

Sex, intimacy and dementia



When someone lives with dementia, it may change their sexual relationship with their partner and the ways in which they are intimate with each other. This can be a difficult subject to discuss with your partner or other people, including professionals. You may feel embarrassed about talking about such personal matters, or disloyal to your partner for sharing any concerns. However, being open about how things are changing may help you continue to enjoy an intimate and/or sexual relationship despite a dementia diagnosis.

Types of intimacy

Intimacy can take many different forms and does not just relate to sexual activity. For some couples, intimacy is physical and includes sex, touching, a massage or cuddling. For others, it could be spending time relaxing with each other, sharing memories, taking part in hobbies and activities together – such as walking, socialising as a couple, visiting a coffee shop, going to the cinema – or simply laughing together.

It is important to keep an open mind about what intimacy means to you. This will help you adapt to the changes in how you and your partner share a sexual or intimate relationship.

If a person with dementia is involved in a sexual relationship, you may need to consider the use of contraception. This is particularly important if they or their partner are female (including those who identify as a different gender but were assigned female at birth) and are still of reproductive age. Barrier contraception like condoms will also offer protection against sexually transmitted diseases (STDs), especially if the person is intimately involved with a new partner.

Changing relationships

Some of the changes in sexual relationships and intimacy that may arise when a person has dementia include:



- one person having more interest in sexual activity than the other
- the person with dementia being unable to recognise and acknowledge previous and/or current relationships
- changes in the ways the person with dementia wants to be intimate with their partner
- the person with dementia transferring their affection to others
- the person having difficulty with feeling empathy, which can make it hard for them to understand how changes in sexual or intimate relationships might affect their partner
- the person losing their sexual inhibitions, eg making inappropriate sexual comments, gestures or advances towards people – even strangers

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Whether your partner has become more or less interested in sex and intimacy, it is important to try to find a balance that works for you both. You may need to explore different ways of being intimate, such as touching, a massage or a cuddle rather than full sex, and enjoying time together – for example, going on day trips, taking up a new hobby together, or watching a film.

If you are struggling to come to terms with the changes in your relationship, it may help to talk to someone you can trust. This could be a family member, friend or a health or social care professional.

You can also speak to one of our dementia specialist Admiral Nurses for support – please see Sources of support on p10.

Consent

It is very important that both partners consent to any sexual activity before it takes place, but as a person's dementia progresses, it may affect their ability to communicate their consent.

Consent can take many forms and may be non-verbal – for example, if the person living with dementia responds positively and with obvious enjoyment when their partner makes sexual advances, there is every reason to believe that they are consenting to sex. Or, if their responsiveness, enjoyment or willingness diminishes, this could be an indication that they do not consent to sex, and this should be respected.

It is equally important for the partner of a person living with dementia to consent to being intimate.

Consent is ongoing and can fluctuate. If the person living with dementia consents to sexual activity on one occasion, it does not necessarily mean that they will consent the next time, and vice versa.



Increased sexual desire

In some cases, dementia can heighten sexual desire – particularly in the case of frontotemporal dementia, which affects around one in 20 people with dementia. The person might, for example, become less inhibited and express their sexual interest more directly and forcefully – sometimes in inappropriate places, for example in public or in front of children.

This can be challenging, particularly if their partner does not want to participate in sexual activity or if they or others around them feel vulnerable, embarrassed or frightened.

It may be helpful to discuss strategies for managing the situation with a professional such as an Admiral Nurse. You can also read more in our leaflet on changes in sexual behaviour – see Sources of support on p10 for details. If you feel at risk, it is best to remove yourself from the situation and seek professional help – this may involve calling 999 for assistance.

Sexual and intimate relationships in care homes

Moving into a residential or nursing home does not have to mean the end of intimacy and sexual relationships. Care home staff should support residents in maintaining these relationships if both partners wish to engage.

If your partner is living in a care home, speak to the manager or their named key worker/carer about your need for private time together. The outcomes of these conversations can be included in the person's care and support plans.

You might want to discuss the person's:

- previous and current relationships
- sexual orientation
- understanding of sexual health
- personal dress preferences
- gender identity

Staff at the care facility have a duty to ensure that both partners have capacity and consent to any sexual activity. All care homes have a safeguarding policy that sets out measures to be taken around sex and consent. Some also have a relationships and sexuality policy that explains how intimate and sexual relationships can be managed.

New relationships in care homes

People with dementia living in residential care may form new sexual or intimate relationships with other residents. If both people have capacity and are consenting, their wishes should be respected.



