

## SECTION 3

# THE REHABILITATION EXPERIENCE

This section gives advice on living with a stroke in the long term, and covers:

- what rehabilitation involves
- feelings about the stroke
- relationships
- adapting to family and household routines
- working toward goals
- the needs of caregivers.

# WHAT REHABILITATION MEANS

The aim of treatment after the initial stage of a stroke is rehabilitation – that is, restoring the person with stroke to their greatest potential and maximum independence.

- Because every stroke is different, there is no single or main treatment.
- If a person is medically stable, they will be able to start rehabilitation 24 hours after a stroke (the sooner the better). Some people will need more rest and medical treatment before they begin specific therapy such as exercises.
- Each person will progress at a different rate, and faster at some times than at others.

Rehabilitation involves therapy; and eventually it must encompass putting back together the life affected by the stroke.

In the fullest sense, rehabilitation means:

- identifying what you want to do
- finding ways to move toward your personal goals
- continually looking for options that will help you to progress
- finding solutions to problems.

## THE REHABILITATION PROGRAMME

As many members as needed of the rehabilitation team (**see page 14**) work together to provide care and therapy for the person with stroke in a programme designed especially for that particular stroke. (**See also 'Therapy' on page 50.**)

Rehabilitation starts immediately, but its extent will depend on what the person can manage. The programme will be:

- designed in consultation with the person with stroke and their family
- adjusted over time to meet changing needs
- aimed at helping the person with stroke to overcome the problems associated with their particular stroke (**see Section 2, starting on page 25**).

It is important that both the person and their family make known to the therapists the personal goals they would like the programme to help achieve, and to express any concerns about progress or how they feel about the therapy.

Details of proposed health care and therapy will be outlined before the programme is begun, and the person and family can accept or reject such plans.

Repetition of active movements or tasks is an important part of rehabilitation. Practice makes perfect. A person with a stroke should practice the skills they learn in therapy throughout the rest of the day.

The success of rehabilitation depends very largely on the motivation, courage and perseverance of the person with the stroke, for example in how they deal with the fatigue that often comes with rehabilitation activity. However, remember that sometimes the stroke can affect the 'motivation centre' in the brain, or depression can affect motivation and must be treated first.

**After eight years, every day I work toward further recovery – sometimes with very small things, but they're important**

## REHABILITATION IN HOSPITAL

As part of the hospital team (**see page 14**) nurses have a very important part to play in the rehabilitation process. Because rehabilitation starts as soon as the person is medically stable it is the nurses responsible for day to day care who will guide the first steps. In particular the specialist rehabilitation nurse will, for example, often help with the first simple exercises while the person is in the ward. It is the nurses who are around throughout the day who can ensure their

**Remember that sometimes the stroke can affect the 'motivation centre' in the brain, or depression can affect motivation and must be treated first.**

patient practices and repeats any exercises the therapists have recommended.

In general, all the nursing staff contribute simply by seeing to it that basic needs are met and that nothing gets in the way of the recovery process. Stroke often affects the most basic needs and activities, and so dealing with functions such as hygiene, eating and communication can be a central part of the rehabilitation journey in itself. Nurses in a stroke unit are trained to deal with all aspects of stroke care and are aware of the particular problems that stroke can create.



## TAKING CHARGE AFTER STROKE

Taking Charge after Stroke (TaCAS) is a new service that the Stroke Foundation of New Zealand is delivering through its nationwide team of Community Stroke Advisors.

It was created in New Zealand and has been designed to put the person who has had a stroke in the driver's seat of their recovery.

The 'Take Charge' programme is undertaken in the home and involves one or two hour-long sessions with a trained facilitator. The 'talking therapy' sessions encourage people recovering from stroke to focus on what, and who, is most important to them in order to best plan their own rehabilitation. Each participant, not the facilitator, lead their recovery process, offering autonomy, harnessing self-motivation, and supporting connectedness with others.

We've included the first three pages of 'Take Charge' in this book (**see page 109**) to show you how it works. If you want further information, contact a Community Stroke Advisor.



# THERAPY

## PHYSIOTHERAPY

The aim of physiotherapy is to assess and treat problems to do with movement and balance.

This includes:

- explaining to the person and family what is involved in physical rehabilitation
- discussing with the person and family what they would like physiotherapy to achieve, so the programme can take into account their goals
- preventing physical problems which may occur later because of immobility, too-tight muscles or the overuse of the good side
- designing a programme of exercise to help the particular physical difficulties resulting from the person's stroke, and giving ongoing instruction and help with exercises
- deciding whether aids, e.g. a walking frame, will be helpful and arranging for these to be provided
- re-evaluating the exercises over time in the light of progress and needs
- advising caregivers how to physically help the person, e.g. how to lift them safely or get them comfortable when lying or sitting.

In the early stages physiotherapy may concentrate on basic things such as positioning the person in bed, sitting up from a lying position, guiding the movement of a limb, practising standing. The person or family/whanau may feel nothing much is being achieved, and be impatient for the 'real' exercises to begin, but the physiotherapist has the training and experience to know how much preparation is required and when to change or step up the therapy. Sitting out in a chair, maintaining balance is an important part of therapy early on.

A range of tests enable the physiotherapist to accurately assess the person's disabilities and put in place specific measures to help overcome these.

### Why can't they show me the exercises to hurry up my recovery?

Once the physiotherapy is under way, the person will be expected to practise on their own what they have been taught. Here the family can help a great deal by being thoroughly familiar with the exercises and techniques, and reminding and encouraging the person to keep up regular, correct practice.



