

Caring for the Carer

Explaining to children

When you are distressed about someone close who has dementia, it is easy to forget just how anxious and bewildered your children may feel. Children need clear explanations and plenty of reassurance in order to cope with the changing situation. Though the facts are distressing, it may come as a relief to know that their relative's strange behaviour is part of an illness and not directed at them.

Of course you will have to adapt your explanations to your child's age and understanding, but always try to be as honest as you can. It is more upsetting for a child to find out later that they cannot trust what you say than to cope with the truth, however unpleasant, with your support.

Giving explanations

- It is always hard to take in distressing information. Children may need explanations repeated on different occasions so be very patient.
- Encourage children to ask questions and listen to what they have to say so you can find out just what might be worrying them.
- Give them plenty of reassurance and hugs and cuddles where appropriate.
- Practical examples such as your relative forgetting an address, getting words mixed up or wearing a hat in bed can often help you make a point more clearly.
- Don't be afraid to use humour. It often helps if you can laugh together at the situation - not, of course, at the person themselves.
- Focus on the things that the person with dementia can still do as well as those which are becoming more difficult.

Children's fears

- Your child may be frightened to talk to you about their worries or show their feelings in case they upset you further. They may need gentle encouragement.
- Young children may believe that they are responsible for the illness because they were naughty or had 'bad' thoughts. Older children may worry that the dementia is a punishment for something their relative did in the past. In both instances, they will need reassurance that this is not so.
- Children will need reassurance that it is unlikely that they or any other relative will develop dementia just because they are related to someone with dementia.

Changes for your child

It is important to remember that when someone develops dementia, everyone in the family is affected. Children need to know that you understand the difficulties they face and that you still love them, however snappy or preoccupied you may seem at times.

Try to put aside time to talk to your child on a regular basis without interruption. Young children will need reminding of just why their relative is behaving in such a strange way and all children may need to talk about their own feelings as new problems arise.



Difficulties they may wish to discuss might include:

- grief at what is happening to the person they love and anxieties about that person's future
- fear, boredom, irritation or embarrassment at their relative's behaviour, perhaps mixed with guilt for feeling this way
- having to assume a responsible role for someone they may remember as being responsible for them
- feelings of loss because their relative can no longer communicate with them or because things are not the way they were
- anger because other family members are stressed and have far less time for them than before.

Expressing feelings

Children all react differently to experience and show distress in different ways.

- Behaviour that may seem attention-seeking or naughty, nightmares or difficulties in sleeping, or inexplicable aches and pains may suggest that your child is very anxious about the situation and needs even more reassurance.
- School work often tends to suffer as children who are upset find it harder to concentrate. It is a good idea to have a word with your child's teacher or head of year so that everyone at school is aware of the situation and understanding about their difficulties.
- Some children put on an over-cheerful front or appear uninterested although they may be very upset inside. You may need to encourage them to talk about the situation and express their feelings rather than bottle them up.
- Other children may be very sad and weepy and need a great deal of attention over quite a long period. Try to give them some time to themselves each day to talk things over, even if you are very stretched.

- Teenage children often seem bound up in themselves and may retreat to their own rooms or stay out more than usual. They may find it particularly difficult to cope because of all the other changes and uncertainties in their lives. They will need reassurance that you love them and understand their feelings. Talking things through in a calm way may help them sort out some worries.

Involving children

Try to find ways of involving your children in the care and stimulation of the person with dementia. But don't give them too much responsibility or let it take up too much of their time. It is very important to encourage your children to continue with their normal lives as much as possible.

- Emphasise that just being with the person for short periods and showing love and affection is the most important thing they can do.
- Try to ensure that time spent with their relative is pleasurable - going for a walk together, playing games, sorting objects or making a scrapbook of past events, for example.
- Talk about your relative as they were and show your children photographs and mementos.
- Take photographs of the person with your children to remind you all of the good times even during the illness.
- Don't leave your child alone in charge, even for brief spells, unless you are sure they are happy about this and can cope.
- Make sure your child knows that you appreciate their efforts.
- Tell your children how proud the person would be of them if they could understand and express themselves.