

Sex and intimate relationships

Dementia causes many changes in people's lives. This includes changes to sex and intimate relationships (relationships that involve romantic and physical involvement). Often these changes can be difficult to discuss. This factsheet explains how dementia can affect the sexual feelings, desires and needs of people with dementia and their partners. It outlines some of the ways in which sexual behaviour can change and suggests some ways for partners to deal with these changes. It highlights some practical issues, and discusses forming new relationships and issues around consent.

Sex, intimacy and dementia

Intimate relationships can take many different forms and sex is not important for everyone. Over time, some partners develop forms of physical intimacy, such as touching, that might not be what they had previously thought of as 'sex'. Keep an open mind about what 'sex' and 'intimacy' mean for you and your partner and focus on all the pleasurable aspects of your relationship.

The onset of dementia does not have to signal the end of a healthy sex life. All relationships experience change over time. Many couples find that they can still be close through their sexual relationship even when other means of expression have diminished. Some couples even come to discover new and different ways of sharing closeness, comfort and intimacy.

Some people find that when they – or their partner – are diagnosed with dementia, this raises some questions about puzzling changes in their sex lives. Once dementia has been diagnosed, you can at least feel assured that these changes are not a reflection on either of you. You may also find it easier to understand what is happening.

For many couples coping with dementia, physical intimacy continues to be a rich source of mutual comfort, support and pleasure for many years. Where sexual difficulties do arise, it's important to remember that there is no single 'normal' way of dealing with this very personal issue. While it may be a difficult subject to discuss, you might find it helpful to talk to someone you trust. If you feel comfortable doing so, you may wish to talk to a good friend or family member. Alternatively, you could raise the issue in a carers' support group to see how others in a similar situation have dealt with their experiences.

Adapting to changes in the person with dementia

As the 'control centre' for behaviour and emotion, the brain is in charge of sexual feelings and inhibitions. Because dementia affects the brain, sexual feelings can change unpredictably for someone who has been diagnosed with dementia. Depending on which parts of the person's brain have been damaged and what medication they are taking, a person with dementia may experience any of the following:

- more interest in sex
- less interest, or no interest, in sex
- more or less ability to perform sexually
- changes in sexual 'manners' – for example, appearing less sensitive to the other person's needs or appearing sexually aggressive
- changes in levels of inhibitions – the person may do or say things that they would not have done previously.

Some couples feel able to adapt to these changes relatively easily. However, sometimes one or both partners may feel varying degrees of upset, loss, anger, embarrassment, anxiety or frustration at these changes.

Reduced sexual interest

Some people with dementia seem to lose interest in sex at an early stage, and can become quite withdrawn. This can also be true of their partners – see ‘Adapting to changes in partners’, below. They may enjoy or feel reassured by being stroked, hugged or cuddled, but no longer be able to initiate any affection themselves. Some people feel content if this side of their relationship ceases, as long as the closeness and affection continue in other ways. For example, where partners no longer share a bed, some people with dementia find it comforting to have something to cuddle, such as a soft toy or hot water bottle.

One person in a relationship may feel guilty if they become less interested in sex than their partner. It is important for the other person to respect that choice, and perhaps to find other ways to maintain their intimacy as a couple. It is equally important that they find an outlet for their own sexual frustration (see ‘Ways of coping with frustration’, below).

Increased sexual interest

Some people with dementia find that their desire for sex increases. Some partners find this a welcome change, while others feel unable to meet the level of sexual demand. Where this is the case, it can be difficult for the person with dementia. In this situation, some partners have said they feel wary of showing normal affection in case it is mistaken for a sexual advance. If the level of sexual demand feels overwhelming, it can be helpful to find something else to do together that can meet the other person’s need for intimacy, rather than making an outright refusal.

