

Sex, Gender and Sexuality in the Context of Dementia:

A guide to raise awareness amongst health and social care workers

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Section 1: Introduction

Sex, gender and sexuality are fundamental aspects of our lives, which influence how we see ourselves, how others see us and our position in society. In recent years, there has been increasing awareness about sex, gender and sexuality and the many different gender identities and sexual orientations that people have. Unfortunately, there is still a lack of information on this topic in dementia care where this central part of our identity is far too often invisible.

We therefore hope to raise awareness and provide health and social care workers with recommendations on how to provide sensitive, appropriate and good quality care and support to people with dementia and their carers or supporters of different sexes, gender identities and sexual orientations. We also hope to challenge assumptions and inequalities and help ensure that everyone is free from violence, discrimination and harassment. Our goal is to ensure good dementia care and support for everyone, irrespective of their sex, gender identity and sexual orientation.

The guide is about the experience and wellbeing of men, women and non-binary people with dementia who are living alone or with a partner and who may or may not be sexually active. It is not limited to the experience of LGBTQ+ people but their experience is often qualitatively different

to that of non-LGBTQ+ people and they encounter several issues that others do not, hence the frequent reference to this group.

The guide is based on the ethics report *Sex, gender and sexuality in the context of dementia: a discussion paper*, published by Alzheimer Europe in December 2021¹. This report was produced by a working group of experts in the fields of dementia, gender studies, ethics, ageing, service provision, training of healthcare professionals, nursing and psychology. The group was made up of men and women with and without dementia, and with different gender identities and sexual orientations.²

We realise that some readers are familiar with the concepts of sex, gender and sexuality and others less so, but terminology is constantly evolving. Some terms have become obsolete or offensive and others have gone a complete circle from being considered offensive to becoming a preferred term. Some require a bit of explanation as they are not used in everyday conversations but they are closely linked to assumptions, practices and prejudice which affect the wellbeing of and respect for many people with dementia. We have therefore included a footnote when they are used for the first time and at the end of the report you will find a more detailed explanation of some of these terms and a concise glossary.



¹ Please see: <https://www.alzheimer-europe.org/resources/publications/2021-alzheimer-europe-report-sex-gender-and-sexuality-context-dementia>

² Please see the list of the members of the working group (and co-authors of this report) on page 20.

Section 2: Diagnosis

The importance of timely diagnosis

It is important to get a timely diagnosis of dementia. A timely diagnosis can help people adjust to their situation and give them access to care and social support, as well as the opportunity to take part in clinical trials. It can also help people plan for the future and even prevent crises. There is not a particular time, stage of dementia or level of disability that is timely. Rather it is timely if, for example, it addresses people's concerns, enables them to obtain some kind of legal protection in connection with their job or personal finances, or helps ensure that they get appropriate support, care or treatment. If the diagnosis comes too late or never, people cannot access appropriate care and support and do not have time to adjust and plan.

Inequality and barriers to diagnosis

Not everyone receives a timely diagnosis. Living alone, for example, often leads to a delay in diagnosis. This is linked to the fact that it is often people who are close to the person with dementia who notice subtle changes and encourage the person to consult a doctor.

People in the early stages of dementia often hide the difficulties they are experiencing from other people, but those who live with them often eventually notice or suspect that something is wrong. In most parts of Europe, more women get dementia and live alone than men and are at a greater disadvantage in terms of timely diagnosis when compared to men. Lesbian and gay people are also more likely to live alone than heterosexual people. Older LGBTQ+ people³ often have less contact with their biological families, may experience social isolation and are less likely to have children. This leaves many women and LGBTQ+ people disadvantaged with regard to getting a timely diagnosis.

To make matters worse, some groups of people who have a higher risk of getting dementia actually have a lower chance of receiving a diagnosis. Older LGBTQ+ people, for example, tend to have poorer physical and mental health and older women (regardless of their gender identity or sexual orientation) often have lower levels of education, lower income and less access to healthcare. Women are also less likely to have a pension in their own right. These factors may interfere with people from these groups seeking and obtaining a timely diagnosis.

The diagnosis of people living in care homes

In residential care, there is a tendency to underdiagnose dementia and there are twice as many women as men over the age of 65 living in residential care or care homes in Europe. Care home staff may suspect that a person has dementia, but often no one makes sure that they get a formal diagnosis. Nevertheless, getting a diagnosis is important both for the person with dementia and for the care home, and must be followed up by appropriate care, support and treatment suited to the person's individual needs. For the managers of care homes, knowing how many people have dementia can help them upskill staff, create a suitable environment and respond better to people's needs and rights. Other factors which negatively impact on diagnosis are that men are less likely to seek medical help and that many diagnostic tools are not appropriate for people from minority ethnic groups.

