers of people with dementia that gender roles, qualities and attributes (such as kindness and empathy) were often associated with women, and tended to reflect stereotypes and societal expectations and norms. They were, however, meaningful to many women involved in their project. They note that these gender-based stereotypes and the belief that caring is 'natural' for women, combined with the perceived low status of caring (as opposed to it being a skilled job), may hinder the involvement of men in dementia care, both privately and professionally.

It is also important to accept and promote the inclusion of people with a broad range of gender identities and sexual orientations in the health and social care profession. LGBT* health and social care professionals should not be invisible members of the workforce. They are key to the true promotion of equitable care and support, and also to challenging heteronormative assumptions in the provision of care and support to people with dementia. In 2008, the National Health Service (NHS, UK) issued an extensive report entitled "Trans: a practical guide for the NHS" which raises awareness and provides practical guidance on how to support and promote the rights and wellbeing of trans colleagues.

Figure 10: Key findings of the review carried out by the Gender Equity Hub (WHO 2019)



“In NHS terms, the need to recruit the most talented staff for the job, and to retain skills and knowledge developed through training and practical experience, means that organisations simply cannot afford the luxury of turning people away or allowing them to be forced from existing jobs on the basis of ignorance, prejudice or poor attention to people’s needs and concerns. Not only is discrimination towards transsexual people unlawful, it wastes talents and lives and must be considered unacceptable by everyone who subscribes to the principles on which the NHS was founded” (Department of Health 2008, p.21).

The following testimonials from lesbian women with dementia in Germany also emphasise the importance of people of all genders and sexual identities having equal access to high quality care, and for professional carers to be properly trained, well paid and to include LGBT* people.

“High quality care is a matter of calculating the expenses and investments in care. It’s a question of who/what organisation runs a nursing home – no distinction between the LGBT or others. If ever I need care, I would choose an organisation that has actually hired LGBT people” (Martina, 51).*

“I think all women, no matter what inclination (i.e. lesbian or not), should get the same high-quality care. In order to get it, we need well-trained staff who are also well paid” (Brigitte, 73).

Live-in carers

Live-in carers, as the term suggests, live in the homes of the people to whom they provide care. In many cases, they offer a more affordable alternative to residential care, enabling family carers to better coordinate their personal and professional obligations, and enabling people with dementia to continue living in their own homes. In the vast majority of cases, they are women (Lutz, Palenga-Möllenbeck & Benazha 2021). Live-in care is poorly regulated in Europe and, in some countries, live-in carers have no official rights and are vulnerable to abuse.

In Austria and the German-speaking part of Switzerland, for example, they are formally recognised whereas in the UK, they are employed on a private basis, with no funding from the state and no official policies governing their terms and conditions of work (Herz 2018). They are increasingly common in Mediterranean countries such as Italy and Spain (Herz 2018). Many live-in carers in Europe are taken on illegally and paid in cash by the care recipient or their family. In such cases, they are not entitled to social benefits or minimum periods of time off, receive insufficient payment in exchange for their services, may lose their jobs in an instant, not receive their pay and would be in a difficult situation if they became ill (Alzheimer Europe 2018). There are also implications for their future wellbeing and even survival if their pension contributions are not paid (impacting potentially on their own future care). Live-in carers with no residency rights (e.g. non-European citizens) are at greater risk of exploitation (Ungerson 2004, Degiuli 2007). However, even for Europeans, certain conditions must be met in order to have the right to reside in a different EU-country on a long-term basis.

In Spain, there is a preference for Latin American women as live-in carers, particularly Dominican, Ecuadorian, Bolivian, Colombian and Peruvian (Romero 2012). Sometimes live-in carers are expected to have certain personal characteristics such as being kind, sensitive and affectionate (Romero 2012). Such characteristics are also traditionally considered as feminine. This practice therefore discriminates against men who wish to work as live-in carers and perpetuates the stereotype of women being natural carers.

Migrant carers, including live-in carers, may have children or disabled or older relatives of their own who also need care. However, they are not all victims of circumstances beyond their control and have not ‘abandoned’ their own relatives (as many make arrangements for care, often using the money they earn, and continue to provide emotional support) but there is an urgent need to develop policies to better support them.

Recommendations

1. Governments should:
 - pursue gender-transformative actions and policies in relation to the care and support of people with dementia,
 - actively promote the inclusion of people from all sexes, gender identities and sexual orientations, including non-discrimination legislation, guidelines and training on inclusion, and structural and procedural changes where necessary (e.g. access to toilets and changing facilities, equal career opportunities, references and images in documents and visual materials that are inclusive and sensitive to people of all sexes, gender identities and sexual orientations),
 - take measures to ensure that healthcare systems and work conditions no longer reflect and perpetuate traditional male life patterns but rather are adapted to the need for flexibility often associated with traditional female life patterns,
 - address the gender pay gap, which has a lifelong economic impact for women, contributing to poverty in old age for many,
 - eliminate the glass ceiling which prevents many talented women working in the dementia field from achieving the same status as their male counterparts,
 - address gender stereotypes and norms that continue to drive occupational segregation (sorting men and women into different kinds of jobs) should be addressed in schools, colleges and universities (not solely at the point of entry into the workforce),
 - regulate the situation, living and working conditions of live-in carers. The rights and wellbeing of all concerned should be promoted (i.e. of live-in carers, of people receiving such care and of those living in the same household),
 - develop policies to help migrant carers to combine working as a paid carer with care responsibilities they may have for a person in their country of origin.
2. Organisations responsible for recruiting health and social care professionals, including live-in carers, should avoid promoting or perpetuating female stereotypes of carers, and consider how to attract men as well as women to the care profession.

5. Conclusions

We have discussed a wide range of issues in this report linked to the experience, needs and rights of people with dementia of different sexes, gender identities and sexual orientations. To achieve this, we have drawn on academic and grey literature, and the personal and professional experience of members of the expert working group of different sexes, gender identities and sexual orientations. Some members of the expert working group have dementia and a small number of people with dementia provided testimonials on some of the issues addressed.