Targeted rehabilitation is an important part of regaining function and assisting recovery, and The Brain Health Store has made it its mission to support a stroke survivor's successful recovery journey. The Brain Health Store is a New Zealand business offering stroke rehabilitation equipment to New Zealand stroke survivors at an affordable lease price of just \$1 a day. For more information, visit [thebrainhealthstore.com](http://thebrainhealthstore.com).

# OCCUPATIONAL THERAPY

The aim of occupational therapy (OT) is to work with the person with stroke and their family/whanau and carers to enable participation in activities of daily living.

This includes a focus on optimising both safety and independence in:

- self-care tasks, e.g. showering, dressing, toileting, eating and drinking
- productivity activities, e.g. cooking, looking after children, work
- leisure and interests, e.g. playing sport or a musical instrument, using a computer.

An OT considers a person's physical abilities as well as all the other skills someone needs to complete daily activities. These include cognitive skills (thinking abilities, including memory, concentration, decision making, planning and organisation) and perception (the way the brain interprets the environment and experiences).

OT may involve working directly to address recovery of function, e.g. practising skills or tasks, or adapting the task or the environment, e.g. providing adaptive equipment.

OT covers a very broad range of life and abilities. The OT will want to discuss what the person's usual roles and routines were before the stroke to identify what areas therapy should address.

An OT works closely with the rehabilitation team and family/whanau in planning for discharge from hospital. This includes assessment of the home environment and making arrangements for any equipment or modifications to the home that may be required.

The OT will explain how the things that have been worked on in hospital can be carried on after discharge. This includes making sure the daily routines give the person maximum opportunity to be independent.

## SPEECH-LANGUAGE THERAPY

The aim of speech-language therapy is to manage communication difficulties and/or problems with swallowing.

This includes:

- assessment of altered communication to determine whether it is a language difficulty or confusion
- finding out the type and extent of any communication problem
- advising family/whanau how to communicate in the best possible way for that person
- preparing and carrying out a programme of management or therapy to encourage the return of communication
- recommending the use of alternative methods of communication where appropriate
- assisting with reading/writing
- assisting, if necessary, in establishing legal competency, e.g. if the person wants to make a will
- assessing and advising on the management of a swallowing disorder (**see also page 18**).

Problems with communication are complex: they can be caused by the muscles that control speech not working properly or the parts of the brain that organise language not working properly. The speech-language therapist makes a detailed assessment of the type of disorder and teaches the person and family the most effective ways to communicate, given the disabilities.

## OTHER THERAPIES

Take out bullet list and write – there are many helpful therapies and your Community Stroke Advisor can advise on services & therapies in your area, e.g. Art therapy, Miri Miri, Neurological Choirs, Hydrotherapy, Tai Chi.

Before looking at alternative therapies, e.g. hypnotherapy, homeopathy, it is important you check with your doctor.

# FEELINGS ABOUT THE STROKE

## THE GRIEVING PROCESS

For both the person concerned and their family/whanau, 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.

**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.**

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

### 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.

## 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

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

- 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

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

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/whanau 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.

### 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).

#### 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.

**Where is God in all this mess?**

## 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 regain abilities, becoming useful again; the family/whanau 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/whanau 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.



# 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 page 21**). 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, e.g. from a hospital social worker, a Stroke Foundation Community Stroke Advisor, Older Persons' Health Service, church support agency or minister.
- A wide range of practical help is available (**see pages 97 – 99**).
- Getting help at an early stage is a sensible step, not an admission of failure.

**(See also 'Life after stroke for caregivers', page 85).**

## FROM HOSPITAL TO HOME

Hospital care, whether for a few days or several weeks, is aimed at getting the person who experienced a stroke to a stage where they can return home in good general health and with the confidence to manage the tasks of daily living in the home environment.

Planning for the return home starts at the beginning of treatment and therapy takes into account the particular needs, wishes and lifestyle of the person and family.

### HOME VISITS AND HOME LEAVE

If the hospital stay is reasonably lengthy, a 'trial run' at home is sometimes organised, to enable the person to test the skills they have been re-learning and give the family a clearer idea about what is involved in living with the consequences of stroke. The Occupational Therapist may undertake a home visit to assist with planning the time away from hospital. Please note, the therapists will change from a hospital to a community team.

If the stroke is severe, it is often best to start with a short visit (say afternoon tea, toilet, then back to the hospital), with a longer visit next time. Overnight and weekend visits should not be attempted without adequate preparation and planning. The rehabilitation team will advise on what will be best.

The experience during the visit enables adjustment to the person's therapy and the family's arrangements to be made if necessary, in preparation for the permanent return home.

**When I went home it was summer. The tomatoes needed tying up. I went into the garden and crashed among the plants. There were tomatoes everywhere.**

After the trauma of the stroke and the separation of the family, the prospect of returning home is naturally much anticipated and coloured with strong emotions – and often ends in strong disappointment when things don't turn out quite as expected or hoped.

The 'trial run' is only a trial and part of its purpose is to show up areas of ability, planning and practical organisation, e.g. home layout and routines, that need further consideration.

**On the first home visit he went to the garage when we thought he was resting and next minute was driving through thick traffic, though totally unaware of anything on his left side. Unbelievably he got home safely with a series of right-hand turns.**

Before the home visit, everyone might consider aspects they feel uncertain about, and seek advice from professional staff on such matters as:

- changing from the hospital routine, e.g. exercise timetable, bedtime
- how to manage the bath/shower at home
- what extra help can be called upon if required during the visit, e.g. if the person fell and wasn't able to get up; or if urgent medical advice was needed
- resuming sexual activity
- tasks such as dressing that may present difficulties (practise these in hospital first)
- explaining changes or limitations in the person to children or visitors
- drinking alcohol
- travel
- driving

- what to do if the home visit should turn out to be unmanageable (the return to hospital may need to be fast-tracked, but this possible event would need to be arranged with hospital staff **before** the visit).

