

Information about dementia for parents and grandparents

This help sheet explains some of the ways that young people may be impacted when a person they are close to has dementia. It lists some of the questions that children may ask and ways for parents and grandparents to deal with these.

Although the vast majority of people with dementia are elderly, there may be young people and adolescents in the household, or close by, who are strongly affected by the illness of someone they love. It could be their grandparent who is diagnosed with dementia, or in the case of younger onset dementia*, their own parent. At a time when they are trying to cope with their own growing up, they find that they also have to cope with a family member who is ill.

Remember that young children may not be able to take in too much information at one time. Keep it simple and try to respond to their questions at their level.

Telling the children

The most important way to help children or grandchildren cope with dementia is to talk openly and be willing to listen. They need the opportunity to ask questions and express their feelings without fear of a negative reaction.

Adolescents

Adolescents are often good at expressing themselves and their feelings, but don't be surprised if they do not initiate discussion. Watch for clues in their behaviour that something is on their mind and then try to talk openly.

* Younger onset dementia refers to dementia which first emerges before a person reaches the age of 65

Some young people may have problems talking with parents because they don't want to worry them or are afraid of making them sad or being an extra burden. They may prefer to talk to people their own age or to a counsellor.

Remember

Young people will react differently depending on:

- Their age and stage of development
- Their personality
- How important the person with dementia is in their lives
- How often they interact with that person

Questions young people may ask

- What's happening to the person with dementia?
- Why is it happening?
- Why can't medicine make it better?
- Did I do something to make them sick?
- Will I get it too?
- Will they die?
- What can I do to make it better?
- Who will take care of me?
- Why is everyone always so sad and angry?
- Why can't things be the way they were?

Emotions young people may feel

- Fear
- Guilt
- Denial
- Jealousy
- Resentment
- Frustration
- Anger

- Sadness
- Tension and stress
- Embarrassment
- Overwhelming sense of responsibility
- Unwillingness to take responsibility
- Despair and hopelessness
- Helplessness

What to try

- Let them know that they are cared for
- Acknowledge that it is tough on them as well
- Give them permission to say what they really feel – don't be afraid of their feelings or yours
- Help them confront and deal with their worst fears. Sometimes these fears may be unrealistic but they are certainly very real to the child
- Maintain as much family structure as possible. Continue to do some of the things you used to do as a family as this will give your children a feeling of security and self-confidence
- Spend some time with them each day. It is important that they continue to have separate time when they are the focus of your attention
- Make family plans and carry them out. Persist even though there may not be overwhelming enthusiasm for your suggestions
- Use respite services such as in-home care to give everybody a break
- Encourage teenagers to get on with their lives and make their own plans
- Deal with conflicts and problems.
- Set aside special times when the family can discuss responsibilities and problems, but try not to make 'helping' the overriding concern
- Notify the child's teacher or school counsellor that someone in the family has dementia. Check with the school from time to time to see if the child has experienced any problems

- Encourage learning about dementia in the school environment.
Contact Dementia Australia to find out about appropriate resources
- Carers need to take care of themselves and reassure children that they will not get sick too

Further Information

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at dementia.org.au



For language assistance phone the Translating and Interpreting Service on **131 450**