As highlighted in Appendix 3, Europe is still heavily influenced by heteronormative assumptions and structures. Our emphasis throughout this report has therefore been on recognising and challenging prejudice, discrimination and injustice, not only towards marginalised minority groups but also towards women (who make up the majority of the population in most countries), hence our adoption of feminism as part of our guiding theoretical framework. This does not exclude or discriminate against men whose needs and interests must also be recognised and who may also be adversely affected by heteronormativity. Moreover, we have shown, drawing on the concept of micro-aggression, that subtle discriminatory treatment and hostile attitudes and behaviour towards certain groups in society, based on their sex, gender or sexual orientation, as well as violence *per se*, unfortunately persist and need to be challenged.

As mentioned above, people with dementia actively contributed towards this report. It is important that the voices of people with dementia are heard in all discussions about dementia support, care and treatment, in dementia research and in every issue affecting the societies in which they live.

But to ensure that policy makers as well as health and social care professionals hear those voices and take on board the issues that are raised, we need to continue our efforts and we will be doing this by disseminating this report throughout Europe (to raise awareness and support lobbying activities), speaking at conferences, and developing more targeted materials for policy makers and constructive guidance for social care professionals.

Everyone can make a difference and a first step is perhaps through self-reflection (i.e. looking at how we define ourselves in terms of sex, gender and sexuality and how we view people who have different sexes, gender identities and sexual orientations to our own). Our emphasis on intersectionality in this report also calls for greater awareness about the complexity of people's identities and experience of life, and therefore for a greater sensitivity towards and a greater acceptance and appreciation of diversity.

We hope that we have raised awareness about some of the invisible, marginalised and ignored groups of people who have dementia and their carers or supporters. We also hope that this report will contribute towards giving them a voice and that unequal and discriminatory power structures and societal inequalities will be taken on board by policy makers, researchers, current and future health and social care professionals and members of the public so as to develop a more ethical, inclusive and humane society for people of all sexes, gender identities and sexual orientations. We do not claim to have all the solutions, to have reached people from all relevant groups or to have managed to cover sufficiently all the relevant issues on this vast and important topic, but we hope to have raised awareness of some of the key issues and to promote further debate.

Appendix 1 – Acknowledgements

Alzheimer Europe would like to thank the members of the expert working group who contributed towards this report. They donated their time and shared their vast expertise and experience in relation to sex, gender and sexuality in the context of dementia, thereby making this report possible. A short biography and photo of each person can be found below. We would also like to thank Kevin, Brigitte, Daniela, Martina and David who all have dementia and provided personal testimonials about some of the issues addressed in this report.



Dianne Gove, PhD, is Director for Projects at Alzheimer Europe and Honorary Visiting Research Fellow at the University of Bradford. She chaired the working group addressing sex, gender and sexuality in dementia. Her background is in psychology, education, psychoanalysis and psychotherapy (analytical Gestalt therapy). Her Master's in Education focused on gender and in 2013, she was awarded a PhD for her research into general practitioners' perceptions of dementia and stigma.



Aileen Beatty is a Registered Mental Health Nurse, working predominantly in dementia care since qualifying in 1987. She studied her Master's Degree in dementia studies at the University of Bradford, and is published in the field, most recently co-authoring 'Dementia, Law and Ethics' with Professor Julian C Hughes and legal expert Charlotte Emmett. Aileen has worked for the NHS, Voluntary sector (Alzheimer's Society) and health and social care regulators including more recently for the Care Quality Commission. She is currently the dementia lead for Akari Care with 35 residential and nursing homes in the UK.



Andrea Capstick is an Associate Professor in the Centre for Applied Dementia Studies at the University of Bradford, UK. She teaches on the MSc Advanced Dementia Studies, leading modules on dementia, human rights and practice change. She holds a Doctorate in Education (EdD) for her work on the use of film and first-person narrative biography in dementia education, and has since carried out a number of participatory research projects using creative methods to elicit the stories of people living with dementia.



Patrick Ettenes is from Barbados and has been living with HIV and early onset dementia. He is involved with many groups and organisations to raise understanding and awareness around these conditions, particularly highlighting the needs of LGBT+ people with dementia. He is a key advisor to the Alzheimer's Society and the LGBT Foundation in the UK, where he helped launch 'Bring Dementia Out', which since 2019 has been working to improve services for LGBT+ people affected by dementia. Patrick was awarded Positive Role Model of the Year in 2019 at The National Diversity Awards and in 2021, he was honoured as an LGBTQ hero at the Attitude Pride Awards.



Jean Georges has been the Executive Director of Alzheimer Europe since 1996. Prior to this, he worked as a journalist and as a parliamentary assistant to members of the Luxembourg and European Parliament. He was responsible for setting up the European Dementia Ethics Network in 2008 and has since contributed towards several ethics projects in that context.



Fabrice Gzil, PhD, is a philosopher and ethicist. He is the deputy director of an ethics centre in Paris (Espace éthique Île-de-France), associate researcher at the French Institute for Health and Medical Research (INSERM) and member of the French National Ethics Committee (CCNE). He is also the author of several books and papers on the ethics of dementia care and research (La maladie d'Alzheimer: Problèmes philosophiques, 2009; Alzheimer, éthique et société, 2012; La maladie du temps, 2014).



Phil Harper (They/ Them) has worked in hospital settings, charities, and care facilities where they specialised in and led dementia care. Phil is currently a senior lecturer and has worked at several higher education institutions/ universities, they often speak at national and international conferences. Phil is currently studying a doctorate, where they aim to explore care staff's understanding of the needs of LGBTQ+ people living with dementia, especially, gender non-conforming individuals.



