# Sex, intimacy and dementia





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## 1 Sex, intimacy and dementia

When a person is living with dementia, their sexual behaviour, needs and desires may change. If you are the partner of someone with dementia, you may find these changes hard to accept. However, many partners still enjoy sex and intimacy in their relationship.

How you express affection for each other may change. Some people discover new and different ways of sharing closeness, comfort and intimacy after a diagnosis of dementia. Relationships can be intimate in different ways. What you and your partner consider as 'sex' may change and become either more or less important to you. You may find new ways of being physically intimate over time. If your partner has dementia, it can be helpful to keep an open mind about what 'sex' and 'intimacy' mean for you both.

Some partners find that a diagnosis of dementia can explain changes they have been experiencing in their sex lives. Some types of dementia, especially frontotemporal dementia (FTD), can affect a person's inhibitions, their sexual behaviour and their attitude towards sex. A person with this type of dementia may, for example, express their sexual interest more directly or openly. FTD may also impair a person's ability to feel empathy, which can affect both partner's sense of intimacy. Some people find a diagnosis of dementia reassuring as it explains the changes that they have been experiencing in their sexual or intimate relationships.

For many people living with dementia, physical intimacy continues to be a source of comfort, support and pleasure for many years. However, some people may experience sexual difficulties. There is no single 'normal' way of dealing with these. It can be a difficult subject to discuss, but you might find it helpful to talk to someone you trust, such as a good friend or family member.

You could also raise the issue in a carers' support group to hear how others in a similar situation have dealt with their experiences. Our online community can be a good source of information and support. For more information go to our **Dementia Support**Forum at forum.alzheimers.org.uk

#### 2 Sex and health

Sexual health is an important part of a healthy sex life. There are many health benefits to having sex, such as lower stress levels, improved self-esteem and positive emotional bonding with your partner. People of all ages who are sexually active are at risk of sexually transmitted infections (STIs). Many people with STIs do not have any visible symptoms. Good hygiene and using barrier protection (such as condoms) can help to avoid the risk of infection for both partners during sex.

If you and your partner are in a new relationship, or in a long-term relationship but haven't had a discussion about safe sex, then it is a good idea to talk about it. You can speak to your GP, or you can find information and advice on safe sex from health centres and the NHS website.

Some health problems and medications can affect sex in other ways. For example, joint pain or arthritis can make sexual activity difficult or painful. A physiotherapist may be able to suggest ways to make things more comfortable. Sexual activity may also not be advised for a person who has had a recent operation, or a heart attack or other health issue. Their consultant will be able to give advice on this, and may suggest waiting a certain amount of time after treatment before having sex.

### 3 Consent and capacity

Giving consent (or 'consenting') means giving permission for something to happen. By law, everybody involved in sexual activity must give consent, and this consent can be withdrawn at any time. A person consents if they:

- agree by choice
- have the freedom and mental capacity to make that choice.

When a person has dementia, it can sometimes be unclear whether they have the ability, or 'mental capacity', to engage in sexual activities. This can be a difficult area for partners of people with dementia to navigate.

In England and Wales, the Mental Capacity Act 2005 says that a person is able to make a decision for themselves if they are able to do all of the following:

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

If they are not able to do one or more of these due to an 'impairment or disturbance in the functioning of the mind or brain' – for example, dementia – then they would lack capacity to make that decision at that time.

A person can have the capacity to make some decisions and not others. Some decisions require them to understand more complex information, or weigh up more options than others. For example, a person may have the capacity to consent to what they want to wear or eat, but not have the capacity to engage in sex. The law in England and Wales about capacity to engage in sex is complex, and developing all the time. It is still being debated which information is relevant to this decision and, as a result, what needs to be understood by the person. This may also be looked at slightly differently depending on whether it is a criminal or civil court that is making the decision.

A diagnosis of dementia does not mean that someone automatically lacks mental capacity. Mental capacity can also change over time. For example, a person with dementia might be able to think more clearly on some days, or at certain times of the day, than others. This means that a person may have capacity to engage in sex at some times and lack it at others.

