

Supporting Children and Grandchildren

THIS FACT SHEET describes how to help children cope with the illness of a parent or grandparent, including how to communicate with them, common reactions to chronic illness, how to involve them and how to maintain a stable environment.

Children have the right to know about things that affect the family. Adults often think they can protect children from unnecessary distress by not discussing serious illness but it can do more harm than good. Children know when something is wrong. They see that adults are upset or behaving differently and they overhear conversations. They see physical changes in their loved one. It is best to talk through the issues with them.

Children have an amazing ability to deal with the truth. Even very sad truths relieve anxiety over uncertainty. Once they understand what is happening, they can also be a support and comfort to you.

Keeping Kids in the Dark

This is what happens when we keep the truth from children:

- > If they are not given a clear and accurate explanation, children often imagine something far worse than the real situation.
- > Someone may tell them anyway or they will gather misconceptions from TV, magazines or other sources.
- > Children can feel very cut-off, forgotten or misunderstood. They may feel they are not important enough to be included.
- > It is very common for a child to think that they have somehow caused or contributed to the illness. Young children feel they have magical powers and that what they wish will come true. For instance: "I got mad at Dad. Now he's sick. Maybe I made him sick."

Delivering the News

- > Explain what is wrong and about any treatment your family member is having.
- > Don't give too much information at one time.
- > Use words that are clear and precise.
- > Don't lie, but don't talk unnecessarily about frightening medical or financial concerns. Do discuss how the child will be affected.
- > Answer questions clearly, truthfully and in an age-appropriate manner.
- > If there are questions you can't answer, don't be afraid to say, "I don't know".
- > Don't make promises you can't keep - "Mummy will be fine, I promise".
- > Reassure young children that nothing they have said, thought or done could cause the illness.

Typical Responses of Children

Chronic illness means that parents have less time and attention for their children. Meanwhile, children are often asked to carry extra responsibilities. All these changes turn a child's world upside down. There can be great frustration and anger, with the responses to match.

Guilt: Some children will feel sorry for themselves when a parent is sick, then feel guilty because they are not feeling sorry for the parent. Some will feel angry at their parent for being sick and wish they weren't there, and feel guilty about that too. Other children try to make up for their guilt feelings by being super-good and setting unrealistically high standards for themselves.

Resentment: Children can resent having to help a sick parent when they are so used to being looked after. Children may act out their resentment and fears by running away or dropping out of school.

Regression: Children of any age may regress in behaviour. Know that it's just their way of saying, "I'm still here!" and "I'm just a kid. I need someone to look after me".

Inappropriate behaviour: Some children laugh or behave badly to cover up their real feelings, their lack of understanding or their discomfort.

Attention seeking: Children sometimes act sick to get attention. Some may also begin to compete for the healthy parent's attention. Some children become clingy, afraid that something bad will happen to their parent when not there.

Confusion of roles: Teenagers face a tough time – just when they are trying to be independent, a parent may need to depend on them. Suddenly the roles are reversed. Some teenagers rebel, some may regress, some are too embarrassed to bring friends home, others may take on heavy responsibilities and mature too quickly. Sometimes kids withdraw, subconsciously trying to become more independent.

Communication breakdown: All children find it difficult to grasp how illness could cause someone they love to treat them differently. Carers have described children who become frightened of their parent's behaviour and who can no longer communicate with them. Some avoid visiting their family member because they can't cope with the changes.

As the Illness Progresses

Keep them well informed: As the symptoms or effects of brain injury appear and progress – personality changes, physical disability, inability to participate, speech and memory problems – explain and discuss these changes with the child. Help them to understand that even if grandpa's face or voice changes, it's still grandpa underneath.

If death is an issue, you need to talk about it. What you say will depend on the age of the child.

Remember that a child's understanding of "soon" and "later" is very different to an adult's. Talk about and share the sadness and the happy memories that will remain.

Some children may need reassurance about how people die. For many, their only knowledge is the violence they see on television. Contact a grief counsellor for suggestions if you feel uncertain about how to discuss death.

Give the child answers about their practical concerns – Who will take them to school if Mum can't? Where will the money come from if Dad isn't working?

Children's fears run easily out of control, so the truth may seem much less frightening. You may find children have concerns you never considered, but no worries about the things you thought would trouble them.

If a child seems worried, ask about their fears or what they think might happen and correct any wrong impressions.

Emotional support: Try to instil children with feelings of hope – while there are things to be sad about, there will still be lots of good times. Reassure them they will always be loved and cared for.

Children will let you know how much they can handle and what they want to know. Remember to listen well and to keep your ears open.

Talk about your feelings, the feelings of the person you are caring for and the child's feelings. Share feelings of sadness and happiness. And don't be afraid to cry in front of children or to let them know that you cry. They need to know that it's part of how we cope.

Involve them: Children need to be told how they can help. For instance, they might visit or talk with the grandparent or parent. You may need to suggest things that they could do together. The child might be able to help the carer in some way, which helps them to feel that they are contributing.

Maintaining Stability in Change

Reassure: The most important thing you can do is to let the child know you understand that things are difficult for them and that you love them as they are.

Routine: Keep things as normal as possible. Stick to a daily routine if possible.

Be flexible: If plans need to be changed because of an emergency, try to be relaxed about it and involve the children as much as possible in the changes.

Inform supervisors: Let the children's teachers and perhaps the school counsellor know about the home situation. Their suggestions and understanding will help if there are any problems.

Flow-on effect: Serious illness in the family can have a flow-on effect, creating disturbances in other areas, such as eating, sleeping, schoolwork or even friendships. Be on the lookout for these.

Maintain discipline: Disciplining children may be difficult, particularly when they are acting up to get some much-needed attention. But a breakdown in discipline can convince a child that something is very wrong at home. Set firm limits and find ways to enforce them, for your sake and the child's. Let the child know that you understand, love and accept them – but not their misbehaviour. Reward good behaviour and let them know how much you appreciate their cooperation.

Express feelings: Keep talking about feelings. If you don't, your children will also bottle up theirs. Children can shut down their feelings if sharing or expressing them is made to seem unnatural. Don't be afraid to express sadness – it's part of life. Sharing feelings can also strengthen the bond between you and your children.

Seek support: There is no need to battle on alone. If problems persist, help is at hand. Talk to people at your school, hospital, church or seek out professional counselling, either for individual members or the family as a unit.

Genetic Testing

Older children may be concerned about the possibility of inheriting their parent's condition.

Some conditions are inherited directly or there may be a genetic predisposition. These possibilities are discussed in fact sheets on each specific neurological condition that can be obtained from BrainLink (telephone: 9845 2950 or free call 1800 677 579). See the introduction to this booklet for a list of fact sheets available.

Genetic testing is available for some conditions. Because the results can be upsetting and create difficult decisions, anyone who chooses to have it must first see a genetic counsellor. Counsellors map out the family tree to identify the pattern of genetic inheritance and to determine a person's risk level before discussing the possible outcomes of testing.

Your condition-specific support organisation (see Contacts pg 7) can provide more information or phone the Victorian Clinical Genetics Service at Monash Medical Centre, telephone: (03) 9594 2028 or Genetic Health Services Victoria at the Royal Children's Hospital, telephone: (03) 8341 6201.

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