After the home visit, any difficulties should be discussed fully with the hospital staff so they can advise how to improve problem areas and ensure that the eventual return home goes smoothly.

A repeated, perhaps longer, home visit might be reassuring and avoid a sense of failure.

### DISCHARGE FROM HOSPITAL

- Discharge should always be arranged in consultation with the person with stroke and caregivers.
- A discharge plan, which includes plans for follow-up care and support at home, should be organised some days before discharge.
- For some patients, early discharge (with appropriate supports and rehabilitation at home) may be appropriate. This is usually done with the help of an 'early supported discharge' (ESD) team, or part of the home based rehabilitation team.

Ideally, the decision to transfer the person from hospital to home will be made only when:

- the hospital team are satisfied that the person is able to manage at home (with appropriate help) and safety issues have been addressed
- the person feels secure about embarking on a more independent routine in the home environment
- the caregiver/family has detailed knowledge of what will be involved in helping the person with daily activities and is confident that the household can adapt to the new circumstances.

Obviously the person and family will have some doubts about what the new life entails, and not all potential problems can be foreseen, but it is important to discuss any misgivings before the discharge and not feel pressured about taking on the new situation.

Early supported discharge (ESD) links inpatient care with community services with the aim of reducing length of stay in hospital. To work effectively, ESD schemes need to ensure that adequate community services for rehabilitation and carer support services exist.

### IS THE CAREGIVER READY FOR HOME CARE?

Sometimes the hospital staff assess a person as ready for discharge, and the person wants only to get home as quickly as possible, but the main caregiver feels anxiety or panic about how they will cope.

#### Points to consider

- Caring for a person at home is a responsible and demanding job and it is sensible to want more information, or more time to gain skills, before taking this on.
- Hospital staff that are trained and deal with strokes every day may forget that others know very little about stroke and its consequences.
- Matters such as finance, responsibility to other family/whanau members or employers have to be weighed up – these are factors which only you are in a position to evaluate.
- The stroke may have limited the person's ability to fully appreciate what is involved in returning home, and meeting all their expectations and wishes may not be realistic.
- Other options can be explored, including rest home care, employing a caregiver in the home, shared caregiving – the hospital social worker will be able to advise on options and costs.
- Unfortunately sometimes planned discharge home is not possible, or it is unsuccessful. It is therefore wise to have a back-up plan than can be put into action if necessary. Your social worker can help you with the preparation work involved in choosing a potential private hospital or rest home.
- Every stroke is different – how other families have managed is not necessarily a guide to **your** situation.

The caregiver is entitled to be listened to and supported by the rehabilitation team, and to ask for whatever further information or assistance they feel they need to prepare for home care.

It may also be helpful to discuss any concerns with a Stroke Foundation Community Stroke Advisor, who works independently of the hospital and can advise on how to approach the situation.

## SETTING UP THE HOUSE

Before the person leaves hospital the occupational therapist will come to the house to assess if any adaptations are necessary, e.g. a ramp over steps, blocks to raise the bed to make it easier to get in and out of, rails in the bathroom, and plan for these to be installed. The occupational therapist will also instruct the person and family in the use of equipment, e.g. toilet frame, bath board and give ongoing advice on any problems.

Essential aids will be provided, but the family may wish to consider further alterations or additions, such as:

- making the shower bigger or walk-in
- a bathroom heater
- repositioning of telephones, additional extensions, a cordless phone
- an intercom system
- a personal alarm
- a suitably high armchair with adjustable back and footrest

- clothing that is more suitable
- a car that will be easier to get in and out of and be able to transport any equipment necessary.

Often it is best not to install too many aids, e.g. clutter the living space with rails everywhere, before it is certain they will be needed – more can be added or existing ones modified to meet particular requirements as indicated by experience.

A wide range of aids for specific tasks and activities is available. The occupational therapist will be able to give you information about these and put you in touch with specialist suppliers. Obtaining such information and studying brochures will enable you to make useful comparisons of the various aids and give you ideas for making improvements that you may not otherwise have thought of.

As well as purpose-made aids that can be purchased, with a little ingenuity and common sense, many adaptations can be made in the home that will make daily life easier, for example:

- rearranging contents of cupboards so they are easy to get at
- replacing double drawer knobs with a single central handle
- putting socks away with each pair laid together and folded over and over (not tucked inside each other and impossible to separate with one hand).



The possibilities are endless, and the best ideas usually very simple.

The key to inspiration is to put yourself in the place of the person with stroke; imagine step by step what is involved for them in a task or movement, and what might help (try doing a simple job using only one hand). Swap ideas with other stroke families and brainstorm solutions to tricky problems.

### Returning home

After being in hospital for sometimes several weeks, adapting to the home environment is often surprisingly demanding. For a start, the expectations of both the person with stroke and the family are naturally going to be quite intense and this, coupled with equally natural uncertainty about the future, can make small problems seem like major disasters.

At home the person is suddenly thrown very much more onto their own resources and may feel quite vulnerable and lacking in confidence. No matter how considerate the family, they must attend to their own commitments, and it takes some time for household routines to smoothly incorporate the person's new needs (**see page 82**).

Returning home does not mean the end of rehabilitation. You should be advised about what rehabilitation is available for you when you are back at home. Sometimes this is provided in an outpatient clinic, but in other areas, members of the rehabilitation team may see you in your own home. Irrespective of where you are seen, what you do in between times is vitally important. This 'homework' is an essential part of the recovery process. The rehabilitation team are like a coach, to guide



**In hospital everything was geared to support me: staff were always on hand to advise and help, established routines meant I didn't need to plan, the tasks of daily living were made easier by specially designed bathrooms, doorways, aids... I felt secure there.**

and encourage you, but they cannot do the work for you. After formal rehabilitation is finished, it is important for you to keep practising those skills or tasks that you want to improve in.