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

#### Giving and communicating consent

There may be times when a person with dementia seems to accept sexual advances without being very responsive. You may feel confused about whether the person is consenting to sex or not. Afterwards, you may feel guilty about whether they really wanted to have sex if they did not give you clear consent. This situation raises some complicated ethical and legal issues. If you have been with your partner for some time, you may know what the person's usual behaviour would be, and be able to recognise if they act differently or seem uncomfortable.

A person with dementia who cannot express their wishes verbally, may consent to sexual activity through non-verbal signs. Physical arousal alone is not consent. As their partner, you should feel confident that you can recognise non-verbal consent before you start any sexual activity. You should never initiate sexual activity without clear consent. You must stop at any sign of reluctance.

Both partners must consent to sexual activity. Sometimes a person with dementia may be unaware of your needs, and it is you who does not consent. Nobody should be forced into any sexual or intimate activity that they are not comfortable with. See 'Challenging sexual behaviour' on page 13 for more advice.

## 4 How dementia can affect a person's sexual behaviour

The brain controls all our behaviour and emotions, including our sexual feelings and inhibitions. This means a person may have more or less sexual feelings than usual, and may do or say inappropriate things as a result. Because dementia affects the brain, the sexual desires and feelings of a person with dementia can change unpredictably.

Depending on which parts of the person's brain are affected and what medication they are taking, a person with dementia may experience any of the following changes:

- more, less, or no interest in sex
- more, less, or no ability to perform sexually
- changes in sexual responses for example, appearing less sensitive to the needs of their partner
- changes in levels of inhibitions the person may do or say things that are out of character and which may be inappropriate
- becoming sexually aggressive see 'Challenging sexual behaviour' on page 13 for more information on this.

If your partner experiences one or more of these symptoms, you may feel able to adapt relatively easily. However, it is common for one or both partners to feel a sense of loss, anger, embarrassment, frustration or anxiety about these changes. These are normal reactions, so try not to feel guilty about this.

For more on how these changes can affect you, see 'How these changes can affect you' on page 8. For more on coping with these changes see 'Coping with changes to your sex life' on page 10.

#### Reduced sexual interest

Some people with dementia lose interest in sex – something that can happen at any stage of the condition. If your partner has lost interest in sex, you might feel frustrated, but it is important to respect their reduced interest. You could look at other ways for you both to be intimate together. For example, your partner may still enjoy being stroked, hugged or kissed, even if they are no longer able to initiate affection themselves. If you miss the intimacy of sex, these expressions of affection can continue this feeling of intimacy between you.

You might find it helpful to discuss the emotions you may be feeling – such as frustration, anger and loss – with a family member, friend, or counsellor. See 'How these changes can affect you' on page 8 for more.

#### Increased sexual interest

Sometimes a person with dementia will have an increased interest in sex. For some partners, this may be a positive change. Sometimes, however, partners feel unable to adapt to an increased desire for sex, which can be difficult for both people in the relationship. Some partners have said that they feel wary of showing any affection at all, in case it is mistaken for a sexual advance by their partner with dementia.

Repeated demands for sex can be a person's way of expressing that they need intimacy, and not that they necessarily want sex. If your partner's level of sexual interest starts to feel overwhelming, it can help to talk to someone outside of the relationship. It could be helpful to find something else that might meet their need for intimacy. This could either be something that your partner does alone such as masturbation, or something that you could do together such as kissing, touching or other forms of physical intimacy.

When you turn down requests for sex, try and do so in a way that acknowledges the person's sexual needs. They may feel embarrassed or rejected. Some people with dementia may become aggressive if turned down for sex – see 'Challenging sexual behaviour' on page 13 for more information on coping with this.

