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## Dementia - emotional changes

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### Summary

- People with dementia continue to need loving, safe relationships and caring touch.
  - Strange behaviour is caused by the illness of dementia, not the person.
  - A person with dementia may have increased or diminished sexual desire.
  - Partners may experience a range of feelings (such as rejection, distaste and guilt) about continuing a sexual relationship with someone who has dementia.
  - Your doctor can refer carers and partners for help or you can contact Alzheimer's Australia to find out about support groups or arrange to speak confidentially to a counsellor.
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Dementia can cause changes in the behaviour of friends and loved ones. Such changes are very common, but they can place enormous stress on families and carers. It can be upsetting when someone who has previously been gentle and loving behaves in a strange or aggressive way.

Coping with changed behaviours can be very difficult and is often a matter of trial and error. Always remember that the behaviour is caused by the condition.

Anger and aggression are often directed against family members and carers because they are closest. The behaviour is out of the person's control and they may be quite frightened by it. They need reassurance, even though it may often not appear that way.

### Talk to your doctor about emotional changes in dementia

Always discuss concerns about behaviour changes with the family doctor, who will be able to check for the presence of a physical illness or discomfort. The doctor will also be able to advise if there is an underlying psychiatric illness.

The Dementia Behaviour Management Advisory Service (DBMAS) is a national telephone advisory service for families, carers and care workers who are concerned about the behaviour of people with dementia.

### Aggression in dementia

Aggression can be physical, such as hitting out, or verbal, such as using abusive language. Aggressive behaviour is usually an expression of anger, fear or frustration. For example, locking the door may prevent wandering, but may also result in frustration. Aggressive behaviour may also be a way for the person to try to get what they want.

### Management of aggression in dementia

Things that you can do to help manage aggression in dementia include:

- activity and exercise to help prevent some outbursts
- approaching the person slowly and in full view
- explaining what is going to happen in short, clear statements such as 'I'm going to help you take your coat off' (so the person is less likely to feel they are being attacked and become aggressive in self-defence)
- checking if the aggressive behaviour is about getting what the person wants – if so, trying to anticipate their needs may help.

### Catastrophic reactions in dementia

Some people with dementia overreact to a trivial setback or a minor criticism. This might involve them screaming, shouting, making unreasonable accusations, becoming very agitated or stubborn, or crying or laughing uncontrollably or inappropriately. This tendency to overreact is part of the illness and is called a catastrophic

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reaction.

Sometimes a catastrophic reaction is the first behaviour change that makes relatives aware of the dementia. It may be a passing phase, disappearing as the condition progresses, or it may go on for some time.

Some causes of catastrophic behaviour include:

- stress caused by the excessive demands of a situation
- frustration caused by misinterpreted messages
- another underlying illness.

### **Managing catastrophic reactions**

This behaviour can appear very quickly and can make carers feel very frightened. However, trying to figure out what triggers catastrophic behaviour can sometimes help avoid it. Some carers find that keeping a diary can help to identify the circumstances under which such behaviour occurs, so that repeating the trigger can be avoided.

### **Intimacy and sexuality in dementia**

People with dementia continue to need loving, safe relationships and caring touch. However, they will vary in their individual ways of giving and receiving affection, and the way in which their dementia affects that ability.

As a result of the condition, some people with dementia may become demanding and insensitive to the needs of others, and less able to provide caring support for their family and friends. They may also experience changes in their expression of sexuality. Some people continue to desire sexual contact, while others may lose interest in sexual activity, or may display inappropriate sexual behaviours.

Partners may experience a range of feelings about continuing a sexual relationship with someone who has dementia. These may include feelings of rejection, distaste and guilt. It can be helpful to discuss these feelings with a professional. Your doctor may be able to help or you can contact Dementia Australia to arrange to speak confidentially to a counsellor.

### **Changed sexual behaviours in dementia**

It is important to remember that any strange or uncharacteristic behaviour is part of the illness and not directed in a personal way. The person with dementia may no longer know what to do with their sexual desire, or when or where to appropriately express their desire.

Some of the changes in sexual behaviours in people with dementia can include:

- increased sexual demands – can result in unreasonable and exhausting demands, often at odd times or in inappropriate places, and aggression if those needs are not met
- loss of sexual inhibitions – can result in sexual advances towards others, undressing or fondling themselves in public, or mistaking another person for their partner
- diminished sexual interest – can result in the person becoming withdrawn or they might accept physical contact from others, but not initiate affection.

### **Managing changes in sexual behaviours and intimacy**

If sexual demands change, the carer may have to keep safely out of the way until there is a mood change. Some partners complain of feeling like an object. Once the person with dementia has had sex or sexual contact, they may immediately forget what has occurred.

On the other hand, carers can feel hurt and bewildered if their partner loses interest in intimacy.

To manage changes in sexual behaviours try to:

- Consider all the possible reasons for the inappropriate behaviour. These could include needing to go to the toilet, discomfort or boredom.
- Gently discourage inappropriate behaviour.
- Remain focused on the person, not the behaviour.
- Distract the person if possible or redirect them to another activity.
- Find ways to include different forms of touch in the everyday routine, so that the person gets some physical

contact. Massage, holding hands and embracing are ways of continuing to provide loving touch.

### **Support for carers**

Like all the challenges faced by families and carers of people with dementia, discussing this with an understanding person can help. Support and affection from friends and family can help many carers. Talking about problems in a carer support group can also help. Knowing that others have been through the same experience may assist you to feel that you are not on your own.

Your doctor may be able to refer you for appropriate professional help. Dementia Australia can link people to a large number of support groups throughout Australia. Many people find comfort and practical assistance by attending these meetings with others who know what it is like to care for a person with dementia.

Support groups bring together families, carers and friends of people with dementia under the guidance of a group facilitator. The facilitator is usually a health professional or someone with first-hand experience of caring for a person with dementia.

### **Where to get help**

- Your doctor
- Your local community health centre
- National Dementia Helpline – Dementia Australia Tel. 1800 100 500
- Dementia Behaviour Management Advisory Service (DBMAS) Tel. 1800 699 799 – for 24-hour telephone advice for carers and care workers
- Cognitive Dementia and Memory Service (CDAMS) clinics Tel. 1300 135 090
- Aged Care Assessment Services Tel. 1300 135 090
- My Aged Care (Australian Government information line) Tel. 18000 200 422
- Carers Victoria Tel. 1800 242 636 (also known as Carers Advisory and Counselling Service)
- Commonwealth Carelink and Respite Centres (Australian Government) Tel. 1800 052 222

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Dementia Australia

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