My Name is Helga Rohra and I'm living in Germany. I was diagnosed with Lewy body dementia at the age of 54 and I have been a strong dementia campaigner ever since. I was the first chair after the founding of the EWGPWD and am currently involved in national research programmes (clinical, care aspects for people with dementia) as an active member in the WHO/Brain Health Unit. I am working on global projects. My contribution to this report is innovative, and LGBT* and dementia definitely represent a challenge in many ways for national policies.



Linn Sandberg, PhD, is Associate Professor in Gender Studies at Södertörn University, Sweden. Her research focus is on gender, sexuality, ageing and later life, and dementia. In a recent study, she investigated experiences of sexuality and intimacy among heterosexual couples where one partner is diagnosed with Alzheimer's disease. She is currently the principal investigator of a project studying LGBTQ people with dementia and dementia care in Sweden. Linn is the co-founder and convenor of the Critical dementia network, a network of academics and researchers with a shared interest in critical approaches to dementia.



Anthony Scerri, PhD, is a lecturer at the Department of Nursing, Faculty of Health Sciences at the University of Malta. He has a background in gerontology, rehabilitation and management and has a doctorate degree in gerontology. He also worked as a charge nurse in a geriatric rehabilitation hospital. Anthony is a member of the Malta Dementia Society, INTERDEM and Alzheimer Europe Expert Advisory Panel.



Charles Scerri, PhD, is a Professor of Dementia Studies at the Faculty of Medicine and Surgery, University of Malta. He is also the Vice-Chair of Alzheimer Europe, Scientific Advisory Board member for JPND and National Focal Point on Dementia (Malta). He also authored the national dementia strategy for Malta (2015–2023).

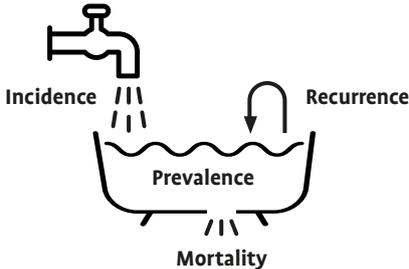


Annemarie Schumacher Dimech, PhD, is a health psychologist and co-founder of Women's Brain Project. She graduated in psychology from the University of Malta, and holds an MSc in Health Psychology from the University of Surrey (UK). In 2010, she obtained her PhD at the University of Bern. Today, she is employed at the University of Lucerne where she developed and is heading its programme of further education in Palliative Care.



Karin Westerlund is a social entrepreneur and has been active for more than a decade in Nordic EU-related advocacy work. Karin holds an executive MBA from Stockholm School of Economics and a Bachelor's degree in financial economics from Stockholm University. Her scientific work has focused on: Screening, diagnostics methods and health-economic planning for MCI, MCI-AD, also including Downs Syndrome. Karin has been a member of the Alzheimer Europe Board since 2018.

Appendix 2 – Glossary

Ableism	This means prejudice and discrimination against people with disabilities.
Andropause	This term describes a collection of symptoms, experienced by some middle-aged or older men, consisting of fatigue and a decrease in libido, generally attributed to a gradual decline in testosterone levels.
Cisgender	This term is used to refer to a person whose sense of personal identity and gender corresponds with the sex attributed to them at birth.
Cognitive reserve hypothesis (CRH)	This concept was developed in the late 1980s based on the observation that people with changes in their brains (observed on autopsy) that were consistent with Alzheimer’s dementia had not experienced any symptoms of dementia. The idea of CRH is that some people build up a cognitive reserve through a lifetime of education and curiosity which helps their brains to cope with challenges better. Harvard University uses the analogy of a powerful car that enables you to change into a higher gear and accelerate so as to avoid obstacles. The obstacles that the brain has to deal with could be stress, surgery, toxins in the environment or other things that put more demands on your brain. If you have a large reserve, you can handle these challenges better, enabling you to function as normal and for longer, before you start to notice problems. (See: https://www.health.harvard.edu/mind-and-mood/what-is-cognitive-reserve)
Gender	This term is used to refer to the social and cultural differences between men and women. It takes into account features like gender roles, behaviour, expectations and attributes that are considered appropriate by society. Characteristics that are considered feminine or masculine in one culture or time period (and generally associated with women/girls or men/boys, but not exclusively) may differ in different cultures and time periods.
Gender identity	This is an individual’s personal concept about their gender and how they feel inside. It is a personal and deeply held internal sense of self and is typically self-identified. The gender category someone identifies with may not match the sex they were assigned at birth. In other words, a person may see themselves as a man, a woman, as having no gender, or as having a non-binary gender, but be defined by other people in a way that does not correspond at all to how they define themselves.
Incidence and prevalence	<p>Incidence means the number of people who develop a specific disease or experience a specific health-related event during a specified period of time (e.g. a year), whereas prevalence is the number of people who have a specific disease at a given moment in time.</p> 
Intersex	Some people are born with hormones, chromosomes, anatomy or other characteristics that are neither exclusively male nor female. It is common practice and usually a legal requirement (e.g. for birth certificates) for babies to be assigned a sex (male or female) shortly after birth. People with variations in sex characteristics might identify as male, female or intersex, and they may consider themselves to be a man, a woman, or to have a non-binary identity.
LGBT*	The LGB refers to people who are lesbian, gay or bisexual and the T* refers to people who are transgender, transsexual, transvestite, genderqueer, gender fluid, non-binary, genderless, agender, non-gender, third gender, two spirit and bi-gender (Westwood and Price 2018)
Male and female	There are terms which may denote a person’s sex and/or a person’s gender.