³ LGBTQ stands for lesbian, gay, bisexual and transgender, the Q stands for questioning or "queer" and the plus sign stands for all identities outside the "traditional" gender and sexuality norms.

RECOMMENDATIONS

- ◆ Be aware of the impact that health inequalities, gender identity and sexual orientation may have on the risk of developing dementia and obtaining a timely diagnosis.
- ◆ Think about various barriers to diagnosis and how you can avoid contributing to them in your work.
- ◆ Be proactive and support people whom you suspect may have dementia but who are not diagnosed and may have difficulties accessing a diagnosis.



Section 3: Living one's sex, gender identity and sexuality with dementia

LGBTQ+ people living with dementia

The likelihood of getting dementia increases with age and yet there is a growing focus in today's society on successful and healthy ageing. We often see pictures of happy, healthy, White heterosexual old couples with grandchildren. These images are not very inclusive and many people with dementia, including LGBTQ+ people, cannot relate to them. There is still, unfortunately, a certain stigma attached to having dementia as well as to having an LGBTQ+ identity. People may experience further stigma linked to age, social class and ethnicity etc. Stigma linked to gender identity and sexual orientation can be challenged and changed but this can be hard if we always assume that people with dementia are heterosexual ("straight"), cisgender⁴ and have children and grandchildren. Some LGBTQ+ people with dementia, however, experience the diagnosis as liberating. As one lesbian woman commented:

"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).

A diagnosis of dementia can sometimes overshadow other parts of people's identity. This is perhaps more complex for LGBTQ+ people with dementia who also have the right to live and express different aspects of their identities fully in the same way as other people can. It is important not to just see John as a person with dementia or a gay man, but also to see that he was a deep-sea fisherman who spent his whole life on a small island before moving into care. Similarly, it is important not to see Ayesha as just a bisexual person with dementia but as an accomplished pianist and founder of a home for retired police dogs.

Coming out, being outed and passing

Coming out, being out and passing are central to the experiences of people in the LGBTQ+ community. Coming

out means sharing your sexual orientation or gender identity with the people around you. Being outed means that someone else shares your sexual orientation or gender identity without your consent; either by accident or on purpose. Passing is when a person presents themselves as belonging to a certain group or category different from their own e.g. if a gay man presents himself (and is usually therefore considered by others) as heterosexual, he is passing as heterosexual. Passing and coming out are not once-and-for-all decisions but often dependent on the situations and the contexts that people find themselves in. Moreover, in care homes and home care services, where high rates of staff turnover are quite common, LGBTQ+ people may frequently be faced with decisions about whether or not to disclose their gender/sexual identities. This can be tiring, frustrating and stressful.

Passing and the process of coming out can become difficult for people living with dementia as the disease and related disability progress. Some people may wish to be out, whereas others prefer passing and may fear being outed by those around them or accidentally outing themselves. This fear may lead to worries about getting help and eventually becoming dependent on informal and formal carers to manage their privacy. They may realise or fear that their friends and family will not always be there (e.g. if they are living in a care home) and that care staff might not, in every situation, respect their need for privacy, with the risk of them being outed to other people without their knowledge.

Passing, expressing and maintaining gender identity

In the case of transgender people living with dementia, passing may be complicated. If we take a transgender man as an example, others may consider his passing as a man as a form of deceit and think that he is not "really" a man, whatever that means. But he himself may experience passing as being seen as his real gender. Symptoms

⁴ Cisgender means that the gender a person identifies with corresponds with the sex attributed to them at birth.

of dementia such as difficulties with remembering, planning and concentration may make it hard for people to maintain their gender identities. Health and social care workers should respect the gender identity of each person with dementia and help them maintain it. This can be related to what kind of clothes the person wears, helping with reminders to take hormone treatments and using the right pronouns etc. This is also important for people with non-binary identities and in general, with regard to all gender identities. It may, for example, be important for some people, regardless of gender, to wear make-up, maintain a certain hairstyle, keep or remove facial hair, or have body modifications such as piercings or tattoos.

Sexual orientations may change and gender identities 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 the gender assigned to them 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 health and social care workers seeking to support them. Apparent contradictions between known gender identities and actual behaviour may sometimes be linked to difficulties with memory.

