

Relationships

The inner qualities that make a person a unique individual are not necessarily lost with stroke, but their expression (verbal or through body language) may be altered or limited by the consequences of stroke. The person may feel they have lost control of their environment. Family/whānau and friends may see a 'different' person.

For the person with stroke, already having a hard time coming to terms with functional loss, it can be devastating to sense that others perceive them as somehow diminished as a person. (This is particularly likely to occur when there are communication problems as a result of the stroke.)

Such an attitude on the part of family/whānau, friends, workmates comes mainly from a lack of understanding of the effects of stroke, and is often tinged with fears and doubts about dealing with the new circumstances – without thinking, people pull back from a situation in which they feel inadequate or which points to their own vulnerability. The result is further break-down in communication which can leave the person feeling more frustrated and helpless.

My business partner didn't visit once. This was hurtful, but I can see now that his own fear kept him away.

Relating to the family/whānau

Reaction to the stroke and its consequences is most intense within the family.

A partner often has to suddenly change the patterns of a relationship that may have spanned decades, give up a planned retirement and take on unexpected duties and responsibilities. Their feeling of bereavement can be made worse by uncertainty about handling the new situation. Their own health may not be good.

Children who have looked to a parent for support all their lives sometimes find it hard to cope with the changes in their parent and may respond with unreasonable anger or withdrawal.

A feeling of having lost a person they previously depended on is fundamental to these reactions. But the 'real' person (who has had the stroke) still exists. Although the changes to their brain function may produce inappropriate behaviour, difficult communication, uncharacteristic emotions, or inability to maintain their usual role, the essential 'Jack' or 'Mary', who is struggling with the problems resulting from the stroke, has the same yearning to relate as the family does. And they want to be recognised and acknowledged as 'Jack' or 'Mary'.

What helps

- Tell your family how you feel about your changed abilities and their reactions, discuss what helps most and least
- Realise that your family are going through a learning process in parallel with your own relearning and it will take time for everybody to adjust
- Identify frustrations and find ways to overcome them rather than letting them build up.

For both the person and family/whānau, redefining relationships is likely to be a slow process, but daily efforts, mutual experience and open communication all help.

Relationships may not be exactly the same as before, but in some ways can be better because they are based on a deeper appreciation.

What I remembered most was the conversations we used to have. How my heart ached to return to those normal conversations.

It was strange having to get to know this new person who was still the old person I loved.

Relating to friends

The family/whānau, almost without realising it, gather knowledge about stroke from the onset of the illness and by the time the person leaves hospital have a fair understanding of needs and some expertise in helping.

Friends, neighbours, work colleagues, on the other hand, may know nothing at all about stroke and are likely to be at a loss as to how to relate to their 'changed' friend when they visit.

You find you've become a bit of a curiosity. People explore you with their eyes and ears, noting how you've changed. They don't know how to react or what to talk about.

What helps

- Be patient with friends, but frank – the more you can explain to them about your experience with the stroke, the fewer difficulties on both sides
- Don't expect too much understanding from friends too soon. Give them time to adapt to the new situation
- A family member may be able to assume the role of stroke educator with visitors, gently explaining, in advance of the visit if possible (and with the person's permission), the problems the person is facing and suggesting approaches the visitor might take
- At other times one of the family/whānau may have to be something of a mediator, patching up the results if a visit didn't go very well
- Friends and relatives could be given a copy of this book to read to help them understand stroke, and pamphlets on specific aspects are also available (see page 174).

Friends and relatives were wonderfully supportive and visited regularly, but often after they left he would be upset and distressed, feeling they regarded him as a child or someone not quite all there.

In time, friends too will feel easier about the situation and it is important that former relationships be kept up, to broaden the horizons of the recovering person and break the sometimes tedious daily home routine. The family may have to take the initiative in maintaining such relationships, and over-ride protestations from the person that friends don't understand, don't want to know, or even are hostile. The person is likely to be super-sensitive to friends' reactions.

Intimacy and sexual relationships

Intimacy is a fundamental part of a couple's relationship and sorting out problems in this area is an important part of rehabilitation.

The first thing to say is that there is no evidence to suggest that having sex will cause another stroke. However, stroke will cause changes in a relationship and partners will need to explore how to continue the physical, sexual side of their relationship. Try and look at this in a positive way; perhaps it is a chance to reignite the spark between the two of you, or to become closer.

Most stroke survivors have a strenuous rehabilitation schedule. This will sap energy levels and the partner with stroke may not feel like resuming their sexual relationship until they have achieved some of their other goals. It takes eight times more energy for a stroke survivor to learn how to walk, talk and dress themselves again compared with energy use pre-stroke. Exercise and rest will need to be carefully balanced and monitored. You have got the rest of your lives in front of you, take it one day at a time. There is no need to rush anything.

Sexuality and body image

It is important to remember that sexuality is not just the act of sexual intercourse. It is about feeling close to someone, feeling loved and special.