Men and women	These terms are used to describe adult male or female human beings. However, 'being' a man or woman may have broader connotations linked to a person's gender identity.																																			
Mentalism	This means prejudice and discrimination against people with mental health symptoms and conditions.																																			
Non-binary gender expressions	<p>Non-binary identifications can lead to a variety of public gender expressions from a neutral androgynous appearance/positioning, to more masculine or feminine expressions. Non-binary people (in relation to gender) may have more specific identities, such as:</p> <ul style="list-style-type: none"> • bi-gender – a mix of both genders, • gender fluid – fluctuating over time across a range of masculine and feminine identities, • non-gender (or agender) – people who do not experience a sense of having any form of gender identity, beyond just being a person/a human being, • genderqueer – widely understood to cover a range of identities and expressions that are not typically related to cisgender men and women. Some people are uncomfortable with this term. Some experienced or witnessed in the past persistent violent attacks on gay men who were at the time described as 'queer'. This term should not be used with reference to gay men, • neutrois – neutral gender, • pangender – covering all genders, • poly-gender – having more than one gender identity, • third gender – a gender that is neither man nor woman, male nor female, • transgender or trans – an umbrella term for people whose gender identity is different from the sex assigned to them at birth. People who have transitioned (see below) do not necessarily identify their gender as trans. They may see their gender identity as a man or woman, or have a non-binary gender identity. 																																			
Non-binary pronouns	<p>People with non-binary gender identities often use neutral pronouns such as they (but to refer to people in the singular) or a range of alternatives. The table below is taken from the University of Wisconsin LGBTQ+ Resource Center¹⁸.</p> <table border="1"> <thead> <tr> <th>HE/SHE</th> <th>HIM/HER</th> <th>HIS/HER</th> <th>HIS/HERS</th> <th>HIMSELF/HERSELF</th> </tr> </thead> <tbody> <tr> <td>zie</td> <td>zim</td> <td>zir</td> <td>zis</td> <td>zieself</td> </tr> <tr> <td>sie</td> <td>sie</td> <td>hir</td> <td>hirs</td> <td>hirsself</td> </tr> <tr> <td>ey</td> <td>em</td> <td>eir</td> <td>eirs</td> <td>eirself</td> </tr> <tr> <td>ve</td> <td>ver</td> <td>vis</td> <td>vers</td> <td>verself</td> </tr> <tr> <td>tey</td> <td>ter</td> <td>tem</td> <td>ters</td> <td>terself</td> </tr> <tr> <td>e</td> <td>em</td> <td>eir</td> <td>eirs</td> <td>emself</td> </tr> </tbody> </table>	HE/SHE	HIM/HER	HIS/HER	HIS/HERS	HIMSELF/HERSELF	zie	zim	zir	zis	zieself	sie	sie	hir	hirs	hirsself	ey	em	eir	eirs	eirself	ve	ver	vis	vers	verself	tey	ter	tem	ters	terself	e	em	eir	eirs	emself
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Non-binary titles	Titles such as Mr, Mrs, Miss and Ms reflect the male/female binary concept of sex, gender and for women (in the case of Miss and Mrs) marital status. The alternative 'Mx' is a gender-neutral title that is commonly used by non-binary people.																																			
Prevalence	See under 'incidence'																																			
Self-determination	This term is often understood as the ability to make choices and manage one's own life but can also be interpreted as including the ability to define oneself.																																			
Sex	This term is used to denote the biological characteristics that define humans as female or male. The term also reflects the reproductive function (irrespective of the desire or ability to bear children), since biological, physiological differences between males and females are linked to the process of reproduction. These differences include hormones, chromosomes and internal and external sexual organs. Sex is also used as an abbreviation for sexual intercourse.																																			

¹⁸ <https://uwm.edu/lgbtrc/support/gender-pronouns/>

<p>Sexuality</p>	<p>According to a WHO-convened international technical consultation (2002), “Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors”.¹⁹</p> <p>Sexual identity refers to a person’s conception of themselves and sexual orientation refers to romantic or sexual attraction (or lack thereof) towards others. The following terms may be used in connection with a person’s sexual identity and to refer to their sexual orientation:</p> <ul style="list-style-type: none"> • Heterosexuality describes a pattern of attraction to people of the opposite sex. The term straight is commonly used to refer to heterosexuals. • Bisexuality describes a pattern of attraction toward both males and females, or to more than one sex or gender. A bisexual identity does not necessarily equate to equal sexual attraction to both sexes; commonly, people who have a distinct but not exclusive sexual preference for one sex over the other also identify themselves as bisexual. • Homosexuality describes a pattern of attraction to other people of the same sex. The term lesbian is commonly preferred for women, and the term gay for men as the term homosexual is increasingly considered outdated or offensive. The term gay is sometimes used to refer to women as well. • Asexuality (sometimes “ace” for short) is the lack of sexual attraction to others, or low or absent interest in or desire for sexual activity. It may also be categorised more widely to include a broad spectrum of asexual sub-identities. Asexuality is not a choice, like abstinence or celibacy (where someone chooses not to have sex with anyone, whether they are attracted to them or not). Asexuality is a sexual orientation, like homosexuality (gay/lesbian) or heterosexuality (straight). • Pansexuality describes attraction towards people regardless of their sex or gender identity. Pansexual people may refer to themselves as gender-blind, asserting that gender and sex are not determining factors in their romantic or sexual attraction to others. Sometimes considered a type of bisexuality. • The term transgender (or trans) is often grouped with sexual identity and orientation (for example, lesbian, gay, bisexual and transgender (LGBT). However, it is independent of whom a person is attracted to and should be considered as separate.
<p>Transgender/trans</p>	<p>Transgender or trans is an umbrella term for people whose gender identity is different from the sex assigned to them at birth. Transgender is the opposite of cisgender (within the context of the gender binary system).</p>
<p>Transitioning</p>	<p>This is a process aimed at aligning how people see themselves and the way they look with their gender identity. It may involve changing their appearance or names and pronouns, and sometimes having medical treatment, such as hormone therapy or surgery. Some people do not undergo surgical procedures but just have the ‘lived experience’ in the gender they identify as.</p>

¹⁹ https://www.who.int/reproductivehealth/topics/gender_rights/sexual_health/en/ – not an official position or definition of the WHO

Appendix 3 – Guiding theoretical and ethics/human rights framework

Heterosexism and heteronormativity

Heterosexism and heteronormativity are two terms that are sometimes wrongly used interchangeably. Heterosexism can be defined as “discrimination in favour of heterosexual and against homosexual people, based on the assumption that heterosexuality is the only ‘normal’ lifestyle” (FRA 2009, p.25). Such discrimination against LGBT* people includes direct and indirect discrimination, as defined in the EU anti-discrimination directives. As heterosexism is based on the belief that heterosexuality is ‘normal’, other sexualities are therefore considered as being deviant.

