Sex and dementia

Carers' advice sheet 514

Dementia causes many changes in people’s lives as time passes. One area in which there are often changes, but which is seldom discussed, is that of intimate relationships. 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 many ways in which sexual behaviour can change and suggests some ways for those with partners to adapt so that relationships remain loving and close.

However much we hear about sex in the media, the reality is that it is not important for everyone. However, everyone is a sexual being, regardless of their age, ability or sexual preference, and has the right to express their sexuality without fear of disapproval. This is no less the case for people with dementia.

Redefining sexual intimacy

Intimate relationships come in many different shapes and sizes. Over time, some partners develop forms of physical intimacy that do not correspond with what they had previously thought of as ‘sex’. By keeping an open mind about what ‘sex’ and ‘intimacy’ mean for you and your partner, you will be better able to focus on the pleasurable aspects of your relationship and less worried by the rest.

The onset of dementia certainly doesn't have to mean the end of a happy sex life. It can lead to some big changes, but then all relationships change over time. Many couples find that they can still be close through their sexual relationship even when other means of expression have diminished, while others find that they come to discover other forms of closeness, comfort and intimacy.

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

For both partners, feelings of guilt, despair, resentment, anger, worry and fear for the future can interfere with their ability to sustain a close intimate relationship, so good communication is vital. Sharing feelings and thoughts is a far more positive response to stress than nursing anxieties and grievances.

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, and that whatever you are going through, other people around the country will have
experienced something similar.

**Adapting to changes in the person with dementia**

As the ‘control centre’ for behaviour and emotion, the brain determines sexual feelings, good manners and inhibitions. This means that in a person with dementia, sexual feelings can change unpredictably. Depending on which parts of the person’s brain have been damaged, and what medication they are taking, a person with dementia may (but may not) 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’s person needs or appearing sexually aggressive
- changes in levels of inhibitions.

Some couples feel able to adapt to these changes relatively easily, but in other relationships one or both partners may feel varying degrees of upset, loss, anger, anxiety or frustration.

**Diminishing 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.) Being stroked or cuddled may give them reassurance, but they may no longer be able to initiate any affection themselves. Some people feel content if this side of their relationship ceases, as long as closeness and affection continue in other ways. Where partners no longer share a bed, some people with dementia find it comforting to have something to cuddle, such as a soft toy, a pillow or a hot water bottle.

Where one person does become less interested in sex than their partner, they may feel guilty. It is important for the other person to respect that choice, and perhaps to find other ways to maintain their intimacy as a couple, as well as 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 overture. If the level of sexual demand feels overwhelming, it can be helpful to find something else to do together, rather than avoiding an outright refusal.

Some people with dementia may become aggressive if their sexual demands are not met. If this happens, it’s a good idea to keep safely out of their way until the mood has passed. Ask for advice from your GP or consultant if this happens frequently, or if you are concerned about it. Medication might be considered as a last resort, but it is likely that the person will become calmer as the dementia progresses.
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 who their partner is. These situations can be upsetting or painful for partners, who should seek support in these cases.

In rare cases, some people with dementia may go through a phase of being sexually aggressive — making repeated demands of sex from their partner or other people. In extreme cases, particularly if the person with dementia is a strong man, the level of physical force may be difficult to manage. For some couples this behaviour may be part of a long history of aggression, which may be exacerbated by the dementia.

It is often helpful to de-personalise challenging behaviour and remember that it is caused by the illness, rather than the person. However, partners and carers must guard their own safety. Irrespective of dementia, if either partner finds themselves agreeing to sex when they would rather not, or at risk of violence, aggression or verbal abuse, it is important to talk to the GP or consultant, or phone the Alzheimer’s Society Dementia Helpline for confidential advice.

Changes in levels of inhibitions

For most people, sex is a very private matter. However much sex is discussed in the media and our world around us, many adults find it difficult to talk about their deepest sexual feelings to their partners — let alone anyone else. We are all sexual creatures, but what we do with that sexuality and how we choose to express it is another, very personal, story. However, living with dementia brings all kinds of private issues into the public domain.

By changing the way a person feels, and reducing their inhibitions, dementia can expose their 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. Sometimes they might make sexual advances to someone who they mistake for their partner.

These situations may be embarrassing for those close to the person, but they may also be very confusing, distressing or frustrating for the person themselves - especially if they cannot understand why their behaviour is considered inappropriate. It can help to be aware that such behaviour rarely involves sexual arousal, and to remember that dementia affects a person’s understanding of social situations, so it may affect people’s ability to behave within social norms.

Sometimes what appears to be sexual is actually an indication of something quite different, such as:

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

**Adapting to changes in partners**

The partners of people with dementia describe a wide range of feelings about their continuing sexual relationships, ranging from pleasure that sex is something that they can still share to confusion at being touched by someone who at times seems like a stranger. As the 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 intimate tasks they have to perform for the person with dementia 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 sexual 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 that 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 way does feel appropriate.
- Some people feel that the dementia can make their partners clumsy or inconsiderate in bed. 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 while others choose to move to single beds or separate rooms. If a partner does decide to move rooms, this can be disorienting or distressing for the person with dementia, so it's important to discuss this with a GP or support worker. 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 ).