The changes that may have happened to the body and mind after stroke will affect sexual function to a certain degree. Feelings about oneself may have changed. If there is paralysis on one side then sensation may be different. Speech may be garbled and emotions may be difficult to control.

Coping with these changes in the body and how you both feel about them can affect how you feel about your sexuality. Accepting these changes takes time and effort. You may experience anger, grief, depression and denial. Dealing with the way you feel will take you a long way towards accepting who you are now.

It is important to discuss feelings and the way the body of the person with stroke has changed. Open communication is the key to every loving relationship.

A stroke need not be a barrier to an active and fulfilling sexual relationship.

Fears about resuming sex

It is highly unlikely that sexual intercourse will cause another stroke. It is normal for heart rate and breathing to become faster during sexual intercourse. Consult your doctor over any medical concerns before resuming your sexual relationship.

You and your partner may have unspoken fears and may avoid intimate encounters as a result of those fears. Delaying intimacy will only increase the anxiety surrounding sexual intercourse; find a way to communicate with each other in order to overcome these unspoken fears.

Fear about partner rejection

The person with stroke may wonder if their partner is turned off by their appearance since the stroke. There may be a fear that sexual intercourse will cause physical pain. Both partners will need time to adjust to all of the changes caused by the stroke. Talking openly about feelings and fears is encouraged. If this is difficult, consider seeking marital counselling.

Fear of failure to perform

A man may find it hard to get a good erection following stroke. For a woman it may be hard to get aroused at first. Both can also experience a lack of interest in sex after stroke. The reasons will be varied; some of the more common reasons are depression, concern about physical appearance, or the effects of medications.

Depression is common after a stroke; your doctor can easily treat this. There is no need to be embarrassed about having depression; stroke causes many significant changes in a very short time. It takes time to totally adjust to new life after stroke.

Taking care of hygiene, grooming and making an effort to look attractive will enhance the way the person with stroke feels about themselves. It will also improve feelings and build confidence in how they see their new self.

Medications

Some medications can reduce libido, erectile function or vaginal lubrication. Think carefully before taking any medication like Viagra to help; talk to your doctor first! Lubricants are readily available from pharmacies or supermarkets.

Intimacy After Stroke booklet

The above information is adapted from a free booklet entitled *Intimacy After Stroke* published by the Stroke Foundation. The booklet provides more detailed guidance on issues relating to sex after stroke such as: hygiene, catheters, paralysis, sensory and perceptual changes, communication, and birth control. Contact the Stroke Foundation for a copy.

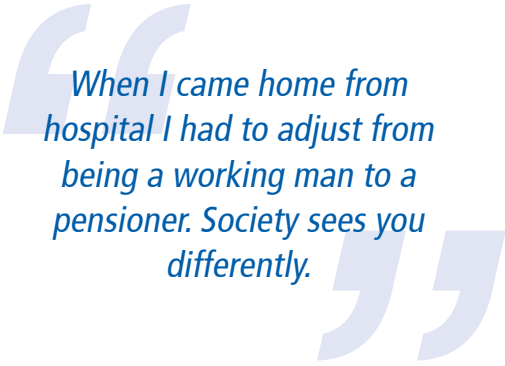
Self-image

When we use the word "I" in thinking or speaking, this word stands for a complex image made up of:

- our main roles (parent/lover/bank manager/tennis player...)
- our status as reflected by the esteem of others
- our special abilities and skills
- our picture of our physical self (well-groomed/vigorous/athletic/sensual...)
- our beliefs and ideas.

A stroke can change this image, or at least substantially rearrange it. . . someone who was used to professional respect can't manage to get their shirt buttoned, someone who brilliantly solved technical problems can't tell left from right. A person with stroke may feel inadequate, fearful, angry, or confused.

While rehabilitation gradually restores many skills, the trauma of having the "I" damaged remains, sometimes undermining even visible progress. The person's fear that they are no longer attractive or esteemed can loom larger than the practical challenges of everyday life. Restored self-image often lags behind restored competency.



When I came home from hospital I had to adjust from being a working man to a pensioner. Society sees you differently.

There is also a tendency to have too rosy a picture of what life and abilities were before the stroke, so the contrast seems even greater.

What helps

Try to 'add value' to each day and:

- take care with your dress and appearance
- make an effort to do something new or make an improvement every day
- keep daily track of progress toward goals (**see page 137**)
- think of something you can do for somebody else.

In the area of self-image the attitude of others is all-important. The caregiver, generally a loved one, is a mirror and what they reflect in the way of affection and respect will count far more than how many steps taken, or dexterity with buttons.

