

Sexuality and people in residential aged care facilities:

A guide for partners and families



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About this booklet



The need for love, affection, physical closeness and contact continues throughout life, as does the desire to look and feel good. These needs are all part of our sexuality which can remain important for older people living in aged care facilities.

Sexuality is a part of being human. We all express our sexuality in our own way. The importance of sexuality and how we express it, can change over our lives. It can be very difficult to talk about sexuality as it is often something we are used to keeping private, or only talking about with people we trust. Health professionals and aged care staff can **also** feel uncomfortable talking about sexuality.

Sexuality can still be important to people when they are living in an aged care facility even though they may: be old and in need of care; disabled; have health problems; or have dementia.

Sexuality can be an awkward topic and it can be difficult to openly talk about it. The information in this booklet has been prepared to help you as a family member, or partner of a person who lives in residential aged care understand about sexuality, what it means and how and why it might still be important to them. We hope this information will help you to be more aware of sexuality and how you, and the aged care facility staff, can support your family member or partner to have a more fulfilling life.

In this guide we have used the term “loved one” for simplicity to refer to any family member or partner living in an aged care facility.

The importance of sexuality



- Being able to express our sexuality is linked to well-being and quality of life. Sexuality is expressed in many different ways. Sexuality is much more than what we do and physical 'sexual' acts. It is who we are.
- We have a basic human need to feel good about ourselves; to have our individuality recognised through the way we dress and groom ourselves and to experience closeness, human touch, warmth and companionship.
- As we get older, there are changes in the way the body functions, which may alter the way we can express our sexuality.

Sexuality and living in an aged care facility

- When a person moves into an aged care facility, the need to express sexuality and experience intimacy with another person can remain important and can offer comfort and pleasure.
- Looking and feeling attractive, by paying attention to personal grooming and the choice of clothing worn each day, can be important for self-esteem and self-worth.
- People living in an aged care facility may still have sexual desires and be capable of having sexual intercourse, or masturbating. Sometimes it can be difficult for a partner or a family member to understand that a person living in an aged care facility may still have sexual desires and needs.
- People living in aged care may stop being sexually active because they have significant health problems, or do not have a partner. This does not mean that they no longer desire to be sexually active.
- Even if sexual intercourse or masturbation is no longer satisfying or possible, the need for affection, closeness and intimacy can still remain.

Sexuality and dementia

- The need for companionship, relationships, intimacy and human touch does not change because someone has dementia. People living with dementia have lived with their sexuality for much longer than they have lived with dementia.
- Sometimes it can be difficult to understand and accept that a person living with dementia may still have sexual needs, especially if they are unable to verbally express these needs.

Relationships

- A person with dementia may forget about the relationship they had before and not know they have a partner and they may look for a new partner. It can be very difficult for a partner or a family member to know that a loved one wants to spend time with someone else living in the facility.
- People with dementia living in an aged care facility who do not have a partner may want to form a relationship with another person living in the facility. They may also have sexual needs and may become frustrated when these are not met.



Making decisions

- There is much debate about whether or not a person with dementia can make decisions. Different decisions require different levels of mental ability. A person with dementia may not be able to make certain choices and decisions that affect their life, but they may still be able to decide who they would like to spend time with, how much time they would like to spend with that person and what level of affection they would like. It is important



to consider whether there is any real risk of harm if a person with dementia starts, or continues, a relationship, and whether their decision to do so should be respected. There needs to be an assessment of every situation to ensure that the person is not being taken advantage of and there is no abuse occurring; but their right to be happy in a relationship needs to be respected.

Changed behaviour

- The brain controls our sexual feelings and inhibitions. Dementia can cause changes in the brain which can affect sexual behaviour. These changes can sometimes be unpredictable. Changes in sexual behaviour can also be caused by some medications. Depending on the part of the brain being affected by dementia (and also the medication being taken), the person may experience:
 - Changes in keeping personal boundaries
 - An increased interest in sex, a decreased interest in sex, or no interest in sex
 - A change in sexual 'manners'. The person may appear to be less sensitive to their partner's needs, or may become more aggressive
 - A change in sexual inhibitions. The person may do or say things that seem 'out of character', or may even appear 'inappropriate' - for example they may make sexual advances towards others. Behaviour that the person may once have been able to control or undertake in private, may now need immediate gratification. The person may have no consideration of the consequences.