Ask your GP or consultant for advice if you find that your partner becomes aggressive, or if you have any concerns. They may be able to suggest ways for the person with dementia to meet their needs in a way which doesn't impact on your wellbeing. This could include masturbation as well as non-sexual activities which might help meet the person's need for intimacy or social interaction, such as activity groups. They may recommend medication to reduce aggression, if they feel this is appropriate.

Most importantly, remember you do not have to do anything you do not feel comfortable and happy doing. If you feel that you or another person is in danger then seek help straightaway. This might include calling the police.

## 5 How these changes can affect you

If you are the main carer for your partner, your role as a carer and the changes in the person's behaviour can affect your desire for sex and your feelings. Partners of people with dementia describe a wide range of feelings about their sexual relationships. Some people find that they and their partner still enjoy sex. Others describe feeling a sense of confusion at being touched by someone who, at times, can seem like a stranger.

Many people who provide personal care for their partner with dementia can find it awkward to do this as well as being the person's sexual partner. You may find that you feel different emotions at different times, particularly as the person with dementia's condition progresses.

You might relate to any of the following experiences:

- Your feelings may not change towards your partner at all.
   You can connect with your partner through sexual activities even if they are finding it difficult to communicate in other ways.
- You feel exhausted by your caring responsibilities and lack the energy to enjoy sex. This can be frustrating for both you and your partner.
- Helping your partner with physically intimate tasks, such as bathing or helping use the toilet, can put you off the idea of sex. This can feel isolating for you both, and you may feel guilty about how you feel about your partner.
- If many aspects of your relationship besides sex have changed, you might find it hard to enjoy a sexual relationship. You may feel that the sex doesn't have as much emotional meaning.
- Having sex is difficult as your partner with dementia may not be as considerate or responsive as they used to be.
   If this is the case, looking at new ways to be intimate can be helpful, and you might find that other forms of intimacy or sexual activity could be more fulfilling.
- If your partner develops an increased appetite for sex, or you don't feel like having sex, you might frequently have to turn down sexual requests and you may feel a sense of guilt.

Dementia affects people in different ways, and everybody is different. However, it can still help to get support and advice, and talk about how you are feeling. You could talk to:

- friends and family if possible, talk to someone who you feel close to and might understand
- your GP, social worker or community nurse they may be able to explain why dementia is causing particular changes to you or your partner
- a counsellor or therapist you and your partner may be referred through your GP, or contact the British Association for Counselling and Psychotherapy (see 'Other useful organisations', on page 19). See factsheet 444, Supporting a person with dementia who has depression, anxiety or apathy
- a support line or helpline adviser you can call us on 0333 150 3456 for information and advice, as well as information on other organisations that could help
- a carers' support group you may find it helpful to discuss how you feel with other carers, who may be experiencing similar emotions. In some areas, carers' centres also offer opportunities to talk to someone in private. Search for a group near you at alzheimers.org.uk/dementiadirectory
- online support groups our online community is for carers and people with dementia to share their feelings and experiences with people who understand. To find out more, go to our **Dementia Support Forum** at **forum.alzheimers.org.uk**

## 6 Coping with changes to your sex life

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

You or your partner may become frustrated if their sexual needs are not met, especially if one of you is more interested in sex than the other. This is normal, and there are things you can do to make it easier.

There are a number of ways to relieve pent-up sexual tension – for example, masturbation. Exercise and other energetic activities may also help reduce any physical tension.

Sexual intimacy can meet needs for closeness, touch, belonging, security, acceptance and warmth, or the need to feel special to another person. if some of these other needs can be met in other ways, a person's desire for sex may be reduced. For example, close non-sexual friendships can help to meet some of the need for emotional intimacy.

Therapies, such as massage and reflexology, which involve physical contact, can be very relaxing. If you and your partner are finding that you are unable to have sex or be intimate, it could be useful to look at other activities which could help reduce any frustration you both may be feeling.