Practising skills and keeping up a specific exercise programme at home may be more difficult than anticipated. The person may feel 'abandoned'. Family can encourage working on those tasks or exercises.

### What helps

- Take charge of your life to whatever degree is possible. You won't get on top of everything at once, but if your aim is to do everything you can to help recovery, every day will open up new possibilities.
- Concentrate on the present rather than brood on the past or future (then you'll be alert to the opportunities each day brings).
- Talk, write, think – express your feelings and ideas, especially to your family.
- Try to think also about the needs of others (this can be more difficult for people recovering from a stroke). Don't forget gratitude – you're alive, people care about your wellbeing.
- Learn as much as possible about your particular stroke and the way your therapy is designed to help your particular problems.



When you have grasped the principles of what is helping you to recover you will be able to maximise therapy, add extra practice, without having to rely on a professional to guide you.

- When you feel too tired to exercise, even going through the sequence in your mind will help to retrain the brain.
- For a while you are likely to have lots of spare time – make the most of it! (how is up to you).
- A stroke is a huge challenge and you may have to dig deep to find the resources to cope with it.
- Never give up.

## STARTING A NEW LIFE

A great deal of patience is required at this stage of rehabilitation. A point of recovery has been reached where the stroke is no longer the central issue, but it is not always possible to just pick up the life that was lived before the stroke.

Patterns of relating to others, as well as dealing with everyday life, have been broken to some degree; life may seem to be 'in pieces', and getting it back together means patiently sorting out the pieces.

Strategies may have to be devised and experimented with to:

- find ways of communicating that may not include language
- manage fatigue

- cope with reduced mobility
- accept the restriction of not being allowed to drive
- accept the need for help with very personal cares such as toileting and bathing
- adapt sexual behaviour to accommodate physical impairment.

Unexpected behavioural problems sometimes arise which the family find shocking or disruptive. They may not realise that excessive swearing, selfishness, angry outbursts or dreadful table manners result from the effects of stroke. The more information the person and family/whanau have about these possible effects, the better they will be able to deal with them (**see Section 2, starting on page 25**).

## Priorities

It will take time to gain enough experience and practice to make all the aspects of daily life fit together smoothly. Before discharge, the hospital staff will have helped to sort out a list of goals to work on at home that includes doing simple but essential tasks safely, for example:

- dressing/undressing
- going to the toilet
- walking round the house
- getting in and out of bed
- feeding the budgie.

It is best to concentrate on these things without worrying too much about other areas. Some of



the tasks will need a lot of practice, so you could choose one or two for special attention the first week; the next week, different items or stages of an activity could be given priority (**see page 77**).

### Sorting out feelings

The priorities listed for each week might not be confined to physical areas. Learning to cope with the emotional changes a stroke brings about is important too.

#### What helps

- You could decide to try to recognise and understand your frustration (for example at not getting some things done as quickly as you would like) and attempt to change this into a more accepting attitude.
- A caregiver might notice they were resenting certain aspects of the person's behaviour and make a conscious effort over the week to try to figure out what caused the behaviour, then cheerfully ignore it.
- Negative emotions take up a lot of energy; if this energy can be used more creatively and constructively, speedier progress toward goals is likely to be achieved.
- Negative emotions can't just be squashed down – they need to be looked at, probably talked about, understood and replaced with a positive attitude before they can be put away.

Social workers, therapists and Stroke Foundation Community Stroke Advisors, who each have different areas of skill and experience, can help by assessing the home situation and suggesting ways of working toward solving particular problems or achieving the aims that are important for that family.



# STRESS

Stress – the feeling of being stretched beyond an acceptable limit – is common when dealing with any illness; the complex nature of stroke and the comparatively long duration of its effects can make stress a serious problem for the person and caregivers.

Stress can be experienced in several ways:

- mental (worries about finance, the future, the implications of the stroke)
- emotional (impatience, pessimism, anger, tearfulness)
- physical (tiredness, tension, lethargy, upset stomach, shortness of breath, pounding heart, poor sleep, poor appetite).

A person with a stroke may be stressed by:

- not being given the opportunity to do things they know they can do
- not being allowed to be as independent as they think they could be
- having to make life-changing decisions
- being hurried
- feeling as though they have no personal freedom or privacy
- being treated as having a hearing or intellectual impairment.

Caregivers can be loaded with responsibilities and daily difficulties that may be accepted, but in truth not welcomed; there may seem to be no light at the end of the tunnel.

**After getting to all the therapy at the hospital, and all the appointments, I was too tired to do anything else. Everything was a hassle.**

## WARNING SIGNS

Stress creeps up. Everybody will have good days and off-days, but several bad days in a row probably indicate that something needs to be done about stress.

Suspect stress if you:

- don't 'bounce back' – an ill-considered remark leaves you brooding for hours, a hitch in the day's schedule turns the day upside-down
- find it hard to relax, even with your favourite people and activities
- lose your sense of humour
- sleep badly, or feel unrefreshed by sleep
- tend to be anxious about little things
- lose your appetite
- smoke or drink too heavily
- feel you're not capable of meeting demands.

## DEALING WITH STRESS

The stressful situation not only drains energy but alters perspective.

Problems become exaggerated and seem to close in, so the sooner you deal with stress, the more chance you will have of getting rid of it.

### Recognise the stress

Be alert for the warning signals, don't brush them off by thinking you're "just a bit tired" or "not myself today".