Interpreting behaviour

- Sometimes how a person is behaving can be interpreted as sexual when it is not. A person may undress in public or touch themselves for example, but this may be because they:
 - Are uncomfortable because their clothing is too tight, or they feel itchy or hot
 - Want to use the toilet
 - Are bored or agitated
 - Want to be cuddled or comforted.
- Sometimes sexual behaviours which are perfectly normal in private, can take place in public living spaces in an aged care facility. Such normal private sexual behaviour when it takes place in a more public place (such as a communal living room), may be labelled as 'inappropriate'. It may be, that there is no private place for the person to go, or the person may be lost and unable to find a private place on their own.
- Situations like those described above can be embarrassing for partners or family members. It can be confusing, upsetting, or frustrating for the person living with dementia also, especially if they cannot understand why others are disapproving of their behaviour.



How might changes in your loved one affect you?

- As a partner it can be hurtful if the person you feel close to no longer remembers your name, does not recognise you as their partner and develops an interest in someone else. It may be especially upsetting if, when you are visiting, you see them sitting or holding hands with someone else. It is normal to feel sadness, loss, upset, anger, embarrassment, anxiety or frustration if this happens. It may take a long time to accept these changes and come to terms with this.
- You may not want to visit the facility because you are upset, or embarrassed by your loved one's behaviour, or because someone else thinks their behaviour is abnormal or inappropriate. Some staff may also experience discomfort or embarrassment when a person living in the aged care facility expresses their sexuality.
- As in any relationship, difficulties can arise when one person expresses a greater interest in sex than the other. It can be upsetting and you may not know what to do if your loved one makes constant sexual demands when you come to visit. Some partners may try to avoid showing physical affection such as hugs and kisses in case the person with dementia interprets this as sexual.
- Try not to judge your loved one's behaviour or take it personally. It may be the dementia or a medication they are taking that is causing certain behaviour.
- If you are upset by demands made by your loved one, you may like to share your concerns with a staff member or other health professional you trust and talk about ways of dealing with this.



- It is important that you and your loved one feel comfortable and safe and any sexual activity is consensual for both of you. Although this may be a difficult issue to talk about, if you feel threatened physically or verbally, it is important that you speak with the facility manager or other staff member about this.
- What appears to be a sexual demand may be a need for closeness or touch. Physical touch may help you maintain a sense of connection and closeness with your loved one and show them that you love them and are there for them. You can do this by sitting with them and holding their hands, cuddling up whilst watching TV, massaging their hands or feet, or some other activity that you are both comfortable with. Your loved one may not initiate any affection themselves, but you can help to reassure them and allow closeness to continue for the both of you. You may like to ask the staff if you can have some private, uninterrupted time together.
- If your loved one is unable to communicate their specific needs, then you might like to discuss this with a member of staff. As the partner or family member of a person with dementia who is unable to verbally communicate, you may like to help the aged care facility staff understand their specific needs and preferences.

How can the residential aged care facility be supportive?

One of the roles of a residential aged care facility is to promote an optimal quality of life for the people who live there. Staff working in residential care facilities often come from a variety of cultural, religious and ethnic backgrounds where sexuality may be viewed quite differently. It is important that the values and beliefs of aged care staff do not interfere with the rights of people living in the facility to express their sexuality when it does not harm others.



It is important to ask questions about how the facility supports the expression of sexuality of the people who live there, including those who have dementia, and who identify as lesbian, gay, bisexual, transsexual or intersex (LGBTI).

Questions to ask may include:

- 1 ? Does the facility have a policy about sexuality and sexual health and has this been communicated to staff?
- 2 ? What are the responsibilities of staff and those of the organisation with respect to supporting the sexual expression of the people living in the facility; for example, have the professional and care staff received education and training on sexuality including residents' sexual rights, privacy, and the recognition of unwanted sexual contact?
- 3 ? Does the facility have a policy about the use of sex workers, sexual aids or the use of on-line 'resources' that a person living in the facility may wish to access?