## 7 Maintaining your relationship

Dementia can put a strain on your relationship. However, there are things you can do to maintain a positive relationship with your partner. Spending time apart, socialising with other people, or keeping up with your own hobbies can boost self-esteem for both of you and give you both something to talk about with each other. Doing things together as a couple, as a family or with friends, can also help you to focus on the positive parts of your relationship.

Depending on how your partner's dementia affects your relationship, you may decide to move to single beds or separate rooms. This can feel sad or be distressing and challenging for you both if you have always slept in the same bed, and your partner may find it disorientating. It can help, if either of you feels lonely in this situation, to take an item of the other's clothing or other personal item to hold in bed. It may be helpful to discuss how to manage with your community nurse, support worker or GP.

Practical issues around sleeping in separate beds, such as knowing when your partner gets up in the night, may be helped by technology such as pressure sensors that turn on lights. For more information see factsheet 437, **Using technology to help with everyday life**.

Sometimes relationships change between people with dementia and their partners. Some people will choose to continue caring for a person with dementia, even if their intimate or loving relationship has ended. Others decide it would be better to find alternative care arrangements for their partner.

Everybody is different, and it can be hard to come to a decision about what is best for you and your partner. This can be especially hard if you each have different views. It's important that both of you have support and an opportunity to talk about what you are feeling. Couple's counselling can be helpful for this. You can contact Relate, a voluntary group that offers confidential relationship counselling and advice (see 'Other useful organisations' on page 19 for details). Alternatively, your GP surgery may offer a counselling service, or you can call us on **0333 150 3456** for information and advice.

## If your relationship was difficult before dementia

Not all relationships are easy. Your relationship with your partner may have been difficult before they developed dementia. You may have negative feelings from the past which affect how you feel now. Your relationship may even have been abusive at times.

If you've had a difficult relationship with the person in the past and want to improve it now, try to get help to develop a healthy and safe relationship with them. If your relationship has been abusive or has become abusive, or you don't feel safe, it's important to tell someone you trust as soon as possible.

If you have caring responsibilities for the person, it should be your decision whether to continue and you should not feel that it's something you have to do, especially if you feel uncomfortable or unsafe. Talk about these issues with someone, for example your GP, social services or a counsellor. See 'Other useful organisations' on page 19 for details.

## 8 Challenging sexual behaviour

Dementia can cause a person to behave in a way that people around them may find challenging. The person with dementia may also find these behaviours challenging. This can include changes to sexual behaviour, including behaving in a 'sexual' way at inappropriate times. These situations can be difficult to understand or deal with, particularly if the person is your partner.

#### Responses to sex

Some people with dementia will respond as they always have during sex. However, some partners say that a person with dementia can appear cold and detached. Others say that their partner forgets that they have had sex immediately afterwards, or no longer appears to recognise them as their partner. These situations can be upsetting and confusing both for the person with dementia and their partner.

For more on coping with these changes, see 'How these changes can affect you' on page 8.

#### Inappropriate behaviour

Your partner may sometimes behave in inappropriate ways towards other people. They may act in a sexual way that distresses care workers when they are providing personal care – for example, when they are helping with washing. The person with dementia might say or do things that are inappropriate. This can cause embarrassment and you might even feel you should stop employing outside help.

The person with dementia might also act in a sexual way around, or towards, children or other vulnerable people. If this happens, you will need to take steps to protect them – for example, stopping unsupervised time between the person with dementia and their grandchildren. Even though you might feel uncomfortable or guilty about this, remember that it's necessary.

It is important that you share any of these concerns with other family members, with the care workers themselves or other health or social care professionals. They may be able to prevent this from happening or suggest how to minimise the impact when it does – for instance by looking at distraction techniques based on your partner's individual likes, dislikes and preferences.

You might also find it helpful to look at factsheet 515, **Supporting children and young people when a person has dementia** to explain changes in the person's behaviour to the children involved.

#### Mistaking a person for someone else

Dementia can cause changes to a person's perception of situations, people and things. As a result, the person with dementia may mistake people (even those who are very close to them) for others, which can be distressing for everyone involved. If your partner mistakes someone else for you, and behaves sexually or affectionately towards them, it is natural that you will feel upset.