### Stand back

Try to look at the situation with fresh eyes, to see the whole picture, not just the problems. Pretend you're an outsider assessing your situation, trying to find solutions. It is helpful to talk to someone who is outside the situation – a friend, health professional or Stroke Foundation Community Stroke Advisor who will often be able to pinpoint things that can be changed or done differently.

**The effort involved in organising an outing is so great I wonder whether to bother, but once we're out of the house, it all seems worthwhile.**

### **Avoid stressful situations**

Not all the factors that cause stress can be changed, but it should be possible to modify some, e.g. change the daily schedule to avoid tight spots. Then you can be on guard against the factors that can't be changed and simply resolve not to react ("I know there's going to be a bit of a tantrum here, but by teatime it will all be over...") In this way you can inwardly take charge of the stress factors instead of letting them push you around.

### **Look outward**

Arrange to regularly spend some time outside the tight circle of stress. Do something different, even if you feel there isn't the time to spare or don't feel enthusiastic at the beginning. Relaxation takes practice! Let other people (cheerful friends, grandchildren, the local sports club) take some of the weight off you. Or plunge into a hobby or special interest.



## POST STROKE FATIGUE

Tiredness can contribute to stress as well as be a cause of it, so it is very important to get to the bottom of persistent or 'unexplained' tiredness:

- The stroke will cause the person to feel tired. Apart from the physical causes, weakness and heaviness in muscles gives an impression of tiredness that adds to the feeling of fatigue
- Thinking with an injured brain is like having to walk with a broken leg in plaster – it takes more effort and the brain gets tired more quickly
- If an altered sense of time is one of the effects of stroke (**see page 31**), the person may wake at night after a couple of hours, feeling ready to start the 'new day'; this can disrupt their partner's rest and make the person tired later
- Looking after a person recovering from stroke is physically demanding and often means long days and broken sleep.
- A partner could sleep in another room some nights to catch up on sleep. If the person feels anxious during the night, it may seem difficult to leave them alone, but the caregiver must have adequate sleep to be able to keep up with all the other cares (and the anxious person may cope better than they expected with spending the night alone).
- As well as making sensible arrangements for help during the day (**see page 85**), the primary caregiver might consider having a helper stay overnight say once a week, to take over if the person needs help going to the toilet or with other cares during the night.

It can be hard to distinguish how much tiredness is due to physical causes like heavy work, intensive therapy or lack of sleep, and how much stems from psychological attitudes which need quite different management. Whatever the cause, take tiredness seriously and discuss it with a medical practitioner.

### What helps

- For the person with stroke, tiredness can be helped by having lots of short rests during the day, and alternating more demanding activities with quieter periods.



# RESTLESSNESS

Restlessness may be a symptom of a number of medical or psychological conditions and may need to be investigated by the family doctor or specialist.

The causes of restlessness may include:

- stimulants such as tea, coffee or alcohol taken in the evening
- some prescription drugs (check with your doctor)
- pain
- bladder problems
- depression
- heart or lung conditions which may lead to poor-quality sleep or breathing difficulties during sleep.



# DEPRESSION

A certain amount of depression is a normal part of the grieving process that usually follows stroke (**see page 52**), but depression can be severe enough to affect functioning, and can slow down the rehabilitation of the person who has the stroke or make a caregiver unable to adequately look after the person.

## WARNING SIGNS

- Feeling sad, hopeless, helpless, worthless
- Thinking of suicide
- Negative self-image
- Loss of appetite or markedly increased appetite
- Loss of sexual drive
- Weight loss
- Negative thoughts about the future
- Poor concentration
- Low energy
- Waking very early in the morning
- Irritability
- Loss of interest in others
- Indecision

There is a fine line between the stress, tiredness and feeling 'down' to be expected after a stroke, and more serious depression, so it is important to fully discuss depressed feelings with the doctor. Expert help and advice can make an amazing difference.

## What helps

- Counselling at an early stage can be helpful.
- Advice from a psychiatrist can be invaluable in planning treatment.

The person with depression can also do a great deal for themselves, for example by:

- recognising the need to accept help
- dealing with stress (**see page 63**)
- understanding that depression is not a 'weakness', but a health disorder
- recognising that depression is part of the grieving process (**see page 54**) and that being depressed is a stage in the recognition of how things have changed
- talking about their feelings and getting more understanding of their psychological state
- changing the depressed behaviour, e.g. making an effort to get going when they don't feel like it, filling an hour with a demanding task or entertaining activity that leaves no room for depressed thoughts. This is a way of controlling the depression instead of letting it take charge. Once the initial effort is made, the hardest part is over.

Joining a social rehabilitation group, such as a stroke club, or rejoining old activities and interests, e.g. attending concerts or sports events, bowling club, senior citizens' club, RSA, etc. will help to alleviate depression, but caregivers may need to take the initiative and take the person along at first in the face of protests.

# FRUSTRATION

Few conditions would give rise to quite the amount of frustration that a stroke does.

It can be frustrating trying to come to grips with what has actually happened – the stroke itself is invisible, there is no warning, no pain, and stroke works in hundreds of hidden ways.

Rehabilitation can be frustratingly slow. Effort often seems not to equate with progress. Caregivers must adapt to the deliberate, unhurried pace that living with a stroke demands, even when they have a dozen jobs to get on with.

Little in this physical situation can be changed, but trying a different approach often works well.

