

Stroke and the family/whanau

Added to the worry about the stroke itself is the abrupt disruption to life and household patterns. A husband may have to juggle a job, housework, hospital visiting; a wife may be faced with making financial, business or family/whanau decisions she feels unprepared for. An adult child may experience conflict between the demands of their own life and family and the needs of their parent. The person with the stroke may feel helpless, thrust into dependence on the people they were formerly responsible for.

Often the main caregiver feels an obligation to 'do it all myself', out of loyalty and concern for the person with stroke and a sense that this is what is expected. Other family/whanau members may be reluctant to intervene in what they see as a private situation, or may simply not be aware of the time and effort the caregiver has to expend. As time goes on they take for granted that the new arrangements are working, that the caregiver is coping.

Plan ahead

When a caregiver assumes the 'main' role it is usually with no concrete idea of what lies ahead. Uncertainty about what is involved in the care of the person over what time period is pushed down by the pressing need to deal with daily demands and tasks, and the background hope that before long things will be more or less normal. It may even seem disloyal or pessimistic to assume that family life may be changed forever.

An open talk among the family/whanau (including, where possible, the person with stroke), with feelings and fears expressed honestly, is likely to remove some of the inner tension from the situation and may turn up some surprisingly simple solutions to problems.

After the stroke is diagnosed and the rehabilitation programme started, the family will be able to obtain enough information and advice from the hospital

team to make a plan for the weeks ahead (see 'Family Meetings' on page 40). With this information they can be more realistic about the impact of the stroke on their family/whanau.

Points to consider

- Adapting to the consequences of a stroke is a learning process, not a set of skills anyone can be expected to have on hand
- Change in roles and responsibilities may be long term or permanent. Adaptation to new family dynamics will be slow, and possibly a matter of trial and error
- Much of what we do in life is habit or routine – any change results in stress until the new tasks become familiar and a new routine is established
- Many tasks or responsibilities can be delegated to family/whanau members who are willing to help
- Asking for and being willing to receive help from family/whanau and friends is actually a kindness (in that it enables them to have the pleasure of giving)
- Support groups can provide invaluable advice based on experience, for both the person with stroke and the carer
- Professional advice is available to help with the adjustment within the family, eg, from a hospital social worker, a Stroke Foundation field officer, Older Persons' Health Service, church support agency or minister
- A wide range of practical help is available (see pages 169 – 173)
- Getting help at an early stage is a sensible step, not an admission of failure.

(See also 'Life after stroke for caregivers', page 149.)