

# Dementia and children

Finding out that someone close to you has dementia, and coping with the ongoing illness, can be distressing for anyone. But children and young people can find it particularly difficult. This advice sheet explains how to talk to children about dementia and suggests ways of helping them feel secure and involved.

Dementia can create some very challenging situations for the whole family, and it can be hard to know how much to explain to any children involved. It is very natural to want to protect children from these difficult or confusing situations. However, experts say that it's important to explain to children what's going on.

This is for a number of reasons:

- Children are often aware of atmospheres and tensions, even when they haven't been told the facts, so it is reassuring for them to understand what the problem is.
- Although the news may be distressing, children may find it a relief to know that the person's behaviour is part of an illness, and is not directed at them.
- It can be more upsetting for the child to find out later that they can't trust what you say than to cope with the truth - however unpleasant - so long as they have your support.
- Seeing how you cope with the situation will also help the child learn valuable skills about dealing with difficult and distressing situations, and managing painful emotions.

The most important message is to try to be as honest as you can, with clear explanations and plenty of reassurance. Of course, you will need to adapt what you say and how you say it to the child's age and understanding, and to sense how much they can cope with.

When someone develops dementia, everyone in the family reacts in their own way. Here, we look at how the situation can affect the children involved, how it makes them feel, and signs of distress to look out for.

## How dementia can affect children

When a close friend or family member develops dementia, each member of the family may be trying to cope with difficult and conflicting feelings, as well as managing the practicalities of caring. Adults may be upset, tired or stressed - or simply not at home as much. All of these changes can make a child feel anxious.

It's important to reassure the child that you are still there for them, and that you understand the difficulties they face. They need to know that, despite all the pressures, you still love them - however preoccupied or snappy you may seem at times.

Make sure you have regular 'quality time' with your child, where you can spend time talking without interruption. Young children may need reminding why the person is behaving in a strange way, and all children will probably need to talk about their feelings as new problems arise. They may feel:

- Grief and sadness at what is happening to someone they love, and anxious about what will happen to them in the future
- Fear, irritation or embarrassment, or boredom at hearing the same stories and questions over and over again - perhaps mixed with guilt for feeling this way
- Confusion about 'role reversal': having to be responsible for someone who in the past was responsible for them
- Loss - because their relative doesn't seem to be the same person as they were, or because it isn't possible to communicate with them any longer
- Anger or rejection if other family members are under pressure and seem to have less time for them than they had before.

## Common anxieties

Your child may be afraid to talk to you about their worries because they know that you are under strain and they don't want to upset you further. Older children and teenagers may feel embarrassed to show their feelings. They may need gentle encouragement to talk.

Young children sometimes believe that they are responsible for the illness because they have been naughty or have had 'bad thoughts', whereas older children may worry that the dementia is a punishment for something that the person did in the past. These feelings are common reactions to any unhappy situation that may arise in a family. It's important to deal with them. Use reassurance and explain clearly the reasons why the person became ill. You may find it helpful to use some of the Society's information sheets to help explain (for example: *What is dementia?*, *Coping with memory loss* and *Understanding and respecting the person with dementia*).

Learning that a relative has dementia often causes another very common concern among older children. They may worry that they, or their parents and other relatives, may develop dementia in the future. You can deal with this by reassuring them that this is very unlikely.

Again, use Society information to show them how dementia develops (for example: *What is dementia?*, *Genetics and Alzheimer's disease* and *Am I at risk of developing dementia?*).

## Signs of distress

Everyone reacts differently to difficult experiences and shows their distress in different ways. This is as much the case for children as for adults. However, if you're worried about how the situation is affecting your child, keep an eye out for the following signs:

- Anxiety-related symptoms - Nightmares, difficulties in sleeping, attention-seeking or naughty behaviour, and unexplainable aches and pains are all signs of anxiety and may need more support. Make sure you give children plenty of time to talk things through. If you're worried, you might want to consider talking to the school counsellor or the GP.
- School work - Children who are upset find it harder to concentrate, and school work may suffer. If this is the case, have a word with your child's teacher or head of year so that staff are aware of the situation and understand the difficulties.

- **Appearing unaffected** - If the child appears uninterested in the situation, or seems unusually cheerful, they may be bottling things up or putting on a brave face. You may need to encourage them to talk about the situation and express their feelings.
- **Being sad and weepy** - Some children respond by feeling very upset, and may need a great deal of attention over a long period of time. Even if you are feeling under a lot of pressure, try to give them some time each day to talk things over.
- **Retreating from the situation** - Older children and teenagers can often seem bound up in themselves, and may retreat to their own rooms or stay out more than usual. They may find the situation particularly hard to handle because of all the other uncertainties in their lives. Teenagers may feel embarrassed to talk about their feelings, but they still need to know that you love them and that you want to understand what they are going through. Try to talk things through in a calm, matter-of-fact way.

## What you can do

### Talk about it

It's one thing to recognise the importance of talking about a distressing situation, but it can be hard to know how to approach it. Here are some tips to help you discuss the situation effectively. Remember that discussing means both talking and listening - and listening may be the most valuable part of the conversation.

- Explain the situation as clearly and calmly as possible.
- Giving practical examples of behaviour which seems strange, such as the person forgetting an address or wearing a hat in bed, may help you to make a point more clearly.
- Focus on the things that the person can still do, as well as those that are becoming more difficult.
- Be patient. You and may need to repeat your explanations on different occasions, depending on the age of the child.
- Once you have set out the facts, encourage the child to ask questions.
- Ask how the person's illness makes them feel. Listen really carefully to what they have to say, and try to imagine the situation from their point of view, so you can find out exactly what might be worrying them.
- Give the child plenty of reassurance and hugs where appropriate.
- Don't be afraid to use humour. It often helps if you can laugh about the situation together.

### Get the children involved

Try to find ways to involve the children in providing care and stimulation for the person with dementia. This will help make the situation seem more normal for them, and will ensure they don't feel shut out. But don't give them too much responsibility or let it take up too much of their time - it's important that children continue with their normal lives.

Some tips for involving children

- Emphasise that simply being with the person and showing them love and affection is the most important thing they can do.
- Try to make sure the time they spend with the person is pleasurable - going for a walk together, playing games, sorting objects or making a scrapbook of past events.
- Talk about the person as they were before, and show the children photographs and mementos.
- Take photographs of the children and the person together, to remind you all that there can be good times, even during the illness.
- Don't leave children alone in charge, even briefly, unless you are sure in your own mind that they are happy about this and will be able to cope.
- Make sure that children know that you appreciate their efforts, and help them see how their involvement benefits the person with dementia.

## **Carers' advice sheet 515**

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