Heteronormativity is more global. It is about how taken-for-granted assumptions about heterosexuality, which lead to heterosexism, are created and perpetuated. It rests on biased, narrow-minded and discriminatory beliefs and attitudes towards LGBT* people and on the belief that heterosexuality is the default, preferred or normal mode of sexual orientation (Harris & White 2018). It rests on the assumption that gender is binary (i.e. that there are only two genders and a person is either one or the other), that everyone is (or should be) ‘naturally’ heterosexual and that heterosexuality is an ideal, superior to homosexuality or bisexuality.

A heteronormative view therefore assumes the alignment of sex, gender identity and sexuality and leads to heterosexual or ‘straight’ privilege. Yep (2002) suggests that heterosexual experience comes to be considered as synonymous with human experience and “renders all other forms of human sexual expression pathological, deviant, invisible, unintelligible, or written out of existence.” However, Ludwin (2022) suggests that it is rather a particular form of heterosexuality within a certain family arrangement that is privileged, namely,

“the individualised nuclear family over all other family arrangements: specifically the privileging of a particular, narrow form of heterosexuality, based on the married, monogamous, heterosexual, reproductive, nuclear family, which relies on (context specific) gender roles” (Kulpa and Ludwin 2022).

People who are straight but either promiscuous or live their whole lives without a partner are not necessarily particularly privileged as they lack the social capital that is typically

acquired through family life and having children. The recent changes in lifestyle and family structures resulting from the legalisation of gay marriages and reproductive technologies/surrogacy has led to a gay version of heteronormativity, sometimes described as homonormativity. This does not, however, have the same power within society.

Heteronormativity goes beyond beliefs and attitudes because it is anchored in social institutions and policies, thereby fostering and perpetuating a climate in which practices, procedures and traditions are discriminatory and hostile towards LGBT* people (i.e. LGBT* people with dementia and their friends, family and/or possible carers in this case).

Sometimes people assume that everyone is or should be heterosexual, without this necessarily being linked to negative or hostile emotions about people who are not. So, it may sometimes be assumed that the partner of a woman with dementia, if she had one, was a man and consequently, any reference to that person in conversations or documents would be to her husband or partner (with the assumption that the partner was male). Similarly, it might be assumed that everyone has or had a heterosexual mother and father. People who are heteronormative may also assume when making an appointment with a male carer for the first time that their partner was female. It could perhaps be argued that expectations are not necessarily linked to negative stereotypes and prejudice against LGBT* people but are based on assumptions which reflect people’s past experience. In other words, someone might expect a man’s partner to be a woman because in their experience, 90% if not more of all the men they have ever met had female partners (and they assumed that those men were born male, that their partners were born female, and that both were heterosexual).

Nevertheless, heteronormativity frequently manifests in rejection, harassment and discrimination based on people’s sexual orientation. It can also be internalised, resulting in self-stigmatisation, with people adopting negative attitudes and beliefs about themselves and in the desire to conceal their sexuality (Szymanski & Mikorskiand 2016). It may reflect underlying homophobia (see following sub-section). In this report, we are drawing on (in the sense of challenging) heteronormativity as part of our underlying guiding theoretical framework because it encompasses

and legitimises heterosexism, and may fuel homo/transphobia, as well as various forms of aggression (see below).

Homophobia, transphobia, violence and micro-aggressions

Homophobia involves an irrational fear of, and aversion to, homosexuality and to lesbian, gay and bisexual people, stemming from prejudice. This can also be directed at transgender people (i.e. in the form of transphobia). It is important to raise awareness about and challenge homophobia but it is also necessary to consider everyone affected by it and to recognise the role of underlying structural and social conditions as well as the broader social and cultural system (Plummer 1988). For example, the term is often associated with gay men and renders the experiences of women invisible.

“Lesbians have historically been deprived of a political existence through ‘inclusion’ as female versions of male homosexuality. To equate lesbian existence with male homosexuality because each is stigmatized is to deny and erase female reality once again” (Rich 1983 in Yep, 2002, p.166).

Moreover, and in relation to the concept of intersectionality (see next sub-section), Yep (2002) suggests that homophobia cannot meaningfully be understood without attention to the dynamics of and interaction between other socially significant categories such as ethnicity, social class and gender. A White gay man with dementia receiving private care and support at home in Sweden, for example, may have a very different experience of homophobia than a lesbian woman with dementia from the Asian community living in Poland in a State-run nursing home.

All too often, intolerance of diversity with regard to people with non-binary gender identities and people who are not heterosexual results in overt hostility and violent acts. A 2009 report by the European Union Agency for Fundamental Rights reported that in thirteen EU Member States it is a criminal offence to incite hatred, violence or discrimination on grounds of sexual orientation (hate speech) but only nine of those consider homophobic intent an aggravating factor in common hate crime. In Finland, homophobic intent is considered as an aggravating factor in common crime but it is not a criminal offence to incite hatred, violence or discrimination on grounds of sexual orientation. In a further 13 Member States, inciting hatred, violence or discrimination on grounds of sexual orientation is neither a crime nor an aggravating factor.²⁰

‘Micro-aggressions’ is the term used to describe derogatory slights or insults, directed at individuals or people from oppressed groups either implicitly (as subtly implied through a person’s behaviour) or explicitly (as clearly stated or shown through actions). These include (Torino et al. 2019, p.4):

- micro-assaults which are “blatant verbal, non-verbal, environmental attack(s) intended to convey discriminatory and biased sentiments”, the majority of which occur when people feel they have some degree of anonymity, when they are with others who share or tolerate their comments or behaviour or when they lose control of their feelings and actions”,
- micro-insults which are “unintentional behaviours or comments that convey rudeness or insensitivity or demean” certain aspects of a person’s identity such as their gender identity or sexual identity (also their ethnicity or religion),
- micro-invalidations which are “verbal comments or behaviours that exclude, negate or dismiss the psychological thoughts, feelings or experiential reality of the target group” and are usually unintentional in that people are not aware of making them.