## What helps

- Take one thing at a time. Focus on whatever you're doing at the moment, unconcerned about the next event.
- Try and see things that go wrong as part of the learning process rather than failures.
- Remember how much progress has been made since the beginning – each day adds to the progress, though it may not seem much of a triumph at the time. (Read back through your diary to be reminded of how far you have come).
- Graph important indicators of recovery, for example, distance walked, or how long it takes to get dressed.
- Realise how much energy frustration uses up and put the energy into effort instead – never give up.
- Find someone to talk to about difficulties and feelings. Share the load. A phone call to a Stroke Foundation Community Stroke Advisor or a friend will bring in a new angle, a ray of light...
- Beware of denial. Denying limitations can be as dangerous as ignoring faulty brakes on a car.
- Learn to let things go! Become adept at changing the subject. Even when you know you are right, deciding not to argue to get a point across can save energy and distress, and before long you're onto new ground.
- Accept the reality of outcomes that cannot be changed.

# PROBLEM SOLVING

Most problems are partly caused by ourselves; changing your own attitude might be the hardest part.

Some problems may require professional advice and help, but if you have gone through the steps below, you will have more insight and knowledge to bring to the eventual untangling of the problem.

Family problems require round-table, frank discussion and group effort.

## Recognise the problem

Admit it exists, see what events lead up to the problem, describe it, talk about it, maybe write it down.



## Observe yourself

Notice how you react to the problem, what makes it worse or better, what feelings are involved.



## Think of solutions

Look at the problem from as many different angles as you can – ‘brainstorm’ solutions. Be innovative, be completely honest, use common sense.



## Carry out the solution

It may take a little practice and adjusting before you get on top of the problem.



## 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/whanau 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/whanau, 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.

### RELATING TO THE FAMILY/WHANAU

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)

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

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

#### 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.

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



For both the person and family/whanau, 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.

## RELATING TO FRIENDS

The family/whanau, 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/whanau 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 100**).

**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.

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



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.

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 78**)
- 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/whanau 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

**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?**

- 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.

### 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.

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.

#### 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.

**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...**

- 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 71**).
- 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.

**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.**



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.

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

### 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.

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 Community Stroke Advisor may be able to provide information.

**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 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.



## GOALS

The aim of rehabilitation is to restore the person to the greatest possible degree of functional ability and independence. The hospital team discuss with the person and family what they would like rehabilitation to achieve and what competencies are especially important to them. The person or family may have unrealistic goals which need to be modified to be achieved.

The overall rehabilitation plan is geared as far as possible to the chosen goals, but the ultimate result cannot be predicted. Every stroke is different and progress is individual.

## SETTING GOALS

Goals could be categorised in different areas, although some will fall into more than one category:

- physical rehabilitation, e.g. regaining movement or strength, walking without help, losing weight, stopping smoking
- family and household, e.g. housework, minding grandchildren, cooking, gardening, driving, using the phone
- social and recreational, e.g. participating in club activities, playing music, going to football matches, knitting, travelling, playing cards
- vocational, e.g. returning to a former job, completing study, writing, using a computer, using specific tools, driving
- personal, e.g. being able to live, shower or dress independently.

**Being realistic can be quite painful. But you just have to concede that your future doesn't include being a brain surgeon or a 747 pilot.**

### Choose realistic goals

Being too optimistic about what can be achieved will only lead to disappointment and frustration. It is better to first choose goals that you and the rehabilitation team agree are well within reach. These can be a stepping stone to bigger or longer term goals.

At the same time, make sure you talk to your therapy team about goals that are really important to you and that you feel you are capable of reaching.

**I've reassessed my goals in life and they don't bear much resemblance to the ones I had before the stroke: I want to dance with my wife again, and walk down the aisle with my daughter on my arm on her wedding day.**





### Choose measurable goals

Be definite about what you want to achieve. A goal 'to be useful' is too open-ended: narrow it down to exactly how you see this aim. Similarly, an aim 'to get better at walking' could be pursued rather vaguely for a very long time – better to have a definite goal, such as to be able to walk to the end of the street and back.

### Keep a log

Write down in your diary the goals you have chosen and the dates you hope to achieve them by. Record daily or weekly progress. Video is an excellent way of recording progress.

**Everyone said no! – but at the end of six months I was able to take driving lessons and passed a defensive driving test. Being able to drive the car again gave me a sense of normalcy and independence.**

**'If he doesn't do it with his head, he won't do it with his body.'**

**Comment from veteran Stroke Club member about new member who wasn't putting much effort into progress.**

### Milestones on the way

Longer-term goals can be broken down into stages. An aim to go to a family/whanau celebration in another town might include:

- being able to get in and out of the car
- riding for two hours in the car
- being able to eat independently
- managing steps

Each stage can become a separate short-term goal, with progress recorded and the milestone suitably celebrated.

### Motivation to achieve goals

The initial enthusiasm to reach goals may lessen as weeks of therapy roll by.

Also, progress in the earlier stages of rehabilitation may be faster than later on – recovery tends to reach a plateau and then continue more slowly. Having reached a stage where progress seems rather static, if there is not sufficient motivation to keep looking ahead, the situation can become difficult, especially for people living alone.

The effects of a stroke may leave a person with reduced motivation or interest in goals (**see page 37**). Anxiety can undermine motivation; for example, fear of falling may hinder regaining mobility. A bad experience can take away the courage to try again.

When the person's motivation is low, family/whanau and caregivers will need to play a bigger part in encouraging and supervising practice of skills. However, remember that just as workers



need holidays, people undergoing rehabilitation need time out – it's hard work!

If a person refuses to try, and their only disability is physical, it is appropriate to be firm about the need for effort. If they also have anxiety, emotional instability or severe mood swings, it can be very difficult to make them extend themselves. Professional help and advice will be needed.