Some people with dementia may become aggressive if their sexual demands are not met. This behaviour is likely to stem from the person’s feelings and interpretation of the situation. A considerate

and sensitive approach towards turning down sexual demands may help prevent aggression. In the first instance, it is best to politely turn down sexual demands, and do so in a manner that acknowledges the person's sexual needs, is respectful and does not hurt their feelings. In some cases it may be a good idea to keep safely out of their way until the mood has passed.

Though this is often a difficult and sensitive topic to discuss, ask your GP or consultant for advice if this happens frequently, or if you have any concerns. Medication might be considered as a last resort. If you feel that you or another person is in danger then do not hesitate to seek help.

If the person is behaving in a way that distresses care workers when they are providing personal care – eg helping with washing – family members can become embarrassed and may feel they should stop employing outside help. It is important that families share these concerns with the care workers or with a care professional. They may be able to make suggestions about the person's individual likes, dislikes and preferences that can help when assisting them with their personal care.

Challenging sexual behaviour

Although for many couples sexual relations will carry on as normal, some people say that a partner with dementia can appear cold and detached during sex. Alternatively, the person might forget they have had sex immediately afterwards, or no longer appear to recognise their partner. These situations can be upsetting and painful for partners.

If the person mistakes someone else for their partner, try to approach the situation in a way that maintains their dignity as much as possible. Try not to make accusations or be offended by their behaviour but instead talk to them calmly in private. This reduces the potential for the person to feel embarrassed or distressed.

In rare cases, some people with dementia may go through a phase of being sexually aggressive – making repeated demands for sex from their partner or other people. In extreme cases, particularly when the person with dementia is physically strong, the level or threat of physical force may be difficult to manage. For some people this behaviour may be part of a long history of aggression – something that may be worsened by the dementia.

It is important to try to not take the person's behaviour personally. Remember that such behaviour is likely to be caused by difficulties and changed perceptions related to dementia. However, partners and carers must look after their own safety. If either partner finds themselves agreeing to sex when they would rather not, it is important to talk to their GP or consultant. The same applies if either partner feels that they are at risk of violence, aggression or verbal abuse. They can also phone Alzheimer's Society's National Dementia Helpline for confidential advice on 0300 222 11 22.

Changes in levels of inhibition

Dementia can reduce a person's inhibitions, which may mean they make public what were private thoughts, feelings and behaviours – including those relating to sex. Sometimes a person with dementia may appear to lose their inhibitions and make sexual advances to others or undress or touch themselves in public. They may also use language that you have never heard them use before or that seems very out of character.

These situations may be embarrassing for those close to the person. However, they may also be very confusing, distressing or frustrating for the person themselves – especially if they cannot understand why their behaviour is considered inappropriate. This kind of behaviour rarely involves sexual arousal. Sometimes what appears to be sexual is actually an indication of something quite different. For example, someone who is inappropriately underdressed may be too warm or may have simply forgotten to get dressed.

Other reasons for behaviour that may appear sexual include:

- needing to use the toilet
- discomfort caused by itchy or tight clothing or feeling too hot
- boredom or agitation
- expressing a need to be touched, or for affection
- misunderstanding other people's needs or behaviour
- mistaking someone for their current (or previous) partner.

Some people will want to protect the person with dementia from others laughing at them or from being shocked by their behaviour. They may ask certain people, such as their grandchildren, not to visit. If you think this is necessary, discuss it with another person first and review the decision later on as the situation may change over time.

Adapting to changes in partners

The partners of people with dementia describe a wide range of feelings about their continuing sexual relationships. These range from the pleasure of sex being something they can still share to confusion at being touched by someone who at times seems like a stranger.

As dementia progresses, the situation often changes, and so may the feelings of those involved.

- Partners' feelings may not change towards the person they are caring for at all. They may find that they can connect with their partner through sex even if they are finding it difficult to communicate in other ways.
- Some partners who are carers feel exhausted by their caring responsibilities and don't feel they have the energy to enjoy sex. This can be frustrating for their partner.