Micro-aggressions could also be linked to what Yep calls ‘discursive violence’ in the context of heteronormativity whereby “words, tones, gestures and image [that] are used to differentially treat, degrade, pathologise, and represent lesbian and gay experiences” (p.170). Comments may sometimes be made in the context of apparently friendly curiosity but are nevertheless about issues that would not be considered appropriate to discuss with non-LGBT* people (e.g. about people’s genitalia or sexual practices). ‘Institutional violence’ refers to the kind of deeply ingrained and strategically invisible heteronormative thinking which leads to the systematic disadvantage and disempowerment of people who do not conform to the ‘mythical norm’ of heterosexuality (Lorde in Yep 2002).

Intersectionality

People with dementia form a diverse heterogeneous group made up of men and women with different characteristics such as different ethnicities, ages, genders, sexualities, disabilities, levels of education and socio-economic backgrounds etc. However, there are many seldom heard groups and an over-representation/domination of white, middle-class, former professional, married, community-dwelling people with dementia in research and advocacy work. As mentioned earlier, this means that findings are often not representative of the wider population of people with dementia.

²⁰ For further information, please see European Union Agency for Fundamental Rights: https://fra.europa.eu/sites/default/files/fra_uploads/397-FRA_hdgso_report_part2_en.pdf

Focusing on certain characteristics can often be helpful in highlighting differences, shared experiences, injustice and discrimination. However, categorising people into neatly defined, separate groups (even though gender and sexual identities are not fixed but potentially fluid) may also contribute towards the construction of ‘otherness’ (Torres 2015). The meanings that are constructed around the different intertwined categories through dialogue and social interaction may reinforce and perpetuate perceptions of normality and deviance, and create new forms of discrimination which are not immediately obvious (Angelucci 2017). This has been described as ‘intersectionality’, a term coined by Kimberlé Crenshaw in 1989 to denote different lines of oppression and marginalisation in society that can affect a person, based on their ethnicity, age, gender, ability, sexual orientation, class or the intersection of two or more of these aspects.

People are often discriminated against on the basis of more than one characteristic (e.g. gender, ethnicity, age and/or religion). Such discrimination can be sequential (being discriminated against on different grounds on different occasions). It can also be additive or multiple (e.g. because someone is a man and a migrant) whereby each type of discrimination can be identified and is considered independently. Intersectional discrimination is different in that it happens “when two or multiple grounds operate simultaneously and interact in an inseparable manner, producing distinct and specific forms of discrimination” (Council of Europe 2021). The cumulative intersection of a range of factors renders the experience of discrimination unique.

“An African American may be a woman, a woman may be a lesbian, a lesbian may be disabled, a disabled [person] may be old, and one person can be all of this at the same time: an old disabled African American lesbian, who may experience very complex forms of discrimination” (Makkonen, 2002, p.9).

The experience of the person in the above example cannot be wholly captured by looking at the individual dimensions of that experience. Makkonen (2002) provides another example related to disabled women who may face specific types of discrimination not experienced by disabled men or by women in general, such as forced sterilisation.

Focusing on single grounds of discrimination (e.g. age or sex) or thinking in terms of the amount of discrimination that people experience (e.g. double or triple discrimination) may render minorities within a minority invisible. This is sometimes called ‘intersectional invisibility’ (Crenshaw 1989). An example of this would be an evaluation of the experience of men as a minority in care homes, without considering whether that experience is different for gay or trans men than it is for straight men. It is important to look at the structures of power which oppress people and to make complex experiences of discrimination visible (Council of Europe

2021). This does not exclude discrimination or prejudice by marginalised or minority groups against other sub-groups or external groups. People from marginalised and subordinated groups can be just as prejudiced and discriminatory as the rest of society and at risk of discrimination both by general society and by the minority group with which they identify (Makkonen 2002).

There is a risk of serious forms of discrimination (e.g. racism, ageism and heterosexism) being attributed to individual bias and prejudice alone. Structural discrimination describes the role of institutions and systems in creating and promoting oppression, discrimination and marginalisation (Torres 2015) (i.e. heteronormativity). Intersectionality is about exploring the relationships between socio-cultural categories and identities. It draws attention to power imbalances and social and cultural hierarchies within different discourses and institutions, whereby some people come to be positioned not only as different or ‘other’ but as troublesome (Knudsen 2006). This is important because there is a risk, when people are considered as ‘other’, of them being blamed, for example, for not being able to fit in. Makkonen points out that people “are not, as a general rule, discriminated against because of who or what they really are, but because of what they are thought to be or represent” and very often this is linked to historical and structural factors within society (Makkonen 2002, p.5), as well as to negative stereotyping, devaluation and perceived threat (Link and Phelan 2006; Stangor and Crandall 2006). This is why an intersectional approach, which reflects on the specific context, is important.