RECOMMENDATIONS

- ◆ Support people with dementia to stay true to their gender identities (e.g. by helping/ensuring that they dress as they wish).
- ◆ Avoid putting pressure on people to express aspects of their identity if they don't want to or don't feel safe.
- ◆ Help trans people with any medical therapy/treatment they may need to maintain their gender identity.
- ◆ Support LGBTQ+ people who wish to continue passing effectively if this is a priority for them.
- ◆ Respect and validate people's gender identities (e.g. by using the pronouns of their choice). 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.
- ◆ 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.
- ◆ Ensure that people with dementia have privacy and can decide for themselves, with support if needed, who knows and who does not know about their gender identity and sexual orientation.
- ◆ Ensure that LGBTQ+ people with dementia have a person of confidence (i.e. a trusted person of their choice) who can help them ensure that their rights are respected and that they receive the privacy they wish to have. If they do not have someone close to them who can fulfil this role, seek and propose a suitable person who would be willing to take on this responsibility.
- ◆ Ensure that support for the rights, dignity and inclusion of LGBTQ+ people with dementia also applies to their friends, partners and family of choice.



Relationships

Close, meaningful relationships can be highly valuable. They can provide support and feelings of security, and they can impact on quality of life and life expectancy, as well as mental and physical health. This is particularly important as people with dementia tend to become increasingly dependent on their partners and families to help maintain their dignity and social inclusion as their dementia progresses. It is often assumed that partners are of the opposite sex, heterosexual and married, but there are so many different kinds of relationships. Not all couples in long-term relationships are married. The number of same-sex couples is increasing even though same-sex marriages/partnerships have only been legalised fairly recently in some countries and not at all in others. Many older adults are in long-term relationships, but many are also single and happy to be single. Others may be dating or looking for relationships and/or sexual partners.

Dementia can substantially change how people with dementia perceive their relationships. It can result in people feeling that they have lost a partner, a friend, a lover and someone to talk to. It can also affect power relations although this may also depend on the nature of the relationship and on gender roles before the diagnosis of dementia. Some partners find it difficult and strange when they are suddenly referred to as carers. On the other hand, LGBTQ+ partners are often not considered as carers, even though, in many cases, it would be helpful if they were. Some people who have dementia care for a partner who needs support or care for another condition.

Sexuality

Sexual relationships can be a positive part of close relationships between people with dementia and their partners. Sex can be a positive experience that they can still share. Unfortunately, relatively little is known about sexuality and dementia and what we do know often comes from research involving White people with “traditional” gender identities. We therefore know very little about sexuality amongst LGBTQ+ people with dementia and also amongst people with dementia from minority ethnic groups.

Enjoyment of sexuality is nevertheless considered a fundamental human right. Unfortunately, people with dementia in residential care settings are often denied this right. In some cases, this is because of a lack of knowledge as well as misconceptions and stereotypes. A common stereotype is that older people are sexless and undesirable, although research shows that many people remain sexually active well into old age.

There are, however, some reports of interest in sex and frequency of sex changing in some way as a result of dementia. This might be in the form of increased desire for sexual activity at odd times or in inappropriate places or, on the contrary, reduced interest and not initiating sexual contact. This may be linked, amongst other things, to medication for dementia, changes in the relationship and difficulties with communication and in expressing needs, as well as to difficulties discussing problems and solutions.

Some types of dementia, especially frontotemporal dementia (FTD), result in people feeling less inhibited, expressing their sexuality more directly or openly and showing less empathy or sensitivity towards their partners. In the context of nursing homes and day care centres, sexuality is often talked about as problematic or abnormal. Terms such as “inappropriate”, “improper” or “hypersexual” are frequently used. Sexuality is often seen as a challenge or a medical problem to be controlled, especially in the case of men with dementia. Showing affection or flirting with staff or other residents may sometimes be a misplaced expression of a need for human contact or intimacy. Sometimes, especially amongst residents, it may be a genuine attempt to attract a partner. However, it may be the place that is the problem and not the act that is inappropriate. Making sure people with dementia have privacy could render the behaviour less “problematic”. Homophobia or transphobia can also make it difficult for LGBTQ+ people with dementia to live out their sexualities.

Key questions to consider are:

- what is your understanding of sexuality and dementia?
- by whom and on what basis is it decided what is appropriate and inappropriate?
- have people with dementia been consulted?

