Dementia and children or young people

Carers' advice sheet 515

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 often find it particularly difficult. This factsheet explains how to talk to children and young people about dementia, and suggests ways of helping them feel secure and involved.

Dementia can create some very challenging situations for the whole family and social network, and it can be hard to know how much to explain to any children and young people involved. It is very natural to want to protect children from these difficult or confusing situations. However, it is important to explain to them what's going on. This is for a number of reasons:

- Children and young people 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 and young people 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 or young person 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 situations such as this helps young people 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 age and level of understanding of the child or young person, and to sense how much they can cope with. It is important to make sure they feel they can ask questions and share the feelings of other people involved.

How dementia can affect children or young people

When a close friend or family member develops dementia, each member of the family may be trying to cope with their own difficult and conflicting feelings, as well as perhaps 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 or young person feel anxious.

It's important to reassure children and young people 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 them, where you can spend time talking without interruption.

Very young children may need reminding why the person is behaving in a strange way, and all young people will probably need to talk about their feelings as new problems arise. These
feelings may include:

- grief and sadness at what is happening to someone they love, and anxiety 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
- a sense of loss if their relative doesn't seem to be the same person that they were, or because it isn't possible to communicate with them in the usual way 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

A child or young person may be afraid to talk to adults involved about their worries because they know that they are already under strain and don't want to upset them further. Older children and teenagers may feel embarrassed to show their feelings, and may hide their emotions by seeming uninterested or detached. 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 and teenagers may worry that the dementia is somehow a punishment for something that the person did in the past. These feelings are a common reaction to any unhappy situation, and it is 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 other factsheets to help explain? for example, Factsheet 400, What is dementia?, Factsheet 526, Coping with memory loss and Factsheet 524, Understanding and respecting the person with dementia.

Finding out that a relative has dementia can cause another very common concern among older children and young people: that they, or their parents and other relatives, may develop dementia in the future. Reassure them that this is very unlikely and, again, use factsheets to help you explain how dementia develops (Factsheet 400, What is dementia?, Factsheet 405, Genetics and dementia and Factsheet 450, 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 and young people as for adults. However, if you're worried about how the situation is affecting a child or young person, keep an eye out for the following signs:

- Anxiety-related symptoms? Nightmares, difficulty sleeping, attention-seeking or naughty behaviour, and unexplainable aches and pains are all signs of anxiety, and show that the young person may need more support. Make sure they have plenty of time to talk things through. If you're worried, consider talking to the school counsellor or the GP.
- Schoolwork? Children and young people who are upset find it harder to concentrate, and their schoolwork may suffer. If this happens, have a word with the teacher or head of year so that staff are aware of the situation and understand the difficulties.
- Appearing unaffected? If a child or young person 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 to express their feelings.

- **Being sad and weepy**? Some children and young people 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 to help

#### Talk about it

It's one thing to recognise the importance of talking about a distressing situation, but it's another thing 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.
- Make the point more clearly by giving practical examples of behaviour that might seem strange, such as the person with dementia forgetting an address or wearing a hat in bed.
- Focus on the things that the person can still do, as well as those that are becoming more difficult.
- Be patient. You may need to repeat your explanations on different occasions, depending on the age of the child or young person.
- Once you have set out the facts, encourage the child or young person to ask questions.
- Ask how the person's illness makes the child or young person feel. Listen really carefully to what they have to say, and try to imagine the situation from their point of view, so that you can find out exactly what might be worrying them.
- Give the child or young person 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.

For more information, see booklet 1507, *Talking to children about your illness*. This can be ordered from Xcalibre on 01753 535 751 or alzheimers@xcalibrefs.co.uk

### Get the child or young person involved

Try to find ways to involve the child or young person in providing care and stimulation for the person with dementia. This will help make the situation seem more normal for them, and will prevent them from feeling shut out. However, don't give them too much responsibility, or let these tasks take up too much of their time? it's important that they continue with their normal lives.

- Emphasise that simply being with the person and showing them love and affection is
the most important thing that the child or young person 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 child or young person photographs and mementos.
- Take photographs of the child or young person and the person together, to remind you all that there can be good times, even during the illness.
- Don't leave a child or young person 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 the child or young person knows that you appreciate their efforts, and help them see how their involvement benefits the person with dementia.

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

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