

Booklets in the Living with dementia series



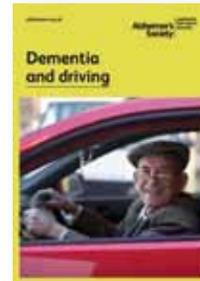
1501



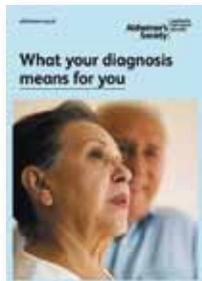
1502



1503



1504



1505



1506



1508



1509

To order one free copy of each booklet (50p for each additional copy), telephone Xcalibre on 01628 529240 or email alzheimers@xcalibrefs.co.uk

Alzheimer's Society

Devon House
58 St Katharine's Way
London E1W 1LB

T 020 7423 3500
F 020 7423 3501
E info@alzheimers.org.uk
alzheimers.org.uk

Reviewed in 2008 by members of the Alzheimer's Society Living with Dementia programme and revised 2010. This series of booklets has been made possible through the generous support of Francelle Bradford.
© Alzheimer's Society 2010

Alzheimer's Society Dementia Helpline
England and Wales 0845 3000 336 Northern Ireland 028 9066 4100

Registered charity no. 296645 A company limited by guarantee and registered in England no. 2115499
1507

Talking to children about your illness



Dealing with your diagnosis is hard – not just for you but also for those around you. In some ways, it may be easier not to talk about it. Research has shown, however, that talking – even when it does not lead to any kind of solution – can help the way you feel about things.

But talking to children may seem a particularly daunting prospect. Understandably, you don't want to upset them. However, you may find that talking can reassure both them and you. Children are often sensitive to atmospheres and tensions, even when they haven't been told the facts. They may worry less once they understand what the problem is. And it may help you clear things in your own mind.

Try to be honest

Although they may find the news distressing, the children in your life may be relieved to know that any changes in you are likely to be because of your illness, and not because of something they have done.

A child can often cope better with the truth – however unpleasant – than finding out that they can't trust what you say. Children often deal with difficult situations remarkably well, as long as they have your support, or support from another adult who loves them.

Seeing how you – and other adults – cope with your illness can also teach the child valuable skills for dealing with difficult and distressing situations, and managing painful emotions.

The key is to be honest, and to allow children to feel their emotions.



For practical information on all aspects of living with dementia contact the National Dementia Helpline on 0845 3000 336 (England and Wales) or 028 9066 4100 (Northern Ireland) or visit alzheimers.org.uk

Talking to children

How you talk to children depends on your relationship with them, how they cope with difficult things in general, and – particularly – how old they are. Talking to a toddler is very different from talking to a teenager.

Preschool-age children

Very little children don't really understand about illness. On the whole, they are mainly interested in what is going on at the moment. They only need simple explanations, but you will probably need to repeat the explanations to them, as they are likely to forget.

School-age children

Children from the age of eight or nine can understand more difficult concepts, such as illness and death. They may be very frank, and ask difficult questions. Encourage them, if you can. Listen to what they say, and try to answer them truthfully and carefully. At this age, children can sometimes react in ways that seem strange to an adult. For example, they might think that they have caused your dementia by being naughty. Another common fear is that they might catch the illness from you.

It may be that their school work suffers, as children who are upset can find it difficult to concentrate. Ask someone to talk to the child's teacher so that the school knows the situation at home.

Sometimes a child will try to hide their feelings. They may have bad dreams, or develop aches and pains that seem to have no cause. These ways of coping suggest that the child is very anxious and needs lots of support.



Be honest, and allow children to feel their emotions

For practical information on all aspects of living with dementia contact the National Dementia Helpline on 0845 3000 336 (England and Wales) or 028 9066 4100 (Northern Ireland) or visit alzheimers.org.uk

Teenagers

Teenage children often appear wrapped up in themselves. It can seem hard to get through to them, even in the best of circumstances. Remember that the teenage years can be a difficult time for many children: they are likely to be struggling with the huge changes in their lives already. Sometimes they don't have the words to tell you how they are feeling.

However frustrating it may be for you, try to allow teenagers time and space to come to terms with the situation in their own way. They are going through a time of intense change, and face many uncertainties. They are often trying to find new ways of being, and they can be very scared of showing emotions. They are easily embarrassed.

Show them that you are able to listen to them, and answer their questions. But don't force them to talk about things if they don't want to. Let them know you love them, and – if you can – show them that you understand their feelings. This can be hard for you, particularly if your teenager seems hostile or uncaring.

**Show children that you are able to listen, but don't force them to talk.
Let them know you love them**

Children's feelings about dementia

Many reactions from children will be similar to those that adults have. They may be afraid for you, and they may well feel grief and sadness and loss.

Anger, irritation and impatience are also common reactions – and children will perhaps be less skilled than adults at hiding these less 'acceptable' emotions. Try not to be upset if the children in your life show these emotions.

Older children, in particular, may appear to be indifferent, or may not react at all. This may be because of embarrassment, and because they are afraid of displaying emotions. Again, try not to let this upset you. Encourage them to talk if you think this will help them, but don't force the issue.

For practical information on all aspects of living with dementia contact the National Dementia Helpline on 0845 3000 336 (England and Wales) or 028 9066 4100 (Northern Ireland) or visit alzheimers.org.uk

Strategies and tips for talking to children

- **Enlist the help of other adults close to you**

Dementia may make it even harder for you to talk to children simply, in ways that they will understand. Don't be afraid to ask other adults close to you to help. You may find it easier to talk to your grandchildren, for example, if their parents are with them. If you are speaking as a parent, perhaps ask a friend or partner to be present. They might be able to explain things that you find difficult.

- **Keep it simple**

Whatever the age of the children you are talking to, keep it simple. Use short, everyday words, and try to avoid medical jargon. Most children will be able to understand the idea of memory problems. You might want to expand on this.

These are some examples of what you could say:

'I have trouble remembering things I've done recently, but things I did a while ago are clearer.'

'Sometimes I might forget an address or a name, or I might have trouble finding the right words.'

'I might do something silly, like wear my hat in bed.'

'I can't always work things out in my head properly. Thinking is harder than it used to be.'

- **Avoid distractions**

Don't try to talk to a child about serious and important issues when there is lots going on around them – particularly if the child is quite young. Wait until you have some quiet time with them. But don't feel you have to make a special effort to have a big serious talk. This might frighten them.

- **Don't avoid the issue**

Make sure you answer all questions as honestly as you can. Don't be afraid to show that you are sad about your dementia.



- **Keep channels of communication open**

Let the children in your life know that they can talk to you. Encourage them to come back and ask you more questions, or tell them that there are other adults they can also talk to.

- **Use humour**

Don't be afraid to use humour. Laughing at some of the more absurd aspects of the illness can help both children and you to keep some perspective. Dementia can seem a very bleak and unfunny prospect but – however strange it might seem to others – humour can keep many people going. It's also a bonding experience – it can be another way of keeping communication going between you and the children who are important to you.

Some don'ts

- Don't use euphemisms that might be even more frightening than the concept of dementia itself.
- Don't lie.
- Don't go into too many medical details.
- Don't make promises you may not be able to keep. (Say 'I think I will be able to...' or 'I'll try to...').
- Don't be afraid to say 'I don't know'.
- Don't push children to talk if they do not want to.

**Keep explanations simple.
Use short, everyday words, and
try to avoid medical jargon**

For practical information on all aspects of living with dementia contact the National Dementia Helpline on 0845 3000 336 (England and Wales) or 028 9066 4100 (Northern Ireland) or visit alzheimers.org.uk