If the people making decisions about what is appropriate are homophobic (see section 4), sexual relations between two men may be seen as inappropriate. If they believe that a person with dementia cannot consent to sex, sexual relations may always be deemed inappropriate. “Inappropriate sexual behaviour” is sometimes referred to as one of the Behavioural and Psychological Symptoms of Dementia (BPSD). However, the term BPSD (and the underlying concept) has been challenged and the definition of inappropriate sexual behaviour is unclear. It is therefore important to reflect on these matters and include people with dementia as much as possible in any discussions about their sexual acts and sexualities.

Consent to sex and relationships

The capacity to consent is essential for anyone engaging in a sexual relationship. The fact that a person has dementia does not automatically mean that they are not able to consent. Consent is always task-specific. In other words, the fact that someone lacks the capacity to manage their finances or to drive a car has nothing to do with their capacity to have a sexual relationship. That said, there may be possible concerns about a person's specific capacity to give consent. The following questions may help when assessing the capacity of someone with dementia to consent to a sexual relationship:

- Does the person know who is initiating the sexual contact? Can they express the level of intimacy that they would be comfortable with?
- Would the person want to have sexual contact if they knew that the person was not their spouse/partner?
- Does the person understand that they are free to choose whether or not they have sexual relations and with whom?
- Is the person aware of possible risks (e.g. pregnancy or sexually transmitted diseases)?
- Can the person assert their wishes and reject any unwanted sexual advances?

Whilst people with dementia should be protected from unwanted sexual contact, it should not be assumed that they lack the capacity to consent to sex. Such assumptions are often based on stereotypes about dementia and sexuality and are sometimes influenced by moral or religious beliefs.

RECOMMENDATIONS

- ◆ Challenge taken-for-granted assumptions about sexuality and relationships in people with dementia (i.e. that people are heterosexual, identify with the sex given to them at birth, are married or in a stable relationship with one person and have or are assumed to have children in the future).⁵
- ◆ Challenge assumptions that sexuality and relationships are inappropriate for people with dementia.
- ◆ Ensure that people with dementia are involved in all decisions relating to their sexuality.
- ◆ Assume that a person has capacity to engage in sexual acts unless there is evidence to the contrary. If you have reasonable doubt, check and prove that someone lacks the capacity if that is the case.
- ◆ Ensure access to unbiased support.
- ◆ Give people with dementia privacy and space to live out their sexuality (e.g. by ensuring that they have a room where they can be together, giving them a 'do not disturb' sign or making it possible for them to lock their own room).
- ◆ Acknowledge that sexual disinhibition in people with dementia may sometimes be the expression of an unmet need.



⁵ The term “heteronormative” sums this all up in one word.

Section 4: Discrimination and the need for awareness

Discrimination, homophobia and transphobia

People from the LGBTQ+ community often experience discrimination and stigma. This includes homophobia (negative attitudes towards and prejudice or discrimination against LGBTQ+ people) and transphobia (negative attitudes towards and prejudice or discrimination against transgender people). Many people in the older generations have experienced and remember severe discrimination, such as being considered as having a mental disorder, being subjected to inhumane medical treatment, being estranged from their families and not having the right to have children. The American Psychiatric Association considered homosexuality an illness until 1974 and in Sweden, for example, it was mandatory until 2013 for

people who changed their gender in the population register to undergo sterilisation. Homosexuality is still criminalised in over 70 countries and some people with dementia may have migrated from one of these countries.

LGBTQ+ 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. In some cases, discrimination and hostility are openly expressed, but often, negative or discriminatory attitudes and behaviour are subtle and even unintentional. This can, for example, be in the form of assumptions that exclude many or all LGBTQ+ people and their needs or it could lie in not acknowledging a person's gender. Although sometimes unintentional, these assumptions and exclusions can be powerful and have a negative impact on LGBTQ+ people.



Fear of discrimination

The fear of discrimination can be just as damaging as actual discrimination and can lead to low self-esteem, isolation, withdrawal, fear and lower quality of life. In the context of care and support, LGBTQ+ people often fear homophobia and transphobia from health providers, staff or other residents. The fear of discrimination and abuse may lead to many LGBTQ+ people hiding their gender and sexual identities. It is important to avoid situations where people feel the need to do this to feel safe. Apart from the emotional and psychological consequences of doing this, it

makes LGBTQ+ invisible in the health and social care system and reinforces the belief that everyone is heterosexual and has a gender identity which corresponds to the sex attributed to them at birth. This is not compatible with person-centred care. Merely putting up rainbow images and supportive statements about accepting LGBTQ+ people or saying things like "We don't have any LGBTQ+ people in the nursing home" or "We treat everyone the same" may not be helpful. Treating everyone exactly the same may sound fair. However, assuming that everyone is heterosexual and cisgender, and treating everyone as if this were the case, excludes LGBTQ+ people and can result in them receiving lower quality care and support.