- Some partners find that the physically intimate tasks they have to perform for the person with dementia, such as bathing or helping them use the toilet, can put them off the idea of sex. This can make a person with dementia feel they have lost their dignity and may affect how they feel about themselves and their partner.
- Many people find it hard to enjoy a sexual relationship if many other aspects of the relationship have changed and little else is shared. This can make it feel like the sex has no meaning. If this is the case, it's important to give the partner with dementia plenty of reassurance and affection in whatever ways feel appropriate.
- Some people feel that the dementia can make their partners clumsy or inconsiderate. If this is the case, partners need to be proactive in finding new ways to be intimate together – whether or not this involves sex.
- Depending on how the dementia affects their relationship, some partners continue to sleep in the same bed as their partner. Others choose to move to single beds or separate rooms. If a partner does decide to move rooms, note that this can be disorienting or distressing for the person with dementia. It may be helpful to discuss such matters with your community nurse, support worker, GP or psychologist (if you have one). Practical issues, such as knowing when the person has got up in the night, may be helped by certain aids such as sensors (see factsheet 437, **Assistive technology – devices to help with everyday living**).

Ways of coping with frustration

In any relationship, problems can arise when one person expresses more interest in having sex than the other. This is a situation experienced by most people in long-term relationships – even when dementia is not involved. If this does happen, try to remember that it is normal, and look for realistic, practical solutions. Finding someone to talk to may also be helpful.

Single people also have sexual needs and may become frustrated when these are not met. This is perfectly normal and a person should not be judged for having such feelings. If you are arranging the personal or household care for someone who is living alone, you may want to talk regularly with the care worker to see if there is anything that they are finding difficult. For a variety of reasons the care worker may find inappropriate behaviour difficult to mention, but it is important to know about their experiences.

There are a number of ways to relieve pent-up sexual tension – for example, taking exercise and other energetic activities can help reduce the physical tension, as can masturbation. Sometimes, sexual desire can be confused with a need for closeness, touch, belonging, security, acceptance and warmth, or the need to feel special to another person. Some people find that if these other needs are met, their desire for sex is reduced. For example, close platonic friendships can help to meet some of the need for emotional intimacy, and therapies, such as massage and reflexology, involve physical contact and can be very relaxing.

Practicalities of sex in care homes

Living in a residential, nursing or shared home need not signal an end to your sex life. Talk to the manager or key worker about your need for private time together and discuss how that can be made available to you. Ask what training is available to staff about relationships, sexuality and sexual health.

Other questions you might want to ask include:

- Does the home have a sexuality policy?
 - What might happen if a resident shows affection or sexual feelings towards another resident or staff member?
 - If you have a same-sex relationship, will your wishes for privacy be treated with equal respect to those in a heterosexual relationship?
- Ask to see the home's equal opportunities policy. Every home should also have an anti-discrimination policy and you can ask for evidence as to whether it has been put into practice.

It is important that every resident is able to express their sexuality in a safe and tolerant environment. For specific information for lesbian, gay and bisexual people with dementia about choosing a care home see factsheet 482, **Moving into a care home: advice for lesbian, gay and bisexual people with dementia.**

Consenting to sexual relations

By law, both parties must always consent to sexual relations. A person consents if he or she agrees by choice and has the freedom and capacity to make that choice. When someone has dementia, it is sometimes unclear whether they have the 'mental capacity' to consent to sexual relations.

In England and Wales, the law says that people are able to make decisions for themselves if they are able to do all of the following:

- understand information that is given to them
- retain that information long enough to be able to make a decision
- weigh up the information available to make a decision
- communicate their decision by any possible means, such as talking, using sign language or even using simple movements such as blinking an eye or squeezing a hand.

Northern Ireland currently has different laws around capacity, although these are changing. For more information contact Alzheimer's Society's National Dementia Helpline on 0300 222 11 22.

In some instances, someone with dementia may seem to passively accept sexual advances without being very responsive. Some partners find this confusing, and may be left feeling guilty if it is not clear whether the person really wanted to have sex. Other people, however, find it normal to continue having sex as before. This situation can raise some complicated ethical as well as legal issues, such as whether or not the person with dementia has the mental capacity to consent to sexual relations.

