

Sexual difficulties

If you are caring for a partner with dementia there will be a great many changes in your relationship as time passes and these may include changes in your sexual relationship. Of course, every couple and each situation is different, but sexual problems, when they occur, can cause great distress.

You are likely to experience a sense of loss if a good relationship ceases or is no longer enjoyable. Rather than bottling up your feelings, it may help you to talk about them with an understanding professional or a good friend. It is important to remember that any strange or uncharacteristic sexual behaviour is likely to be part of the dementia and is not directed at you personally.

Of course, this may not be an area of concern for you at present. You may be able to continue with a satisfying sexual relationship for some years to come, or you may be content if this side of your relationship ceases and you continue to be affectionate and close in other ways. Persons with dementia may also forget appropriate public behaviour and may fondle or undress themselves in public or use vulgar words.

Before the diagnosis

You may be aware of puzzling changes in this area of your lives in the period before dementia is diagnosed. Perhaps your partner has become less interested in sex and you feel hurt and rejected or perhaps they have become more sexually active but less loving and considerate.

With a diagnosis of dementia you can at least feel assured that these changes are not a reflection on you and perhaps make allowances for their behaviour. It may help to talk to your doctor or another professional about why the dementia is affecting your partner's sexual behaviour in a particular way.

Please contact the DEMENTIA SA Office

Support | Awareness | Education | Counseling | Training | Resource centre | Advocacy

info@dementiasa.org or support@dementiasa.org

www.dementiasa.org

National Helpline 0860 MEMORY / 0860 636 679

Diminishing sexual interest

Many people with dementia seem to lose interest in a sexual relationship and may become quite withdrawn at an early stage. Being stroked or cuddled may give them reassurance but they may no longer be able to initiate any affection themselves.

Sometimes people with dementia may passively accept sexual overtures without being very responsive. For some partners this is better than nothing as it helps the relationship to feel more normal. Others may be left feeling guilty because the person does not seem to be making a choice. Again, it may help you to talk this through with someone else.

Increased sexual demands

“Sometimes people with dementia may passively accept sexual overtures without being very responsive.”

You may find that your partner’s desire for sex has increased, sometimes resulting in unreasonable and exhausting demands, often at off times or inappropriate places. This may make it difficult for you to show normal affection in case your partner mistakes it for a sexual overture.

Increased sexual demands can be particularly upsetting if – at the same time – your partner seems cold and detached. You may feel demeaned and as though you are being treated as an object.

Such feelings will be even stronger if your partner forgets having had sex immediately after it occurs or no longer recognizes who you are. This can be very painful. Do seek support for yourself.

If the person with dementia seems to be very frustrated it may be appropriate to encourage masturbation in private.

Some people with dementia may become aggressive if their demands are not met. If this occurs it is a good idea to keep safely out of their way until the mood has passed. Ask for advice from your GP or specialist if this happens frequently or if you are frightened. Medication might be considered as a last resort. It is likely that the person will become calmer as the dementia progresses.

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Carers' reactions

Carers describe a wide range of feelings about continuing a sexual relationship with their partner ranging from pleasure that this is something that they can still share to distaste at being touched by someone who seems like a stranger. As the dementia progresses the situation often changes and so do their feelings.

- Some partners find that the intimate tasks they have to perform for the person with dementia puts them off the idea of sex.
- Many partners find it hard to enjoy a sexual relationship when so many other aspects of the relationship have changed and little else is shared. Sex seems to have no meaning.
- Some partners find that their partners are clumsy and inconsiderate because of the dementia but they don't want to undermine their confidence. Sex becomes something to be endured rather than to be enjoyed.

Carers often feel guilty about their reactions and feel the need to talk to someone who understands the situation.

Way of coping

- Realise that sexuality and the need for touch are very human instincts.
- Some partners continue to sleep in the same bed while others move to single beds or separate rooms.
- Avoid becoming angry or arguing

A discreet relationship with someone else provides a safety valve for some people when their partner's dementia is advanced. Others may find this impossible while the person remains at home though they may be prepared to consider it if the person goes into continuing care.

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- Masturbation may bring relief and enjoyment for some partners. Others find this unacceptable and find it more helpful to channel their energy in other ways.
- Don't shame or ridicule the person.
- Be sensitive and re-assuring
- Set clear limits in a gentle way.
- Distract/re-direct attention to a different /favourite activity.

Everyone is different.

Getting Support

- There are no magic solutions but support and affection from friends and family may help you to cope with the situation.
- It may help you to talk in a carers support group with other carers who are in the same position as yourself. Having a good cry or a good laugh in the company of others who understand can also help.
- You may prefer to talk about your feelings on a one to one basis. Perhaps your GP, social worker or close friend can give you the time and understanding you need.
- If you find it difficult to talk to someone you already know about such an intimate subject, talking to a trained counselor may help.
- Counselling will not alter the basic situation but it may help you to come to terms with it and make some choices for yourself.

If you do seek help from a counselor make sure it is someone who is properly trained and experienced in this field. Anybody can set themselves up as a counselor. Ask for a recommendation from someone you trust. You will probably have to pay for this service; fees vary considerably so check on these beforehand.

Inappropriate sexual behaviour:

- Does the person crave affection, touch and affirmation?

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Inappropriate undressing:

- Is clothing too tight?
- Is he/she too hot?
- Does he/she need the toilet?
- They may not realize time of day, e.g. want to go to bed

Inappropriate advances:

- Changes in brain leading to loss of inhibition/ insatiable sexual desire.
- May misunderstand circumstances.
- May mistake some one else for their partner.
- Forgetfulness or boredom

Reduced sexual interest :

- Physical illness
- Depression
- Hormonal imbalance
- Side effects of medication
- Sensing partner's withdrawal
- Other ways to adjust yourself to the changed behaviour :
- Accept that your sexual relationship will change.
- Retain a sense of intimacy through touching and reminiscing
- Prepare yourself for the time when your partner will no longer recognize you.
- Don't take on guilt.
- You may need to take the lead in a continuing sexual relationship as long as is possible.
- Recognise that it's common for you as caregiver to lose interest in sex because of the demands of caring.
- Take care of yourself
- Join a support group

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