Smaller support networks

LGBTQ+ people with dementia, and people with dementia with no children, face additional challenges linked to their care and support. Older LGBTQ+ people, for example, may have less contact with their biological families and this can be a big disadvantage when they develop dementia. Heterosexual men and women are more likely to have a network of relatives who are able and willing to support them, although older people with no children may have a more limited network. Older LGBTQ+ people tend to be more socially isolated because of declining friendship networks. This has been linked to higher levels of depression, lower quality of life, mental and physical abuse in residential care settings and a faster progression of dementia symptoms. Many LGBTQ+ people worry about who will take care of them if they get dementia, whether they will be alone and whether they will be able to afford residential care.

Of course, not all LGBTQ+ people have the same experience. Studies show that bisexual older adults tend to have lower levels of social support and often lack a sense of belonging to a community compared to lesbian and gay older people. Together with transgender people, they are also less likely to have supportive biological families. Families of choice can provide valuable emotional support, but LGBTQ+ people may have lower expectations of them when it comes to providing long-term care. But even within those groups, people may have very different experiences.

Structural discrimination

In addition to homophobia, transphobia, discrimination and sexism, some of the differences that can be seen in relation to family networks, financial resources or entitlement to care and support are closely related to structural discrimination. Examples of structural discrimination, which can lead to less financial security and limited support networks for many LGBTQ+ and most single people, include:

- unmarried and single people usually paying higher taxes on their salaries
- single people, especially women, finding it more difficult to take out a mortgage
- in some countries, LGBTQ+ people still not being allowed to adopt children and LGBTQ+ and/or single women not being allowed access to in vitro fertilisation
- gender gaps in pension schemes (also linked to many women having stayed at home with their children and spent fewer years in paid employment)
- many women having had part-time jobs or contracts that did not pay retirement benefits
- a global gender pay gap, whereby women are generally paid less for their work.

RECOMMENDATIONS

- ◆ Do not assume that all people with dementia are cisgender and heterosexual.
- ◆ Try to understand the challenges that LGBTQ+ people with dementia and their supporters face.
- ◆ Raise awareness about the experiences, rights and needs of LGBTQ+ people and ensure that everyone is made to feel welcome, accepted and valued irrespective of their sex, gender identity or sexual orientation.
- ◆ Reflect on your own assumptions and language.
- ◆ Avoid inappropriate humour or banter based on appearance, dress or mannerisms, and challenge this when it occurs.
- ◆ Bear in mind that people's current situation (e.g. marital status, whether they have children and where they live) are not necessarily solely the result of their own choices and preferences.
- ◆ Ensure that all people with dementia are free from violence, discrimination and harassment regardless of their gender identities or sexual orientation.
- ◆ Try to create and communicate a feeling and atmosphere of safety and acceptance of everyone, regardless of sex, gender identity or sexuality.
- ◆ Be aware of different family structures and include friends, partners and chosen family in the care and support of people with dementia.
- ◆ Help create an openly positive atmosphere and environment that is welcoming to people of all gender identities and sexual orientations, in which sexist, homophobic or transphobic residents and staff would probably not wish to work or reside.

Section 5: Care and support

Person-centred care and support

It is widely accepted that care and support for people with dementia should be person-centred. It should focus on supporting the well-being, dignity and autonomy of the whole, unique person and not only on the dementia and symptoms. The services that are adapted to the needs and wishes of people with dementia should not only consider people's cultural and religious backgrounds, but also acknowledge and respect other aspects of their identity such as their gender and sexual orientation. For some people, being recognised as a man, woman, non-binary, straight or LGBTQ+ is an essential part of being recognised as a person. For others, other parts of their identity may be more important. Unfortunately, care and support is often heteronormative, which means that it is not truly person-centred. Whilst this is not necessarily intentional (as it is so deeply ingrained in society), it can nevertheless be harmful.

In recent years, the term person-centred has been expanded to include everyone giving and receiving care and support. The term relationship-centred has been used to describe the interdependence between carer and care receiver and the importance of relations and interactions in care. The partners of LGBTQ+ people and unmarried straight couples are not always acknowledged and may not even be recognised as partners or carers. For people who do not have a spouse or biological family, it is important to recognise the people who are important in their lives so as to be able to provide person-centred and relationship-centred support and care.