**Ways of coping with frustration**

In any relationship, problems can arise when one person wants to have sex and the other doesn't. This is a situation that most people in long-term relationships go through at one time or another, and it's important to remember that it can arise irrespective of dementia. If this does happen, it is important to remember that this is normal, and try to find realistic, practical solutions.

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 seen as 'dirty' for having such feelings.

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 prized by the other. Some people find that if they can meet these other needs, 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 residential care**

If you or your partner are in a residential, nursing or shared home, this does not need to mean an end to your sex life together. Talk to the manager about your need for private time together, and discuss how that can be available to you. Ask what training is available to staff about relationships. Other questions you might want to ask include:

- Does the home have a sexuality policy?
- What might happen if a resident becomes confused and shows affection or sexual feelings towards another resident or staff member?
- Do you or your partner have special needs that should be taken into consideration?
- If you have a same-sex relationship, will your wishes for privacy be treated with equal respect to those in a heterosexual relationship?

**Forming new relationships**

Just because someone has dementia, this does not mean that they are not 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 be a sexual being, or find it difficult if the person finds a new partner who appears to be taking the place of a parent who has died. All adults, regardless of their age, have the right to make choices about their relationships and to have a private life. If those closest to a person with dementia are satisfied that their friend or relative is not physically or mentally vulnerable as the result of a relationship, and that no one else is being harmed, then they should not attempt to interfere, but may need to discuss their feelings and thoughts with a support worker to help understand the situation.

As long as the person with dementia has the mental capacity to make decisions about their life (see ‘Capacity to consent to sexual relations’, below) then it is important to respect these decisions.

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 and loved ones. It’s important that both parties seek support and have an opportunity to talk about what they are feeling.

**Capacity to consent to sexual relations**

Whether or not one person within a relationship, or their partner, has dementia, by law, both parties must consent to sexual relations. A person consents if she or he agrees by choice and has the freedom and capacity to make that choice. When someone has dementia, it is often unclear whether the person has the ‘mental capacity’ to consent to sexual relations.

The legal definition for someone who cannot make decisions for themselves is if they are not able to undertake at least one of the following:
- understand information 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 simple muscle movements such as blinking an eye or squeezing a hand.

Sometimes, someone with dementia may seem to passively accept sexual overtures 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, while others 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 read 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’) and it is the partner who needs to safeguard their rights.

Simply having a diagnosis of dementia does not mean that someone does not have the mental capacity to make their own decisions and to understand the implications of those decisions. However, particularly in the less advanced stages of dementia, the ability of a person to understand the implications of a decision may vary from occasion to occasion. 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 express their wishes and views. (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 may need to intervene to protect the person. Talk to a professional involved with the support and care of the person with dementia or their carer, such as the GP or a social worker. Initially, you may find it helpful to talk in confidence to the Alzheimer’s Society Dementia Helpline to discuss what to do.

If you do decide to talk to professionals about matters that will disclose information about the sex life of someone with dementia or their partner, it is essential to respect the dignity and right to privacy of both parties. The professionals involved need to determine a number of things, including whether both parties are:

- comfortable with the relationship
- able to avoid exploitation
- behaving in a way that is consistent with their prior beliefs and values
- capable of saying no.

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 much you can do to keep a relationship positive. Spending time apart socialising, or following 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, such as putting together photo albums, joining a local group, or going on day trips, can also help people focus on the positive aspects of the relationship.

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/or your partner may be eligible for referral through your GP, or contact the British Association of Counsellors and Psychotherapists (see 'Useful organisations', below). See also Factsheet 445, Counselling: how can it help?
- A helpline adviser? Phone the Alzheimer's Society Dementia Helpline.
- 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. Details of local groups are available from the Alzheimer's Society Dementia Helpline (see the end of this factsheet for details).

**Sexual health**

The risk of sexual infection does not diminish with age. Contraception should still be a consideration for men of all ages and for younger women in heterosexual relationships. Sexually transmitted diseases (STDs), including HIV (human immunodeficiency virus) which causes AIDS (acquired immunodeficiency syndrome) are a potential danger to all those who are sexually active. Although most people in long-term relationships will have addressed the need for safe sex, in new relationships it is important that both partners discuss how they are going to protect themselves. GPs are a good source of advice on both family planning and safe sex.

It is also important to remember the need for good hygiene to avoid the risk of infection for both partners - any sign of unusual discharge, itchiness or discomfort should be checked with your GP.

For details of Alzheimer's Society services in your area, visit alzheimers.org.uk/localinfo
For information about a wide range of dementia-related topics, visit alzheimers.org.uk/factsheets

**Useful organisations**

**British Association for Counselling and Psychotherapy (BACP)**

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

**Dementia Advocacy and Support Network International**

PO Box 1645
Mariposa
California
United States 95338

A worldwide organisation run by and for people with dementia, working together to improve their quality of life. As well as information about dementia, this website has links to chat rooms where people can meet on-line and to their email community.

**Relate**

Premier House
Carolina Court
Lakeside
Doncaster DN4 5RA
T 0300 100 1234
E enquiries@relate.org.uk

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

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