Try to approach the situation in a way that maintains the dignity of the person with dementia as much as possible. Although it might be difficult, try not to take your partner's behaviour personally. Remember that this behaviour is likely to be caused by difficulties and changed perceptions caused by dementia. Try not to make accusations or be offended, and instead talk to them calmly in private. This should help the person not to feel embarrassed or distressed.

#### Aggressive behaviour

In rare cases, some people with dementia may go through a phase of being sexually aggressive – for example, making repeated demands for sex from their partner or other people. If this happens, you might find it helpful to remove yourself or others from the situation until they calm down. It can be useful to ask any care workers if they have also noticed any inappropriate behaviour.

If the level or threat of physical force is difficult to manage, it is important that you still feel safe. If you do not feel safe, it is best to remove yourself from the situation and seek help.

There are professionals and organisations who can support you, for example the non-emergency police line on 101, the Samaritans or Refuge (see 'Other useful organisations' on page 19). If you feel that there is an immediate risk of violence to yourself or others then you should call the police by dialling 999. You may feel uncomfortable or guilty about doing this, however it is very important that you and others are safe.

#### Sexual behaviour in public

Dementia can affect a person's inhibitions, which may mean they express private thoughts, feelings and behaviours – including those related to sex – publicly. These thoughts, feelings and behaviours may be out of character. Sometimes a person with dementia may 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.

These situations can be very confusing, distressing, shocking or frustrating for someone with dementia, as well as for those close to them. The person with dementia may not understand why their behaviour is considered inappropriate. They may:

- feel they are just expressing a need for affection
- be misinterpreting other people's behaviour, and think that they are reacting appropriately
- have mistaken someone for their current or previous partner and be behaving as they normally would towards them.

If your partner behaves in a way which could be seen as sexual in public, you may feel embarrassed or upset. You might feel that you want to protect them from other peoples' responses to the behaviour – for example, if people are laughing or are shocked. It can help to quietly explain to others why the person with dementia is behaving in that way, for example, you could show a helpcard which explains the person's diagnosis.

It can help to realise that behaviour that appears sexual doesn't always indicate sexual desire. Instead, the person might be feeling or trying to indicate something different. If you can understand why someone is behaving in a certain way, it might be easy to understand their behaviour.

- Someone who begins taking their clothes off in public may be too hot and trying to cool down. Or they might be uncomfortable – for example, if their clothes are itchy or tight – and be trying to undress, while not realising that this isn't appropriate in a public place.
- Someone might also touch their genitals because they need to use the toilet.
- They may be agitated or bored.

#### 9 Care homes

Living in a residential, nursing or shared home does not mean people cannot continue to have sexual relationships and be intimate, if they want. If your partner is living in residential care, talk to the manager or key worker about your need for private time with your partner. You can discuss how that can be made available to you, and 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 is the home's view on consent and capacity? Do they monitor mental capacity in residents who are sexually active?
- Does the home provide any advice, information or support for the residents about sex?
- How do they ensure the safety of their residents in terms of sexual activity? What is their safeguarding procedure?
- What might happen if a resident shows affection or sexual feelings towards another resident or staff member?
- What steps does the home take to ensure privacy and respect for the people involved?
- If you are in 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 that it has been put into practice. It is important that every resident feels able to express their sexuality.

It may be difficult for staff to make sure residents have the privacy they need with their relationships as well as making sure that they are properly cared for and looked after. For example, a person may need assistance washing and bathing after sex. Staff should always respect the confidentiality of relationships.

For more information see booklet 476 Care homes – when is the right time and who decides?

### 10 New relationships

People with dementia who live in residential care may form new sexual relationships with other care home residents. Between consenting adults, relationships can provide joy, comfort and partnership for people with dementia. The care home staff should respect this. The care home staff have a duty to ensure that both partners have capacity and are both willingly consenting to any sexual relationship.