Gendered activities and support

Some activities in care homes and day care centres, such as knitting, yoga and flower arranging, are more likely to attract women than men and may leave many people (including some women) with no opportunities for social interaction and cognitive stimulation. Gender-specific activities and support are often not the best solution but sometimes may appeal to groups of people whose needs and interests might be otherwise neglected (e.g. garden shed or football reminiscence groups which typically appeal to men, or support groups for trans people with dementia). However, it is not an either/or matter. In countries which have support groups for male carers, 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. If activities are divided into those aimed at men or women, this can also exclude non-binary people.

There is often a lack of formal services and support that reflect the needs and interests of LGBTQ+ people with dementia. Living arrangements and staff providing care and support are not always inclusive and respectful towards LGBTQ+ people with dementia. Some people therefore prefer to use services and support that are specifically for LGBTQ+ people, including care homes. Some have created their own support networks and spaces where they feel safe to share experiences of discrimination and prejudice as well as talk about sex and emotional needs. However, such services are not yet widespread and not everyone agrees that there should be services dedicated only to LGBTQ+ people. It is also a personal matter whether or not an LGBTQ+ person with dementia wants dedicated services and support.

Complex care needs

Paradoxically, the fact that older LGBTQ+ people often have less contact with their biological families, are more likely to experience social isolation and are less likely to have children, means that they are both disadvantaged in getting a timely diagnosis and in greater need of professional care and support. Some conditions such as diabetes, hypertension, HIV and renal and liver disease, are more common amongst people with certain gender identities or sexual orientations and may result in additional care needs. 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. The stigma associated with a disease like HIV can lead to further isolation, mental health problems and lack of support, and may lead to people hiding that they have HIV.

Trans people may also have complex care needs. Hormone treatments, which are taken in order to transition, may put a strain on organ systems and there is insufficient knowledge about the long-term use of hormonal drugs. Trans people with dementia often need help managing hormone medication as well as dementia drugs, especially with regard to drug interactions, contraindications and polypharmacy (the use of multiple medicines). People with intellectual disabilities, such as Down's Syndrome, may also have more complex care needs in relation to sexuality, and may need some support to ensure that their right to sexuality is respected.

Having increased or complex care needs can be particularly challenging when combined with a lack of informal support from biological families, although clearly this is not limited to LGBTQ+ people as many people have little or no contact with their biological families for all kinds of reasons.

RECOMMENDATIONS

- ◆ Remember that a person is more than their gender identity/sexual orientation.
- ◆ Seek the views and preferences of everyone with dementia.
- ◆ Think about how to respect, promote and help people maintain their gender and sexual identities when discussing and planning care and support.
- ◆ Give partners and chosen family (whose relationships are not formally or legally recognised) the same rights and access to care and support as biological families have.
- ◆ Don't assume everyone has a biological or chosen family.
- ◆ Include people with minority gender identities/sexual orientations when developing services and support so as to ensure that they respond to people's diverse needs and interests.
- ◆ Avoid focusing solely on activities that are stereotypically associated with one gender.
- ◆ Do not exclude people from activities on the basis of their sex or gender.

Section 6: Gender and sexual identities of staff

In the health and social care sector in most countries, the majority of both patients and healthcare workers are female, but the decision makers and policy makers are not. The social care profession in particular is predominantly female and this may be partly due to it offering the possibility to combine paid employment with personal responsibility for the care of dependent children and adults (which is still largely the domain of women). The low pay, poor working conditions, unstable contracts and poor career prospects in the health and social care sector are therefore experienced by more women than men.

Male students and care workers sometimes experience exclusion and questioning about their suitability for such work. This is not conducive to attracting more men to the profession and yet, some men who need care or support may feel more comfortable or simply prefer to discuss certain issues with another man or to receive certain types of care and support from another man (e.g. for personal hygiene, dressing, issues related to sexuality

or relationships). Being in an environment that is almost entirely female may therefore impact on the quality of care provided to them and affect some men's wellbeing.

Health and social care workers, especially those who identify as LGBTQ+, are key to promoting equal care and support and to challenging heteronormative assumptions in the care and support of people with dementia. They should therefore not feel threatened or be rendered invisible in the workforce. Progress is needed at the level of policies and procedures to enable health and social care workers to feel comfortable about being openly LGBTQ+ in the workplace. This might take the form of quotas and gender balance policies to ensure a good representation of different genders at all levels in health and social care organisations, as well as established practices and procedures which openly promote diversity. Practical guidance on how to support and promote the rights and wellbeing of LGBTQ+ health and social care staff are needed⁶.