If the person cannot express their wishes, it is important to learn to recognise non-verbal signs and to stop at any sign of reluctance. At other times, the person with dementia may be insensitive to the needs of the person they want to have sex with (see 'Challenging sexual behaviour' above), and it is the partner who needs to show that they do not consent.

Simply having a diagnosis of dementia does not mean that someone lacks the mental capacity to make their own decisions and to understand the implications of those decisions. Furthermore, capacity is always specific to a particular decision at a particular time. Someone may lack the capacity to make a decision about receiving a new medication, but this does not automatically mean they lack capacity to make a decision about wanting to have a bath. The ability of a person to understand the implications of a decision may also vary on different occasions. It is important to consider whether the person with dementia has the ability to recognise who the other person is, and most importantly, whether they have the ability to say no or to express their wishes in other ways.

For more information about mental capacity see factsheet 460, **Mental Capacity Act 2005**.

What to do in cases of suspected abuse

If you are concerned that you, your partner, or someone you know is at risk of any form of abuse, whether emotional or physical, it is important to share these concerns. Sexual abuse is a criminal offence, and in cases of abuse the local authority or police may need to intervene. While some cases of sexual abuse can involve a degree of violence or force, it can also take the form of making a person watch or participate in activities, such as watching pornography. Talk to a professional such as your GP or a community nurse if you are concerned. Initially, you may find it helpful to talk in confidence to Alzheimer's Society's National Dementia Helpline or Action on Elder Abuse (see 'Other useful organisations').

If you do decide to talk to professionals about information concerning the sex life of someone with dementia or their partner, you must respect the dignity and privacy of both parties. The professionals involved need to consider whether both parties are:

- comfortable in the relationship
- not being exploited or being taken advantage of
- acting in a way that is in keeping with their values
- willing and able to consent to the relationship.

Forming new relationships

A person with dementia is still capable of forming new and intimate relationships. Family, and especially the children of people with dementia, can often feel uncomfortable in recognising that the person may still have sexual needs. They may also find it difficult if the person finds a new partner who appears to be taking the place of a parent who has died. However, if the person wants to pursue the relationship and is not at any risk of harm as a result, family and friends should try not to interfere.

As long as the person with dementia has the mental capacity to make decisions about their life (see 'Consenting to sexual relations', above), then it is important to respect this.

Difficulties can arise. For example, it may appear that the person with dementia is being exploited or 'groomed' so people can take advantage of them. This can occur in residential settings or when the person is living in the community. For example, the person may build up a relationship with someone who is trying to make them part with their money.

Sometimes relationships break down between people with dementia and their partners. Some partners will opt to continue caring for a

person even if their relationship has ended. This situation may be relatively simple for people to accept, or it may lead to conflict and distress for both parties, and for their families. It's important that both parties seek support and have an opportunity to talk about what they are feeling. You may wish to contact Alzheimer's Society's National Dementia Helpline or Relate, a voluntary group that offers confidential relationship counselling and advice (see 'Other useful organisations' for details). Alternatively, your GP surgery may offer a counselling service.

Forming new relationships in care homes

People with dementia in care homes may form new sexual relationships with other care home residents. As long as both parties agree and have capacity to consent to these relationships, then care home staff should respect such relationships.

It may be difficult for staff to balance residents' needs for privacy against their need to be cared for and looked after. For example, a person may need assistance washing and bathing directly following sex. Staff should also respect the confidentiality of relationships between residents and do not have to disclose information to relatives and other parties.

Maintaining a healthy relationship

Living with dementia can put a strain on relationships, both for the person with dementia and for their partner, particularly if they are in the early stages of dementia. However, there is plenty you can do to maintain a positive relationship. Spending time apart socialising, or keeping up with satisfying or creative pursuits can boost each partner's self-esteem and give them something to share with the other. Taking part in activities as a couple or a family unit can also help people focus on the positive aspects of the relationship. Such examples could include putting together photo albums, joining a local group, or going on day trips.