Sometimes, a person with dementia forms a relationship in a care home when they already have a partner outside the home. This might happen if the person misses the intimacy they had with their partner at home, if they no longer recognise their partner, or if they believe the other resident is already their partner. These situations should be treated with sensitivity and respect for everyone involved, as they can be very distressing.

If your partner is pursuing a new relationship, it is natural to experience emotions such as anger, grief and a sense of betrayal. Other family members may also be affected, especially children or teenagers who may be confused or distressed about the behaviour of a parent with young onset dementia.

It is important to know that often, people in care homes seek a new relationship for comfort and company rather than sexual intimacy, and that these changes are the result of their dementia.

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It is vital that you have support in this difficult situation. This could be from care home staff, a family member or friend, a support group for family carers, or a health or social care professional. Your GP or social worker should be able to tell you about any groups or services in your area. You may also wish to seek counselling to help you with your emotions: you can speak to your GP to be referred or refer yourself (please see Sources of support on p11).

With support, some people can rebuild a relationship with their partner or come to terms with their changing behaviours and needs. You may, for example, be able to see the new relationship as a friendship rather than a romantic or intimate relationship and still enjoy time together yourselves, even if in a different way.

Any discussions about the person with dementia starting a new relationship should involve the person themselves, as far as possible, care home staff and family members. If the person no longer has the mental capacity to decide if starting a new relationship is appropriate, a 'best interests meeting' may be called to decide on the best way forward to ensure everyone involved is safe, consenting and treated with dignity and respect.

Please see Sources of support on p10 for our information on capacity and decision-making.

If there is a concern about a person's welfare or safety, it is important that this is reported to the care home, to a health or social care professional or, if necessary, to the police.

LGBTQ+ relationships

People in LGBTQ+ relationships may experience specific challenges if one of them lives with dementia. For example:

- The person with dementia may experience changes in their sexual or gender identity
- You or your partner may feel you need to disclose your sexuality to health and social care professionals – perhaps because you want to attend appointments together – when ordinarily, you might not have chosen to do so
- If the person has come out about their sexuality or gender identity, they may forget about this and become anxious about others 'finding out' – even if they already know
- They may come out about their sexuality or gender identity when they had previously chosen not to because of changes in their inhibitions, which could also affect their partner if they did not want to be open about it

You may also find it difficult to speak to family, friends and professionals about changes in your relationship – for instance, if you need support with issues around sex and intimacy and feel they do not understand.

Some people find it helpful to seek support from LGBTQ+ organisations and services, such as the LGBT Foundation and its Bring Dementia Out campaign. You can also contact Dementia UK's Consultant Admiral Nurse for the LGBTQ+ Community for specialist support – please see Sources of support on p10.

Sources of support

If you are caring for someone with dementia or living with the condition yourself, you can register for our free online sessions, 'Dementia: what next?' Hosted by dementia specialist Admiral Nurses, they cover topics like types of dementia, symptoms, financial and legal issues and planning for the future. Sign up at

Odementiauk.org/dementia-what-next

To speak to an Admiral Nurse on our free Helpline, call **o8oo 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email **> helpline@dementiauk.org**

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit **O dementiauk.org/book**

Dementia UK resources

Book an appointment with the Consultant Admiral Nurse for the LGBTQ+ Community
dementiauk.org/lgbtqappointment
Capacity and decision-making
dementiauk.org/capacity-decision-making
Changes in relationships and roles
dementiauk.org/changing-relationships-and-roles
Changes in sexual behaviour
dementiauk.org/changes-in-sexual-behaviour
Keeping safe when you care for someone with dementia
dementiauk.org/keeping-safe-when-you-care-for-someone-with-dementia



Looking after yourself as a carer
dementiauk.org/looking-after-yourself-when-you-care
When a person with dementia stops recognising you
dementiauk.org/when-someone-doesnt-recognise-you
Young onset dementia section
dementiauk.org/young-onset-dementia

Other resources

Find NHS relationship counselling

nhs.uk/service-search/other-health-services/relationshipcounselling

Find an NHS psychological therapies service (including information on self-referral)

• nhs.uk/service-search/mental-health/find-an-NHS-talkingtherapies-service

LGBT Foundation: Bring Dementia Out lgbt.foundation/bringdementiaout

Relate relationship counselling

relate.org.uk

To speak to a dementia specialist Admiral Nurse about any aspect of dementia:

Contact our Helpline: **0800 888 6678** or **> helpline@dementiauk.org**

> Book a virtual appointment: • dementiauk.org/book

Our charity relies entirely on donations to fund our life-changing work. If you would like to donate to help us support more families:

- Call **0300 365 5500**
- Visit O dementiauk.org/donate
- Scan the QR code

Thank you.





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