

Dementia, Intimacy and Sexuality

The Alzheimer Society of Canada's "Conversations" series was created to help people with dementia, caregivers, and healthcare providers have conversations about complex and sensitive topics related to living with dementia. This sheet provides information on how to address the intimacy and sexual needs of people with dementia and their partners as the dementia progresses. To read other issues in the Conversations series please visit www.alzheimer.ca/brochures.

People with dementia, caregivers and healthcare providers are encouraged to have conversations about all of the topics in this series early and throughout the progression of the disease. Even though talking about these topics can be difficult, it is only by having open conversations that it will be possible to be better prepared for the challenges that often come with the disease.

Dementia, intimacy and sexuality

All of us, including people with dementia, have needs and wishes for friendship, belonging, companionship, intimacy and the expression of our sexuality. These needs can be met in many ways, through a wide range of interactions with others including sharing of personal thoughts and feelings as well as handholding, hugging, kissing and more private forms of expression such as sexual touching, masturbation or intercourse.

Dementia is a brain disorder. Because the brain directs how we feel and act, dementia can change how the person expresses their wish for companionship and intimacy. Because of brain changes, the person with dementia may express their desire for intimacy in different or unusual ways. For example, the person with dementia may become more open about or interested in sexual activity, or experience the opposite by being less affectionate. Because of this, sexual behaviour may become more unpredictable and harder to understand as the dementia progresses. It is important for caregivers to understand that these changes in behaviour are common and that the person with dementia may not be aware that their behaviour has changed.

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In this sheet you will find information about dementia, intimacy and sexuality, including:

- An overview of how dementia may affect intimacy and sexuality
- Issues to consider when having conversations about intimacy and sexuality
- Tips and strategies for caregivers, people with dementia and healthcare providers on having conversations about intimacy and sexuality
- Strategies to help caregivers and healthcare providers understand and respond to changes in sexual behaviour
- Information for healthcare providers on how to help individuals with dementia and their partners maintain their intimacy in long-term care homes
- Information for healthcare providers on how to support lesbian, gay, bisexual, transgender or queer individuals with dementia
- A list of useful resources

Sexuality and intimacy are complex human needs that lead to emotional and moral reactions. We are often not comfortable talking about these reactions with others when we need to, or when they need to. It is important for the person with dementia and their partner to talk about issues related to sexuality, intimacy and sexual expression as soon as the diagnosis becomes evident and as the dementia progresses. By addressing worries and expectations openly, partners who wish to be intimate can continue to be so with mutual agreement and with an understanding that how they express intimacy may change as the dementia progresses. Often it is not a matter of ceasing sexual activity, but finding different ways of expressing intimacy. Talking with a trusted healthcare provider can help partners anticipate changes that may come as a result of the disease and consider strategies for them.

How does dementia affect intimacy and sexuality?

The changes in the brain caused by dementia may result in behavioural changes, including how the person expresses their need for intimacy. If the person with dementia is experiencing depression or taking new medications, this may also result in behavioural changes. Some of the changes that the person may experience include:

- **Reduced sexual energy and interest.** With treatment of depression, sexual interest often returns.
- Socially inappropriate behaviours, often referred to as **disinhibited behaviours**. Disinhibited behaviours tend to occur when people with dementia do not follow generally accepted social norms and act in ways that are considered inappropriate or in ways which their partner may find unusual, unexpected, or even distasteful. For example, the person with dementia may behave in ways they did not before, or in ways that others might consider embarrassing and inappropriate, such as flirting with strangers, graphically speaking about sex, or disrobing in front of others. The person with dementia may also engage in masturbation in public, rather than keeping this private. This is because the usual brain mechanisms that keep us from acting on our impulses may no longer be working.
- As the ability to remember sexual interactions decreases, a person's **desire for sexual intercourse can increase**. In rare instances, this increased need for sex is constant. This may create conflict in the relationship between the person with dementia and their partner or others around them.