RECOMMENDATIONS

- ◆ Promote diversity and the inclusion of people with different gender identities and sexual orientations in health and social care work.
- ◆ Be aware of and fight discrimination against LGBTQ+ people.
- ◆ If you experience prejudice or discrimination on the basis of your sex, gender identity or sexual orientation report it and seek support from a trusted colleague or organisation.
- ◆ If you witness prejudice or discrimination against one of your colleagues or someone in your service on the basis of their sex, gender identity or sexual orientation stand up for them, report it and offer support.

⁶ See, for example, the National Health Service (NHS, UK) 2008 report "Trans: A practical guide for the NHS" at <https://docslib.org/doc/4342370/trans-a-practical-guide-for-the-nhs>

Section 7: Summary and take-home messages

Europe is still highly influenced by heteronormative assumptions and structures. This is also the case in dementia care and support where we tend to assume that everyone is heterosexual, cisgender and in a close-knit biological family. The societies we live in have developed structures of care and support around these assumptions. This is reflected in negative stereotypes about the sexuality of older people and people with dementia, and broad generalisations about what men and women with dementia want or need in life.

With this guide, we hope to show that men and women with dementia have different gender identities and sexual orientations, that many face discrimination, both from other people and through structures and procedures within society, and that inequalities based on sex, gender and sexual orientation affect not only people with dementia but also their families, carers and health and social care workers.

Everyone can make a difference, especially health and social care workers like you who work closely with people with dementia. The first step is to become aware of our own assumptions about sex, gender and sexuality and then to start working actively to promote greater acceptance of diversity and more inclusive care and support.

Specific discrimination against LGBTQ+ people with dementia and against those working in the health and social care domain must be challenged. We need to ensure that everyone with dementia feels accepted and valued for who and what they are, that they feel safe to be open about their gender identities and sexual orientations, and that they can all enjoy the same rights, respect and opportunities as other members of society. This will not happen overnight. There are many obstacles and there will be some resistance from individuals and groups who do not have the same awareness, priorities or values, but you, as a health and social care worker, can make a big difference.



Key concepts and glossary

Defining sex, gender and sexuality

Sex refers to biological differences between people, usually in terms of being male or female. Sex is assigned at birth but does not necessarily reflect one's gender identity. Gender, on the other hand, refers to social differences between men and women. Under the umbrella of gender, there are also non-binary identities that do not fit in with the strict division of being either a man or a woman. Gender identity describes how a person experiences their own gender as a man, a woman, non-binary or in another way. Sexuality is a broad term covering both gender identity, body image, sexual desires and sexual orientation. Sexual orientation is a part of sexuality which is about who a person is attracted to (e.g. to people of the same sex, the opposite sex, both sexes or to no one). Gender identities and sexual orientation are sometimes considered as being the same, but are inherently different and one does not imply the other. For example, a person may be considered biologically male at birth (male sex having been assigned based on the child's external anatomy), experience herself as female in terms of gender identity, and be attracted to women in terms of sexual orientation.

LGBTQ+ and what is commonly perceived as the norm

Many people assume that older adults and people with dementia are heterosexual ("straight"), married or have been married, that they have children and that they are either male or female. This is not something that is specific to dementia care or older adults, but is related to what we call 'heteronormativity'.

Heteronormativity is the assumption that everyone is heterosexual and identifies with the biological sex they were given at birth. This is seen as the norm and everyone else is therefore considered as deviating from the norm. There are other assumptions linked to this, namely that everyone wants to or can have children and that our biological families form our closest bonds.

The term LGBTQ+ is an abbreviation used to refer to the wide variety of people with different gender identities and sexual orientations (i.e. other than heterosexual people who identify with the biological sex assigned to them at birth). LGBT stands for lesbian, gay, bisexual and transgender, the Q stands for questioning or "queer" and the plus sign stands for all identities outside the "traditional" gender norms. There are many other abbreviations for people's gender and sexual orientations such as LGBTQA+ and LGBTI, to name but a few. One of the reasons that there are so many terms is that there are so many gender and sexual identities and a desire to be inclusive. In this guide, we are using the term LGBTQ+. We acknowledge that it is not ideal and emphasise that the people included under "+" are just as important as those covered by the "LGBTQ" and as people with "traditional" identities.

Diversity and the complexity of people's identities

Everyone is different and although we might think there are recognisable groups, people don't fit neatly into different categories. To understand the experiences of people with dementia, we also need to understand the diversity of these experiences and how they intersect with other aspects of a person's identity. This is sometimes called "intersectionality". The World Health Organisation⁷ links gender and intersectionality to discrimination,

"Gender is hierarchical and produces inequalities that intersect with other social and economic inequalities, such as ethnicity, socioeconomic status, disability, age, geographic location, gender identity and sexual orientation, among others."