Torres (2015) suggests that treating men and women exactly the same does not necessarily lead to fairness and non-discrimination because it does not create equity and amounts to treating a woman as if she were a man (and vice versa) which is not the case. Such gender blindness ‘brushes the issue under the carpet’ and fails to acknowledge and truly accept various gender identities and people’s right to express them (see later reference to self-determination). Similarly, Gerard Quinn (2021) argues that an intersectional approach suggests the need to move away from a narrow legal focus (a ground-centric and litigation-based approach) towards a broader human rights focus. This means not attending solely to achieving true equality relative to other groups (e.g. legally challenging discrimination on the grounds of gender and/or sexual orientation) but also to finding better ways of acknowledging and valuing difference, and repairing the injustices of the past.

It might seem that identity politics, which encourages mobilisation around a single defining axis of human traits (such as gender or sexual identity), is at odds with intersectionality. However, it does not necessarily reduce complex individuals to one defining feature and may recognise that people often identify more strongly with some personal characteristics

than others at certain times or in certain situations. Indeed, recognition of the possible impact of different intersecting identities does not mean that categories *per se* should be denied or rejected but rather that broad and sweeping categorisations (bordering on stereotypes) should be avoided (Knudsen 2006).

Ethics and human rights

The term ‘ethics’ refers to standards which tell us how we ought to act in various situations and how we ought to live with one another (including with people who are not of the same sex, gender or sexual orientation as ourselves). It is also about reflection, questioning and dialogue about such standards. Ethics is often framed in terms of rights, obligations, duties, benefits to society, fairness or specific virtues (Velasquez et al. 2010). These standards of behaviour are based on perceptions of right and wrong or good and bad. Ethics is not just about big societal issues such as immigration, war, abortion or euthanasia but about everyday matters such as ensuring that all people with dementia have access to services and support that correspond to their needs and wishes, and respect their legal rights (e.g. to reasonable accommodation/adaptation).

Law and ethics are both important, albeit in different ways when seeking to promote the rights and wellbeing of people with dementia of both sexes and with all gender identities and sexual orientations. Such rights and wellbeing often reflect shared values, such as dignity, fairness, equality, respect and independence, and are the bedrock of much ethical reflection. However, ethics is not simply about doing what feels right or abiding by culturally determined norms and it should not be equated with religion, science or following social conventions (Velasquez et al. 2010). The fact that a lot of people do something or react in a certain way does not make it right. Whilst many religions strive for ethical behaviour, they do not address all ethical issues and some religious teachings condone behaviour which some people consider unethical.

Laws have often been used to enforce actions which with hindsight and greater ethical awareness are now considered as wrong. Following the law does not therefore exempt people from the necessity to reflect on whether their behaviour is morally justified. For example, regulations may state that in certain care situations, such as end-of-life care, only relatives can be admitted or consulted but this does not justify the exclusion of life-long unmarried or same sex partners. Similarly, some professional carers may, based on religious beliefs and doctrines, feel that homosexuality is unacceptable but this cannot justify any kind of negative behaviour

or discrimination against LGBT* people with dementia, their partners, friends, family or possible carers.

Philosophers have debated issues of right and wrong for centuries and have developed a number of ethical standards based on a range of theories. For example, it could be claimed that an action or approach was ‘good’ or ‘right’, depending on the approach adopted, because:

- it results in the most pleasure and the least pain to those affected (utilitarian approach),
- it treats everyone equally or if unequally then fairly, based on a standard that is defensible (fairness approach),
- it is based on commonly agreed moral rules according to which the action can be justified to others and is essentially an interpersonal matter (contractualist approach),
- it is defensible based on outcomes, which would maximise people’s happiness or welfare (consequentialist approach),
- it contributes towards the good of the community (common good approach),
- it is consistent with what a virtuous person would do (virtue approach),
- it is in accordance with our duties as rational/feeling individuals living in interdependent societies (‘amended deontological approach’).²¹

According to the principlist approach developed in the 1970s by Beauchamp and Childress (drawing on the deontological and the outcome-based consequentialist approaches), a person can be said to have behaved ethically if they have respected certain principles, namely, respect for autonomy, beneficence (i.e. doing good), non-maleficence (i.e. avoiding doing harm) and justice/equity. These principles were intended to serve as a framework to guide professional medical ethics but have since been applied in a wide range of contexts. There are also other principles and values which are perhaps equally important in everyday interactions with other people, in relationships with friends and family, in social care and in residential care settings, such as trustworthiness, honesty, integrity, compassion, wellbeing, confidentiality and respect for privacy, personhood and dignity. The Declaration of Sexual Rights is particularly relevant to our work on sex, gender and sexuality in relation to dementia. This is a statement on sexual rights that was developed by the World Association for Sexual Health in 1997 and revised in 2014.²² This declaration addresses a wide range of issues that are reflected in this report.

When trying to decide what is right and wrong, we tend to rely on systems or structures of thought and belief that

²¹ i.e. not linking duties solely to rationality.

²² http://www.worldsexology.org/wp-content/uploads/2013/08/declaration_of_sexual_rights_sep03_2014.pdf

help us to reflect systematically and critically on human behaviour. Key questions might therefore be:

- What makes something right or wrong?
- What ought I to do (e.g. to take measures to ensure that LGBT* people feel safe and at home in a nursing home, that expressions of sexuality by men with dementia are not unduly framed as problematic or abnormal and that people of all sexes, genders and sexualities receive a timely diagnosis of dementia etc.)?
- What ought to happen in society (e.g. what should priorities, procedures and practices look like)?

Such deliberations are usually based on normative perspectives (shared norms and understandings) of good and bad and on values which are socially defined. However, at the same time we should be able to reflect critically and with compassion about what is right and wrong, leading us to challenge the way that values are defined and interpreted within society. This is why we are using the theoretical framework described in this Appendix to take a step back from everyday taken-for-granted assumptions and deeply held beliefs when examining various issues linked to being biologically and socially male, female or neither and having different sexual orientations. The next Appendix provides a brief overview of some key terms related to ethical principles and values.