Issues to consider when having conversations about intimacy and sexuality

Misinterpretation of behaviour as sexual

- Some people may interpret the behaviours of people with dementia as inappropriate sexual behaviour when the person may actually be trying to communicate a different need. For example, a man may remove his pants in public to indicate that he has to go to the bathroom. In some cases, touching the genital area can mean the person has a urinary tract infection. Similarly, attempts to kiss a new acquaintance could reflect loneliness, not a desire for sexual touching.
 - It is important that we do not assume the activity is a sexual one. Doing a thorough investigation of why the behaviour is occurring is critical if we are to address the person's needs and respond in the most helpful way possible.
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Changing needs of the person with dementia and their partner

- People with dementia can continue to have a healthy intimate life with their partner for many years. However, dementia can change the way people behave in their relationships. The changes in relationships and sexual needs of both the person with dementia and their partner can cause fear, confusion, anxiety, embarrassment and sadness.
- Some people can feel lonely and express this loneliness and isolation in sexual ways.
- Dementia can have an effect on the person's interest in sex which may conflict with a partner's needs. For example, people with dementia may masturbate in public, make explicit sexual comments and use graphic or crude language around others.
- Partners may feel guilty if they no longer want to be physically intimate with the person with dementia; they may not know how to respond to unwanted sexual behaviours. As partners take on more of a caregiving role, they may no longer have sexual feelings or the desire to continue a physically intimate relationship. As the needs of the person with dementia and their partner change, some couples may discover different ways of sharing closeness, comfort and intimacy.
- The partner may experience grief over the loss of simple acts of intimacy, such as sharing the day's events over dinner. This grief while the person with dementia is still alive, is often referred to as "ambiguous loss". To learn more visit www.alzheimer.ca/ambiguousloss

Seeking companionship with a new partner

- As the dementia progresses, the person may no longer recognize or remember their partner, and may seek companionship and physical intimacy with someone new. This may happen when the person with dementia is meeting new people in a day program or living in a retirement home or a long-term care home. If possible, staff should talk to the person with dementia and their new partner to ensure that they have both given consent to the new relationship. Family members and staff may find this upsetting and try to prevent the person with dementia from forming intimate relationships with someone other than their partner. Counselling and ongoing support should be offered, as adjusting to the change in relationship may be very emotional.
- Similarly, the partner may miss the intimacy that they shared with the person with dementia and seek to meet their needs outside this relationship. Partners may feel guilty for seeking intimacy outside the relationship and their friends and family may not support them on this decision. Healthcare providers can be helpful in supporting the partner to reflect on their feelings, and how to balance the needs of the person with dementia with their own.
- In some cases, a person with dementia may develop a new relationship with someone of the same gender, or the opposite gender, even if that was not their identified orientation in the past. Any of these instances can challenge personal values and beliefs and can create concerns about sexual safety (e.g. are appropriate measures being taken to avoid sexually transmitted diseases and infections?).

Having conversations about intimacy and sexuality

The needs for companionship and physical intimacy of a person with dementia and their partner should be addressed with respect and dignity for both parties. When the physical intimacy needs of the people in the relationship differ, it may take an open and honest discussion and creative thinking to find ways to meet each partner's needs. If the partner of the person with dementia is requesting sexual intimacy but, due to cognitive decline, the person with dementia is unable to provide consent, alternative ways of providing comfort should be explored (e.g. dancing or giving the person with dementia a foot or a back massage).

It is important that partners and healthcare providers understand that:

- Having dementia does not mean that the person is no longer interested in being physically intimate. Similarly, having dementia does not mean that the person's needs must be met or met in the same manner as was done in the past.
- As the dementia progresses, the person with dementia may no longer be able to recognize their partner and may explore a relationship with someone else. This can be very difficult for the partner and for other family members. If the person with dementia develops a relationship with a new partner, it is important to ensure that the person with dementia and the new partner both agree to the relationship and that this new relationship is sexually safe (e.g., appropriate measures should be taken to avoid sexually transmitted diseases/infections and consent should always be given).
- The person with dementia may behave in ways that their partner may find unusual, which could cause the partner to feel uncomfortable. As the dementia progresses, healthcare providers are encouraged to ask partners if they still feel comfortable engaging in sexual relations with the person with dementia. In addition, partners are encouraged to discuss any discomfort with a trusted healthcare provider.
- To reduce the influence that personal biases may be having on the care provided, healthcare providers are encouraged to learn about later-life and same-sex relationships. Their own feelings and attitudes toward sexuality, sexual orientation, sexual expression and later-life relationships can influence the care they provide.

