

Sex, intimacy and dementia



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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.

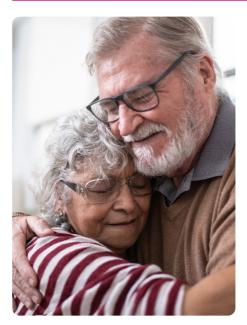
For some couples, intimacy is physical and includes sex, touching, a massage or cuddling. For others, it could be spending time relaxing with each other, sharing memories, taking part in hobbies and activities together – such as walking, visiting a coffee shop, or going to the cinema – or simply laughing 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.

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 to people – even strangers

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 friend or family member 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 p7.

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 have 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

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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.

This can be complex, particularly if their partner does not want to participate in sexual activity.

It may be helpful to discuss strategies for managing the situation with a professional such as a dementia specialist Admiral Nurse – see Sources of support on p7 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 doesn't 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 worker 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 because 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

LGBT+ relationships

People in LGBT+ relationships may experience specific challenges if one of them lives with dementia. For example, you may feel you need to 'come out' to health and social care professionals – perhaps because your partner wants to attend appointments with you – when you might not usually do so.

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 don't understand.

Some people find it helpful to seek support from LGBT+ organisations and services, such as the LGBT Foundation and its Bring Dementia Out campaign (see Sources of support on p7). You can also contact Dementia UK's Helpline or virtual clinics for non-judgemental support.

treated with sensitivity and respect for everyone involved, as they can be very distressing – in particular for you as their partner, but also for their children and other family members.

If your partner is pursuing a new relationship, it is natural to experience emotions such as anger, grief and a sense of betrayal. 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.

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 about this, or refer yourself by visiting nhs.uk/service-search/mental-health/find-a-psychological-therapies-service

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.

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 safe and appropriate, a 'Best Interests meeting' may be called to decide on the best way forward. Please see Sources of support on p7 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.

Sources of support

To speak to a dementia specialist Admiral Nurse about sex and intimacy or any other aspect of dementia, please call our Helpline on **o8oo 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email helpline@dementiauk.org

To book a phone or video call appointment with an Admiral Nurse, please visit **dementiauk.org/closer-to-home**

Dementia UK resources

Changes in relationships and roles dementiauk.org/changing-relationships-and-roles

Capacity and decision-making dementiauk.org/capacity-decision-making

When a person with dementia stops recognising you dementiauk.org/stops-recognising-you

Looking after yourself as a carer dementiauk.org/looking-afteryourself-when-you-care

Young onset dementia section dementiauk.org/young-onset-dementia

Changes in sexual behaviour dementiauk.org/changes-in-sexual-behaviour

Other resources

Find a relationship support group nhs.uk/Service-Search/ other-services/ Relationship%20counselling/ LocationSearch/400

Relate relationship counselling relate.org.uk

Find an NHS psychological therapies service (including information on self-referral) nhs.uk/service-search/mental-health/find-a-psychological-therapies-service

LGBT Foundation: Bring Dementia Out Igbt.foundation/ bringdementiaout The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support

Dementia UK, please visit dementiauk.org/donate or call 0300 365 5500.

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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email **helpline@dementiauk.org**

Open Monday-Friday, 9am-9pm Saturday and Sunday, 9am-5pm



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