### What helps

- Re-evaluate goals.
- Re-prioritise goals.
- Don't give in to thoughts that further recovery won't happen.
- Adjust goals so they are more achievable, and break them down into sub-goals (**see page 78**).
- Make sure the goals are what the person wants rather than what the health professionals or family think should happen.
- Review the diary and celebrate progress made already.
- Make a graph or chart that records progress made, and display it prominently as a daily reminder and incentive.
- Joining a support group, e.g. a stroke club, where others are experiencing similar problems, may help to take away some fears and bring difficulties more into the everyday world where they can be looked at and dealt with.

**Following the stroke my wife had problems with swallowing. Now the problem doesn't exist, but she is still fearful about going out to a meal where they might serve salads – we have to take a sandwich for her, just in case.**

If a person is reluctant to take on challenges, the family member/caregiver could discuss the situation with a Stroke Foundation Community Stroke Advisor or therapist, who would take the time to find out what would interest the person and introduce them into a new group. With permission, a Community Stroke Advisor could contact former associates, e.g. an RSA or senior citizens' club, and advise them about how best to support the person when they returned.

Getting back into the community, pursuing old interests or new challenges can make a person feel better about themselves and continued improvements may follow naturally.



# INDEPENDENCE

Loss of independence and the resulting feeling of helplessness is one of the most devastating effects of stroke. It makes some people angry, and others retreat into resignation.

## LEARNING BY DOING

From the beginning of rehabilitation, hospital staff will be working to assist the person to regain independence. To the family/whanau this may be misunderstood if they think the person is ill and should be looked after more. The person may feel resentful at being 'left' to cope with a tricky situation. But encouraging the person to do as much as possible helps them in the long term and speeds recovery and the regaining of self-esteem.

### What helps

The family have to learn to stand back.

- Let the person try things they want or feel able to do.
- The person may need to attempt things they previously did in order to find out their present

**One of my biggest hassles was people who wanted to help me all the time.**

limits, work out alternative strategies and build confidence.

- Encourage the person to be assertive so they feel comfortable asking for or refusing help
- Resist the inclination to help more than necessary, even when a simple task is becoming chaotic and everybody is getting frustrated.
- Allow the person plenty of time to complete a task – don't take over before it is finished because time is short.
- Be mindful of unhealthy dependence, a tendency to 'give up' – this is hard to deal



with because the person may appear unable to do more and caregivers may have to put the person in a situation where they need to manage.

- Try to take a consistent approach to encouraging independence.

**One minute she'd expect me to do everything, the next minute she'd be doing everything for me.**

## WHAT IS INDEPENDENCE?

Each person who has had a stroke will have to think long and hard about their personal goal of independence. Their definition of independence will likely change over time; at the beginning it may mean being able to get to the toilet and dress and eat without assistance. As competence with daily activities is achieved, taking a place in the wider world becomes a condition of independence. The goal expands, with aspirations always a step ahead of accomplishments.

A stage may be reached where recovery from the stroke seems to have come to a plateau, but hasn't quite reached the hoped-for independence. It may take a little more time before the person comes to realise that independence includes an inner attitude, and that the qualities acquired from having to deal with limitations can be a source of strength for themselves, their family/whanau and others.

The 'inner person' can continue to grow, regardless of what the body is doing.

**Most people with a stroke fiercely crave independence, because we've had a real taste of what it means to be dependent.**



## ORGANISING THE DAY

After experiencing a stroke, all the activities of daily life take longer, and have to be fitted in around a schedule of therapy, medical check-ups, extra phone calls and visitors – there can be little room for flexibility.

### MAKING A TIMETABLE

To help avoid panics, bottlenecks or being late for appointments, write out a timetable for the main items in each week, set out on a day-to-day basis. These might include:

- meals
- shower/dressing
- therapy appointments
- socialising
- stroke club
- practising exercises
- visits to doctor/dentist/lawyer/bank
- working toward goals
- rest times
- times to take medicine
- favourite TV programmes or other interests
- getting ready for bed

The timetable could also incorporate the help roster (**see page 86**) and include the times helpers are going to arrive. Keep the timetable where it can be easily seen, e.g. on the fridge.

### Allow plenty of time

Allow more time than you think you'll need for each item – it is important to avoid hurrying the person who has experienced a stroke. Try to keep to the timetable, but on a trial-and-error basis at first, with the schedule adjusted in the light of experience.

### Avoid pressure

If possible, arrange for more demanding tasks to be alternated with more relaxing activities. The timetable will enable you to see at a glance that, for example, Thursday is impossibly packed with events and one of the appointments should be shifted back to Tuesday; or Friday looks relatively free and would be a good day to have someone over for lunch.



**TV can be a trap. It's too easy to get anchored there.**

### Keep to the schedule

Keep the schedule going, fine-tuning the timing until experience shows the timetable is working well. Among the many benefits:

- the person with stroke will feel more secure about being able to manage their daily life
- helpers can quickly familiarise themselves with the household routine
- poor motivation can be jogged along by a definite plan
- 'free' time can be enjoyed without the worry that you should be doing something else.

### WORKING TOWARD GOALS

Planning the day should take into account the rehabilitation goals (**see page 77**), with time set aside for practice of specific skills necessary to achieve these goals. Many of the day's ordinary activities can be structured to help progress towards goals and give more sense of purpose to tasks.



## RETURNING TO WORK

If the stroke is reasonably mild and a return to work is planned, discussion should be held with the employer at as early a stage as possible about keeping the job open, or providing a different job, e.g. less physical, or shorter hours.

The employer may request permission to write to the specialist for an opinion on progress and an estimate of the time you need for rehabilitation before returning to work.