For example, the discrimination experienced by a heterosexual, White man with dementia may be radically different to that experienced by a transgender woman with dementia from a minority ethnic group.

7 WHO (2022), https://www.who.int/europe/health-topics/gender#tab=tab_1

The glossary below explains some of the terms used in this report. Please bear in mind that those referring to different aspects of sex, gender and sexuality are only aspects of people's identities, not the sum total of who or what they are. Please also bear in mind that terminology varies and

changes over time, but not at the same pace or in the same way everywhere. It is therefore important to be sensitive to language usage within particular communities and contexts, and to adapt accordingly.

Glossary in the report	
Cisgender	Refers to a person whose sense of personal identity and gender corresponds with the sex attributed to them at birth.
Gender	Refers to the social and cultural differences between men and women, including gender roles, behaviour, expectations and what is considered appropriate by society. These things change over time.
Gender Identity	Is an individual's personal understanding of their gender and how they feel inside. This may match the sex given at birth (as in cisgender), but can also differ (e.g. in the case of non-binary or transgender people).
Heterosexuality	Refers to a romantic or sexual attraction, or sexual behaviour towards/between people of the opposite sex or gender. Sometimes, heterosexual people are referred to as being "straight".
Heteronormativity	Refers to the taken-for-granted assumptions that people are heterosexual, cisgender, married or in a stable relationship with one person and have or will have children. It rests on biased and discriminatory beliefs and attitudes towards LGBTQ+ people and on the belief that these heteronormative characteristics are the default, preferred or normal mode of sexual orientation and gender identity.
Homophobic	Term used to describe people who have negative attitudes towards and prejudice or discrimination against LGBTQ+ people.
Homosexuality	Refers to romantic or sexual attraction, or sexual behaviour towards/between people of the same sex or gender. Often, the term is considered too clinical or offensive, so men may prefer to be referred to as gay and women as lesbian.
Intersex	Refers to people who are born with hormones, chromosomes, anatomy or other characteristics that are neither exclusively male nor female. Intersex people may identify as male, female, intersex or with a non-binary identity.
LGBTQ+	The LGBT refers to people who are lesbian, gay, bisexual and transgender. The Q stands for questioning (when a person is exploring their sexuality, gender identity and gender expression) or alternatively for queer (see below). The plus (+) refers to people who are genderqueer, gender fluid, genderless, agender, non-gender, third gender, bi-gender or non-binary etc.

Glossary in the report

Non-binary	Non-binary refers to people whose gender identity does not exclusively fall into the binary gender classification of either “man” or “woman”. They may identify with either masculinity or femininity in some way, both or neither (i.e. having a neutral androgynous appearance). It is a gender identity on its own but is sometimes used as an umbrella term for many gender identities.
Queer	<p>Queer is a broad term, which is used to describe gender identities and sexual orientations that do not fall within the heteronormative assumptions of being heterosexual and cisgender.</p> <p>It is sometimes used to describe nonbinary gender identities, sometimes to describe homosexuality or bisexuality and sometimes used to describe the whole LGBTQ+ community. The term is quite controversial. Whilst some people identify as queer or don't object to the term being used, others find it offensive because in the past, it was often used as a slur against gay men.</p> <p>To some extent, the term has been reclaimed in much the same way as “Black” has been (i.e. “Black” went from being considered offensive, and thus replaced by “coloured”, back to being considered a respectful way to refer to Black people, with “coloured” now generally being considered offensive). This shows how words matter and how meanings are constantly being constructed and reconstructed across time.</p>
Sex	This term is used to describe the biological characteristics that define humans as female or male. These characteristics include hormones, chromosomes and internal and external sexual organs. Sex is also used as an abbreviation for sexual intercourse.
Sexuality	Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.
Sexual orientation	Sexual orientation refers to romantic or sexual attraction (or lack thereof) towards others. This can include heterosexuality (being attracted to the opposite sex), bisexuality (being attracted to both males, females and/or other genders), homosexuality or gay/lesbian (being attracted to people of the same sex), asexuality (the lack of or low sexual desire) and pansexuality (being attracted to people regardless of their gender), as well as other sexual orientations.
Transgender/trans	Refers to people whose gender identity is different from the sex they were given 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.
Transitioning	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.
Transphobia	Term used to describe people who have negative attitudes towards and prejudice or discrimination against transgender people.

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