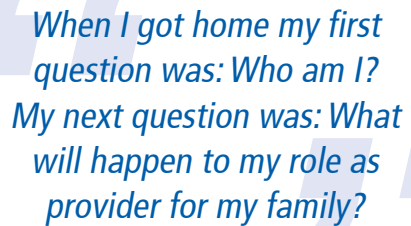
Re-establishing a place in the family

The role of a parent or partner who has changed abilities and needs can be rebuilt daily in small ways:



What helps

- Ask the person's advice
- Encourage them to make choices and decisions
- Don't be overprotective
- Find tasks for them that are easily achievable but not childish
- Celebrate recovering abilities
- Confide thoughts and concerns about family matters
- Be careful to avoid the impression that family/whānau members are talking about the person behind their back or 'leaving them out' (ungrounded though this impression may be)
- Remind teenagers, in particular, not to 'talk down' or exhibit impatience
- Involve the person in household matters, e.g. negotiations with tradespeople, holiday plans
- Have the person sign cheques for household expenditure if this was normally their role (ask their opinion about purchases, discuss with them any relevant details)
- Be mindful of what tasks or responsibilities can be gradually handed back – the initial dependence after a stroke can become taken for granted and the person's role downgraded for longer than necessary.



*When I got home my first question was: Who am I?
My next question was: What will happen to my role as provider for my family?*

Rejoining the 'outside' world

Apart from the physical confinement of hospitalisation and the need to spend a great deal of time resting and in therapy during the early weeks after a stroke, the person's thoughts may be dominated by the stroke and its consequences. Their world can become small. The caregiver may also find that the daily routine revolving around the needs of the person leaves little time to get through ordinary chores, let alone socialise.

After a few weeks of semi-isolation and preoccupation, the first outing may present a whole range of doubts and difficulties.

We were going to a movie. I insisted on starting to get ready two hours before it was time to leave, in case there were any unexpected hold-ups. All the time I was worrying about things like: Maybe there wouldn't be a parking space near enough to the theatre. If my wife dropped me off while she parked somewhere else, how would I manage, waiting in the crowd on the footpath? Were there any stairs into the theatre? We'd have to get seats near an exit. And near the main exit, in case I needed to go to the toilet. How would I get out in the dark? Should I take a torch? A torch and a walking stick might be awkward to manage. In any case the seat would need to be on the aisle, I couldn't get past a row of knees. The toilet might have those bouncing sprung doors...

Through it all the caregiver has to patiently respond and reassure, negotiate real and imaginary obstacles. A simple trip to town can become a complex logistical exercise, carried out in slow motion.

Socialising with other people can bring more subtle potential predicaments.

A feeling of being under scrutiny can undermine confidence gained in the home; communication problems may be accentuated; recovering self-image can feel fragile.

You feel as though you're throwing yourself to the wolves, but you've got to start somewhere – and you do tend to smarten up in front of strangers.

What helps

- Plan the activity carefully, with a realistic timeframe
- When possible do a reconnaissance beforehand. This can allay many fears and enable the outing to be enjoyed with more confidence. Think about access to toilet facilities, or a place to sit and rest
- Choose places to visit (shopping centres, cinemas, motels) where you know the facilities are good. Prior enquiries about access or layout can be made by phone. Checking them out for yourself is even more reassuring
- Challenge irrational fears. Ask what is the worst thing that can possibly happen, then put it into perspective
- Inviting people to the home, one or two at a time, for short visits or a meal, enables the person to practise social skills in a secure environment (see page 125)
- The person may feel more comfortable at first interacting with strangers, whose opinions or reactions are not so important, e.g. they could have lunch at a café or do some shopping
- If things go wrong, keep a sense of humour.

By joining a stroke club the person has the opportunity to join in outings that compensate for changed abilities, yet prove it is possible to enjoy eating at a restaurant, going to the casino or picnicking at the beach, thus gaining the confidence to undertake more independent outings. Problems are put into perspective by the realisation that they are common, and that others have found ways to overcome them.

Social rehabilitation has the twofold advantage of offering challenges and encouragement to the person, and providing regular 'time out' for the caregiver.

Re-establishing a place in the community

A work role lost can feel irreplaceable. This may be the area in life in which the greatest number of years and daily hours have been spent. A parent remains a mother or father no matter what the circumstances, but the status and rewards attached to a job can disappear overnight.

Being unable to work may be felt most when rehabilitation has progressed some way and the basic tasks of daily living are no longer the main challenge.

A breakthrough in this isolation might come from within or without. Those who know the person best can search for ways to rekindle interest, get some enthusiasm going – they should not feel rebuffed if their first attempts don't work.

People in the street stared at me, but the worst part was that shopkeepers ignored me.

After 30 years as a GP and on the staff of a large private hospital, I couldn't accept that I was a patient. For two years I refused to have anything to do with the local Stroke Centre, saying I didn't need it. Then my wife suggested they might need me! I became involved, and later was invited to speak to medical students about my stroke. This led to years of satisfying work as a lecturer and guest speaker.

The person may or may not wish to join a stroke club. They may need assistance to find out about activities and resources in the community. Hospital services or a Stroke Foundation CSA may be able to provide information.

The very qualities that made a person good at a job may resurface as ideas on how to use their expertise in a different capacity. The experience gained from coping with disability can be of enormous benefit to others, e.g. people with a recent stroke.