Feminism

Feminism is not a single unified body of theory, but core to all groupings within the feminist movement are the following beliefs:

1. Women and girls have been, and still are, treated unjustly in almost all human societies, which privilege men and boys and prioritise their interests. This privileging of male power and interests is sometimes described as a 'patriarchal' system.
2. Action must be taken to achieve equality between women and men by campaigning for women's rights and challenging gender stereotypes.

Despite these shared beliefs, there are significant differences between the various factions and 'waves' within feminism. For example, separatist feminists believe that men have no part to play in achieving equal rights for women, whilst Marxist feminists argue that social class is also important and that working-class women and men may have more in common with each other than either with members of the middle or ruling classes.

Although it has been known for many years that dementia disproportionately affects women (as diagnosed individuals, family caregivers and paid health and social care providers), feminist theory has rarely been employed

explicitly to theorise these inequalities. Clearly, not all writing about women and dementia takes a feminist viewpoint, and while there have been a number of reports in recent years on the impact of dementia on women, these do not necessarily take a feminist perspective. The Alzheimer's Disease International report 'Women and Dementia: A global research review' (Brooker et al. 2015) provides a useful international overview of the prevalence of dementia among women, risk factors and workforce implications, for example, but does not overtly link this disproportionate impact explicitly with unequal life chances and lack of resources in later life for women. By contrast June Andrews, writing in the same year, does make such connections, linking, for example, risk of dementia, relative poverty and lack of independent pension entitlements for older women. Alzheimer Europe's 2001 report 'Equality in the Provision of Care at Home' (EPOCH), which explored differences between male and female carers, including LGBT* people, in 15 countries in Europe, also highlighted factors which lead to and maintain the gender imbalance linked to caring. The report specifically highlighted structural discrimination in relation to employment and retirement pensions, and emphasised increased poverty rates amongst women as well as gender differences in the ability of carers to maintain leisure/social activities.

Part of the reason for the historical reluctance to politicise dementia as a feminist issue is the patriarchal nature of the dementia field, which still has a concentration of male power at the top of professions such as biomedicine, psychiatry and associated research. This drives the research agenda, and tends to privilege quantitative research into medical treatments, whilst marginalising and excluding the greater number of women working and researching in the field who have typically been more interested in enhancing wellbeing and quality of care. Indeed, female dementia researchers themselves have sometimes been ambivalent about adopting an openly feminist stance, fearing that this may discourage other women from taking part. Savitch et al. (2015, p.33) note in their report 'Dementia through the eyes of women' that the project team "found it hard to talk about looking at dementia through a gendered lens without people assuming that an active, hostile criticism of men was implicit in their stance". In addition, whilst dementia studies has been slow to incorporate critical perspectives from elsewhere in the humanities and social sciences, it is also fair to say that other relevant disciplines such as critical and feminist gerontology have often had little to say on the subject of dementia.

The relatively small number of writers who have taken an overtly feminist standpoint in their writing about women and dementia include Bartlett et al. (2018), who point out that public discourse on dementia tends to homogenise those with a diagnosis as 'people with dementia' as though gender is insignificant. Correspondingly, much of

the research carried out on dementia to date has been gender-blind. Inability to view dementia through the lens of gender can lead to disadvantages for both women and men. For example, the care home population in Europe is so predominantly female that often few activities or facilities are provided with men in mind, and men with dementia can find the resulting feminised environment difficult to adapt to.

The implications of drawing on a feminist perspective in dementia studies are multi-dimensional and too diverse to be summarised here, but they require a politicisation

of the gender divide in dementia, as opposed to simply describing the problem. This means advocating on behalf of women who have dementia, particularly those whose voices are less often heard; for example, women living in care homes and women from minority ethnic groups. It also involves challenging the tendency to attribute blame for failings in dementia care to low-paid, predominantly female care workers, and advocating on behalf of predominantly female, unpaid caregivers regarding issues such as loss of income and pension entitlements, as well as practical and emotional support.

Appendix 4 – Ethical principles and values

Autonomy	Traditionally described as the condition or quality of being independent and being able to decide what should happen or be done to you. However, it is increasingly recognised that people exist in the context of relationships, engage in give and take, and are interdependent. Relations, institutional conditions, legislation and dementia therefore affect the exercise of individual autonomy.
Beneficence	All forms of action intended to benefit or promote the good of other people.
Compassion	Deep awareness of the suffering of others coupled with the wish to relieve it.
Conscience	Our personal, inner judge of what is right and wrong, based on shared understandings and practices.
Confidentiality	Keeping information we have learned in confidence secure and private; not divulging it to other people without permission.
Discernment	Having sensitive insight and being able to make judgements and decisions without being unduly influenced by personal attachments and external influences.
Equality	Equality involves treating everybody in the same way without taking into account differences between people, which may be inherent, linked to circumstances or structurally determined.
Equity	Equity is not about simply providing everyone with the same opportunities but about fairness and equality in outcomes. Issues related to inequity need to be addressed when striving for equal opportunities and outcomes. This often calls for some people to be treated differently.
Integrity	Strict adherence to a set of consistent moral values and principles; acting in accordance with one's core beliefs.
Humility	Not feeling that you have any special importance that makes you better than anyone else.
Justice/equity	Treating people fairly and ensuring that they have equal opportunities and potential outcomes (which does not necessarily mean treating everyone the same).
Non-maleficence	Not doing what might be harmful or hurt somebody.
Privacy	Freedom from unauthorised intrusion or observation.
Self-determination	The ability to make decisions for yourself.
Singularity/Personhood	What makes a person unique and determines who they are and their individual interests.
Relationality	The importance of trusting relationships. The way we experience ourselves in relation to others.
Truthfulness/fidelity	Telling the truth/being true.
Trustworthiness	The state of deserving confidence.
Virtue	An inner disposition which enables a person to live well or flourish as a human being.
Vulnerability	Needing special care and protection especially in situations where one's rights and needs might not be respected.

Appendix 5 – References

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