There may come a time when you no longer see the person with dementia as your partner. For example, your relationship may have changed and you may have needs that your partner no longer fulfils. You may feel guilty for ending the relationship with your partner, or for starting a new relationship. It is important to remember that everyone's circumstances are unique and there is no single 'right' way to deal with the situation.

A person with dementia may also want to have a sexual or romantic relationship with someone new while they are in residential care. Family members, including children, may feel uncomfortable recognising that the person with dementia still has sexual needs. They may also find it difficult to accept the situation if they feel that the person is 'replacing' a partner. However, if the person has capacity, wants to pursue the relationship and is not at any risk of harm, family and friends should try not to intervene.

Sometimes a person forms a relationship in a care home when they already have a partner outside the home. These situations can be very distressing, and should always be handled sensitively and with consideration and respect for everyone involved. Sometimes these relationships happen because the person misses the affection they had with their partner at home. Other times this can be a case of mistaken identity, where a person believes that another resident is their current partner. It can be difficult to know how to approach this situation if it happens. Everybody and every situation will be different so any decisions should be made based on the person's individual circumstances.

If a person does have a new relationship while in residential care, there may be concerns that the person is being exploited or taken advantage of. As long as the person with dementia has the mental capacity to make decisions about this relationship (see 'Consent and capacity', on page 3), and wants to pursue the relationship, then this relationship should be respected.

However, 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.

## 11 What to do if you suspect abuse

If you are worried that you, your partner or someone you know is at risk of abuse, it is important to share these concerns. Abuse can be physical, emotional, financial or sexual. Many types of abuse are a criminal offence and, in cases of abuse, the local authority or police may need to intervene.

Abuse may not always be obvious, especially if it is not physical. For example, sexual abuse may involve violence or force, but making a person watch or participate in activities such as watching pornography is also abuse. If you are unsure whether or not something is 'abuse', consider whether everybody involved:

- has the mental capacity to be able to consent
- is not being exploited or being taken advantage of
- feels comfortable in the relationship
- is acting in a way that is in keeping with their values.

Talk to a friend or family member, or to a professional such as a GP, a social worker, or a care home manager if you are concerned. You may also find it helpful to talk to us on **0333 150 3456** or Action on Elder Abuse (see 'Other useful organisations' on page 19). If you do decide to talk to professionals, it is important to respect the dignity and privacy of everybody who is involved.

### Other useful organisations

## British Association for Counselling and Psychotherapy (BACP) 01455 883300 bacp@bacp.co.uk www.bacp.co.uk

BACP works to promote counselling and psychotherapy. It provides information about different types of therapy and contact details of local counsellors and therapists.

#### Hourglass 0808 808 8141 (helpline, 9am-5pm Monday-Friday) enquiries@wearehourglass.org www.wearehourglass.org

Hourglass is the working name of Action on Elder Abuse, and works across the UK to protect, and prevent the abuse of vulnerable older adults.

#### NHS www.nhs.uk

The NHS website provides information about NHS services in England to enable people to make choices about care and treatment.

#### Refuge 0808 2000 247 (helpline, 24 hour every day) helpline@refuge.org.uk www.refuge.org.uk

Refuge is a charity that supports victims of violence and abuse, including sexual violence.

### Relate www.relate.org.uk

Relate offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face-to-face, by phone and through its website. (For Relate in Northern Ireland visit www.relateni.org or call 028 9032 3454.)

#### Samaritans 116 123 (helpline, 24 hour every day) www.samaritans.org

Samaritans provide a helpline for people to talk about any problems they are having with a trained advisor.

Switchboard 0300 330 0630 (10am-10pm every day) www.switchboard.lgbt

Switchboard is a charity which supports LGBTQ+ people. It has information and advice on a range of issues.



Factsheet 514

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

To give feedback on this factsheet, or for a list of sources, please email **publications@alzheimers.org.uk** 

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We have more information on **Living** with dementia.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk** 

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