It is also important that you both have plenty of support to help you adjust to any changes. If you are worried or upset by something, discussing your feelings and concerns with someone who understands can often help.

Consider talking your feelings through with:

- friends and family – choose to talk to someone who you feel might understand
- your GP, social worker or community nurse – they may be able to explain why the dementia is causing particular changes to you or your partner
- a counsellor or therapist – you and your partner may be eligible for referral through your GP, or contact the British Association for Counselling and Psychotherapy (see ‘Other useful organisations’, below). See also factsheet 445, **Talking therapies (including counselling, psychotherapy and CBT)**.
- a helpline adviser – Alzheimer’s Society’s National Dementia Helpline (0300 222 11 22) can provide information and advice as well as pointing you towards other organisations that could help. The helpline advisers offer support to all people with dementia and carers, including lesbian, gay, bisexual or transgender (LGBT) people
- a carers’ support group – if you are the carer of someone with dementia, you may find it helpful to discuss how you feel with other carers, who may well be experiencing similar emotions. In some areas, carers’ centres also offer opportunities to talk to someone in private. Details of local groups are available from Alzheimer’s Society’s National Dementia Helpline (see the end of this factsheet for details).

Sexual health

Some health problems and medications can affect sexual pleasure and performance. If either partner has joint pain or arthritis, their local

physiotherapy department should be able to suggest ways to make sex more comfortable. If either partner has recently had an operation or had a heart attack, take the consultant's advice before having sex. They may advise to wait until after they have discharged or 'signed off' the patient. This is usually about eight weeks after treatment.

People of all ages who are sexually active are at risk of sexually transmitted infections (STIs), and STIs in older people are increasing. Any sign of unusual discharge, itchiness, discomfort, or any blisters, sores, spots or lumps around the genitals or anus should be checked with your GP. Many people with STIs do not have symptoms. If you've had unprotected sex but feel healthy it is still important to get tested. It is also important to remember the need for good hygiene to avoid the risk of infection for both partners.

Anyone starting a new relationship, or people in a long-term relationship who haven't already done so, should have a discussion about safe sex. Speak to your GP in confidence, or alternatively seek information and advice on safe sex from health centres and websites such as NHS Choices.

Other useful organisations

Action on Elder Abuse

PO Box 60001
Streatham SW16 9BY

T 0808 808 8141 (UK helpline)
E enquiries@elderabuse.org.uk
W www.elderabuse.org.uk

Charity that works across the UK to protect, and prevent the abuse of, vulnerable older adults.

British Association for Counselling and Psychotherapy (BACP)

BACP House
15 St John's Business Park
Lutterworth
Leicestershire LE17 4HB

T 01455 883300
E bacp@bacp.co.uk
W www.bacp.co.uk

Organisation working to promote counselling and psychotherapy. Provides information about different types of therapy and contact details of local counsellors and therapists.

Relate

Premier House
Carolina Court
Doncaster DN4 5RA

T 0300 100 1234E enquiries@relate.org.uk
W www.relate.org.uk

Offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face-to-face, by phone and through its website.

Stonewall

Tower Building
York Road
London SE1 7NX

T 08000 502020
E info@stonewall.org.uk
W www.stonewall.org.uk

A charity offering information on lesbian, gay and bisexual issues.

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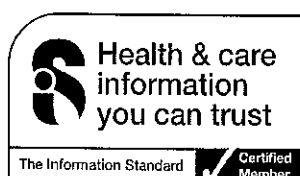
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This factsheet has also been reviewed
by people affected by dementia.

A list of sources is available on
request.



Alzheimer's Society National
Dementia Helpline

England, Wales and Northern Ireland:
0300 222 11 22

9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

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leading support and research charity
for people with dementia, their
families and carers.

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