Communication with staff

The best way to improve the quality of life for the person living in an aged care facility is through teamwork. Care staff cannot provide total care without the input from partners or family members. Mutual trust, respect, empathy, understanding and familiarity are important building blocks for positive relationships between staff and the partners or family members of people living in the facility. It is important that communication avenues are established right from the time your loved one's move into the aged care facility is being planned.

Some people living in aged care would like to be able to talk about sexuality with a trusted and qualified health professional. The role of aged care staff is to provide the person living there with opportunities to discuss their needs, if they wish to do so. Care staff should respect the individuality of each person and encourage the expression of this in their life. To provide the best individualised care, it is important that staff are given information about the person living there that they, and you, are comfortable sharing. Such things can include their gender identity and sexual orientation; physical presentation and grooming preferences; likes and dislikes; life history and other things that they may value. Of course, not everyone will feel comfortable discussing such things and it is a person's right not to share information if they do not want to.

Meeting the needs of the person living in aged care

- Personal appearance, dress, style and grooming can be very important to how a person feels about themselves. Aged care staff can assist by helping the person to dress in their preferred clothes and attend to their personal grooming and care. You may be asked questions about your loved one's personal presentation, grooming, and dress, to help with care planning and documentation. You, as the partner or family member, can help by ensuring that the clothes provided are what your loved one would like to wear.
- Care staff should maintain a non-judgemental and respectful attitude and provide the opportunity for your loved one to express their sexuality, providing this doesn't infringe upon the rights of other people.
- Staff are there to support the lifestyle of the people living in aged care. If you and/or your loved one need professional counselling, information, or referral about sexuality or relationships, ask the staff if they can make this available.



- If you need written information for yourself and your loved one about: sexually transmitted infections (STIs) and sexual health; mandatory reporting and sexual assault; or how the facility ensures that there is no sexual discrimination ask the staff if they can provide this.
- Good assessment and care planning requires that staff ask questions about whether your loved one wishes to discuss their sexuality and intimacy needs with appropriately trained staff.
- Uninterrupted privacy is important to allow your loved one to explore their sexuality (with a partner, or on their own). You or your loved one should not be made to feel uncomfortable making such a request. When you and your loved one need private time, ask the staff if they can provide a 'do not disturb' sign for the door. Staff should always knock before entering your loved one's room and should wait for permission to come in before entering. Be aware however, that staff may need to enter the room for medical or emergency reasons.
- If there is the space, staff may be able to organise a double bed for you and your partner.



Some useful resources

Alzheimer's Australia (2010). **Understanding Dementia Care and Sexuality in Residential Facilities.**

Freely available from:

https://fightdementia.org.au/sites/default/files/20101001_Nat_QDC_6DemSexuality.pdf

Doreen Wendt-Weir (2006). **Sex in Your Seventies.**

Can be ordered at: <http://www.sexinyourseventies.com>

Australian Centre for Evidence Based Aged Care, La Trobe University (2015). **Supporting Families and Friends of Older People Living in Residential Aged Care: A Guide for Families.**

Freely available in Arabic, Greek, Italian, Vietnamese, Mandarin, Spanish, Macedonian and Russian from: <http://qualitydementiacare.org.au/project/improving-staff-family-relationships-for-people-with-dementia-living-in-residential-aged-care>

Website also includes education modules for aged care facility staff.

Australian Government, Department of Health and Ageing (2012).
National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy.

Freely available from: <https://www.dss.gov.au/ageing-and-aged-care/older-people-their-families-and-carers/people-from-diverse-backgrounds/national-lesbian-gay-bisexual-transgender-and-intersex-lgbti-ageing-and-aged-care-strategy>

Australian Centre for Evidence Based Aged Care, La Trobe University (2014). **Sexuality Assessment Tool (SexAT) for Residential Aged Care Facilities.**

Freely available from: <http://www.dementiaresearch.org.au>



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