

Feelings about the stroke

I felt so bullet-proof that at first I didn't even tell my wife, who was away, that I'd had the stroke. Outwardly I handled it well and seemed to spend a lot of time reassuring visitors. I never really grieved. One day, months later, when I was watching a rugby test match, my Scottish heritage had me misty-eyed when the Scottish team sang the national anthem – then the real tears came. I grieved for my life before stroke.

The grieving process

For both the person concerned and their family/whānau, a more serious stroke usually produces a spectrum of strong feelings that are essentially a grieving process. The person with stroke grieves for the loss of abilities, the family grieves for the loss of the 'person' they knew, especially if the stroke has caused difficulties with communication or understanding.

The grieving process, a typical reaction to any loss, has been described in stages. Not all the stages are experienced by everybody, they don't always happen in the same sequence, their duration varies with each individual, and they often overlap.

Sometimes people go back to the start of the process and go through the stages again, particularly if they have not dealt with the loss. This repeat can be triggered by another loss – even something as small as losing a piece of jewellery – and produce feelings out of all proportion, because the initial loss (the stroke) was not fully resolved.

All the stages of grieving are natural and will lead in time to a more positive approach.

1. Shock

The first reaction is a dazed sense of unreality, with confusion about details, a feeling of numbness or being distanced from what is actually happening. This stage is a kind of protective barrier that nature puts up to give you a little time to rearrange your thinking and let the facts sink in.

What helps

- Take as much time as needed to go over the facts
- Ask again about aspects you don't understand
- Ask for information to be written down – when you are in shock it is hard to remember clearly what you are told
- Realise that this stage will pass quite soon and 'life will go on'
- Accept the support of those around you
- The family should keep to their usual routine as far as possible.

2. Denial

The second phase is a rejection of a reality that may be too painful to cope with at this time. The person with a moderately bad stroke may flatly refuse to accept the idea that they may not recover completely. The family may assert that everything will get back to normal. Both try to escape from the suggestion

Shock

What is happening?

Denial

This can't be happening

Reaction

We have suffered a loss...

Anger

This is not fair!

Action

We can find ways to improve the situation

Coping

We can get on with a different but satisfying life

that their future has taken a turn into unknown and therefore frightening territory, with implications that at this stage are overwhelming.

I kept thinking I'd wake up in the morning and I'd be normal.

What helps

- Recognise that at this stage you simply don't have the tools to deal with the situation – everything has happened too quickly
- Have confidence that as the days go by you will learn more about the likely consequences of the stroke; ways to improve the health and abilities of the person will be worked out and put into action
- Realise that little by little you will be able to come to terms with all the aspects of the stroke and help to minimise its effects, instead of feeling helpless and disbelieving.

I didn't want to talk about it or listen to anything about his stroke.

3. Reaction

At this stage you start to become aware of the full impact of the stroke and the loss it means in your life. If the stroke is severe, it can seem like a kind of death – the same person is no longer there, yet the issues are not as clear-cut as in ordinary death.

Mourning for the 'lost' self or family member commonly takes the form of depression which can make it hard to keep going with all the work required to achieve the aims of therapy and rebuild interrupted lives.

It is common to feel guilt – for having in some way caused the stroke, for not preventing it, for 'deserving' it, for not taking good enough care of the person...

I thought of all the things I liked doing and realised that now I couldn't do any of them!

What helps

- Allow time to work through the mourning period and to come to know and appreciate the 'new' person
- Look on this time as one of adjustment. In ordinary circumstances ageing brings significant and sometimes drastic changes to abilities and relationships, but these are encountered and absorbed gradually; the adjustment is almost imperceptible. In a stroke the changes are too sudden to cope with all at once
- Be realistic about guilt. Most of it is imaginary, and, although an understandable reaction, can become a form of self-pity that stands in the way of progressing to more constructive feelings
- Both the person and the family/whānau need to allow themselves a lengthy period to explore and evaluate the life and relationship changes
- Professional advice and counselling is often beneficial at this stage, particularly for partners or caregivers.

*I felt absolute despair.
He wasn't the same but I
couldn't put my finger on it.*

4. Anger

Anger is a natural reaction to loss and the sense of unfairness that often accompanies it. It can be seen as part of nature's 'flight or fight' survival mechanism. Whereas depression is a more inward reaction, turning away from the threatening facts, anger deals with the threat by attacking. Often the anger is irrational, aimed at the person (for having the stroke, for causing upheaval in the family) or caregivers (for not understanding or doing anything right, for possessing independence while the person with stroke has none).

Where is God in all this mess?

What helps

- Acknowledge the anger and frustration
- Try not to bottle it up or feel guilty about it – instead try to fully experience it, clearly look at it and gain the understanding that it is just a reaction to the situation rather than an expression of your feelings toward another
- Talking about your feelings, with the guidance of a counsellor if necessary, will help towards understanding and may diffuse the anger.

5. Action

Having worked through the stages of reacting, it becomes possible to act. ‘The stroke’ is no longer an overpowering entity, but a fact of life which can be worked with, lived with, made more manageable. While loss is still felt, the person can be enthusiastic about trying out slowly regained abilities, becoming useful again; the family/whānau may be more creative in finding ways to help and adapt. This phase is positive, but not the end of the road.

The doctor asked me if I thought of suicide. I said hell no, not with the savings we’ve worked for!

What helps

- Be realistic about gains and goals
- The family/whānau should be sensitive to the effort required to maintain progress and equilibrium. Climbing back into good health is hard work.

When I first had my stroke I just wanted to die. Now life is good again and I wouldn’t be dead for anything!

6. Coping

This is the last stage of the grief process. You accept the consequences of the stroke and learn to come to terms with any disability or difference. The coping stage is not a clearly defined milestone or a guarantee that previous stages will no longer hold sway from time to time, but by now you have the skills, knowledge and acceptance to get on with life.