Strategies for responding to inappropriate sexual behaviours

If the person with dementia's sexual energy is expressed in inappropriate ways or places, or directed towards non-consenting people, strategies may be adopted to address their needs in more appropriate ways. These may include:

- Trying behavioural approaches to redirect sexual expression and sexual tension to activities that will help the person focus on something else, such as inviting them to join a physical exercise program.
- Learning about the person's patterns of sexual expression and intimacy in order to understand their current behaviour. What are they trying to tell us about what they need?
- Learning about sexuality and aging, including sexual orientation. This will provide a better understanding of how aging and dementia may affect the need for companionship and sexual expression.

Some situations may require management with medications but this is typically considered as a last resort. If this strategy is considered, medication use should be re-evaluated regularly.

Conversations About --- Dementia, Intimacy and Sexuality

Helping people with dementia and their partners maintain their intimacy in long-term care homes

To help the person with dementia and their partner maintain their intimacy while the person with dementia lives in a long-term care home, staff and management can:

- Help them have privacy for sexual expression, such as providing them with a private room during their visit
- If safety is not a concern, provide overnight private accommodation for couples wishing to be alone
- If physical intimacy is not possible, encourage a variety of ways of demonstrating comfort, love and affection

Supporting a lesbian, gay, bisexual, trans or queer (LGBTQ) individual with dementia

Recognizing sexual orientation, gender identity and gender expression are important elements of respecting individuals and maintaining their highest possible quality of life. Persons who identify as LGBTQ may have difficulty expressing themselves, not only due to dementia but also as a result of prejudice and discrimination they may have experienced regarding their sexual orientation or gender identity. This issue is often magnified in residential settings where intimacy needs may already be disregarded or viewed negatively; in fact some LGBTQ individuals believe they must “return to the closet” upon admission to a long-term care home. As a healthcare provider supporting an LGBTQ person with dementia, you can make a difference in the comfort of the person with dementia in your care by:

- Examining your personal values and beliefs regarding sexual orientation, gender identity and gender expression to ensure that they are not negatively influencing the care you provide; look for resources to help with this if it is a new subject for you
- Treating the person as an individual and respecting their wishes
- Talking to the person about what pronoun they wish others to use when referring to them
- Learning about available LGBTQ resources in your community for the person with dementia and for their partner
- Using non-judgemental and inclusive language to make it clear that you want to provide the best possible person-centred care. This can help the person to feel safe expressing their gender identity or sexual orientation
- Respecting and supporting the person’s wishes if the person lives in a long-term care home and they do not want to disclose their sexual orientation with other residents or with staff broadly
- Speaking to colleagues and staff leaders about ongoing professional development opportunities to become more skilled in supporting people with dementia who identify as LGBTQ
- Using gender neutral language such as “partner” or “significant other,” when talking about a sexual or relationship partner
- Considering and affirming an individual’s “chosen family” (e.g. people who are not related by blood). Give them the same respect and privileges as you would to a spouse or someone’s “family of origin”

For more information on how to support LGBTQ older adults please visit www.the519.org/education-training/training-resources/our-resources/still-here-still-queer

Useful Resources:

It's time to end the taboo of sex and intimacy in care homes. An article from *'The Conversation Canada'* available at www.theconversation.com/its-time-to-end-the-taboo-of-sex-and-intimacy-in-care-homes-75740

Inclusive services for LGBTQ older adults: A practical guide to creating welcoming agencies
www.lgbtagingcenter.org/resources/pdfs/NRC_guidebook.pdf

Alzheimer Society



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