### What helps

- Make sure the employer and workmates have enough information about stroke to understand potential difficulties, i.e. slowness or fatigue – this will make both them and you feel more comfortable about resuming a work relationship. You could ask the Stroke Foundation Community Stroke Advisor to give them background details.
- Have the work site and your role assessed for suitability (discuss this with the occupational therapist).
- Get in contact with a Stroke Foundation Return to Work Advisor. They provide expertise and support to guide stroke survivors through the process of returning to gainful employment. This is a free service available to stroke survivors of working age throughout New Zealand.
- Find out about equipment to make your role easier, e.g. a shoulder rest for a telephone to allow you to write while taking a call.
- Be honest with yourself and others about your present capabilities.
- Don't overcommit or overstretch yourself: remember that for a while you will continue to tire more quickly.
- Plan your working day – with the idea of taking pressure off yourself, not seeing how many extra things you can fit in.
- Plan a gradual return to work, e.g. start with only a few hours a day.



### When it is not feasible to return to a former job

- Discuss with the occupational therapist and other members of the rehabilitation team the possibility of preparing for different work that will accommodate limitations caused by the stroke.
- Be flexible about changing occupation, adapting lifestyle, developing new or latent skills – in a year's time the future is going to look quite different to the one envisaged when you first learn you 'can't go back to work'. Give yourself time to absorb the implications and adapt.
- If it is not possible to return to paid work, consider voluntary work, transferring your skills to another area.
- Getting back to work of any kind will put structure into the day and do wonders for confidence.
- However, remember there is a time in life to be retired! Some people with a stroke have a very 'successful' retirement.

# LIFE AFTER STROKE FOR CAREGIVERS

For almost every caregiver, the role of looking after a person with stroke at home is a new experience. Even a trained health worker would find a big difference between caring for strangers in a hospital and doing the same tasks day and night for a person with whom they have strong emotional ties, in a house that also has to accommodate other lives and needs (including their own).

Knowledge of exactly what is involved in the caregiver role can be gained only by experience. The hospital staff and the Stroke Foundation can give a lot of information, other caregivers can provide more insight, but every stroke is different and no one can fully prepare you for what lies ahead.

## DON'T TAKE ON TOO MUCH

Right from the beginning, avoid taking on more duties than you feel you can comfortably handle. Before the person with stroke comes home, write down a rough daily schedule that allocates time for:

- helping to shower, dress, groom
- phone calls/visitors
- housework and making meals
- therapy appointments
- earning an income
- gardening
- quiet time together
- shopping
- mail, accounts, banking
- quiet time by yourself
- house maintenance
- time with other family/whanau members
- sleeping
- keeping up with own hobbies/friends
- free time to manage unexpected events.

The first draft of the daily schedule is likely to add up to more than 24 hours, yet everything on

**I'm constantly in demand, constantly tired and constantly on the go. The sense of responsibility is overwhelming.**

the list needs to be done. To think: "I'll manage somehow," is to ignore the reality of the situation. Thinking that "this is expected of me" is simply not true.

You may get through the first few days or weeks, but the routine is likely to become an increasing struggle as you get more tired and basic household tasks get more behind. Tiredness may lead to irritability, depression, poor sleep, apathy... the situation gets worse (**see page 63**).

Friends and relatives are more inclined to rally round in the early days of the stroke, then as the person's health improves and you insist you're able to cope, they become immersed in their own lives again.

The most sensible way to approach the job is to get as much help as you think you may need, from the start. It will be easier to take on more duties later (if this becomes desirable) than to off-load aspects of care that you have already established as part of your role.

## What can be handed over?

Consider the tasks each day brings and ask yourself: "Am I the only person who can do this?" or "Is this essential for today?"

Getting help with some of the routine daily work will take strain off you and give the person you are looking after the stimulation of fresh faces and conversation, and provides a break from the intensity that tends to surround everything to do with the stroke. A couple of hours in the house by yourself, even if you use the time to clean windows, is a change and can be a relief.

Areas for extra help might include:

- transport to therapy
- having some meals prepared and brought over
- regular cleaning
- assistance with outside jobs like lawns and gardening
- having someone take over for a few hours on a regular basis
- taking the person for a drive
- arranging for the person to have a short holiday with a suitable family/whanau member or friend, or respite care in a facility of choice

### Disregard protests

Some people may object to 'strangers' helping with care, but this is not a reason to abandon ideas of getting help. The person will benefit from being less dependent on you, and you'll both benefit from a more relaxed and possibly more appreciative relationship – being together every minute of the day is a recipe for friction even without the complications of stroke.

### Arranging for help

The first step in getting help is to ask. Some family/whanau and friends may have offered to 'do something'. Tell them what is needed, what you have decided you would like from them. Realise that this will give them great satisfaction and pleasure. It will take away their feelings of helplessness and uncertainty about what to do.

Some family/whanau members or close friends may, through lack of experience or a feeling of inadequacy, not offer anything. Ask them, too. They will be pleased at your confidence in their ability and friendship.

Younger family who live at home, even if they work or are studying, may be asked to take some share of the care. Directly helping the person with stroke will give them invaluable experience and may open them up to more spontaneous involvement.

In the community, numerous organisations are set up to provide help of all kinds (**see pages 97–99**). No one need be without help.

### Help rosters

The best way to organise the help is on a roster basis. Make a list that covers the week, with times, names and what these people are going to do. (Better still, let a family member or friend organise the roster for you.) It will help the helpers to be able to plan what they're doing and when, and the person with stroke to anticipate who is coming and when.

### Re-evaluating the help needed

As rehabilitation progresses, the need for help is likely to change. Once the household routine settles down, transport to activities or having someone accompany the person on longer outings may be more of a priority.

Assess the help roster regularly and adjust it to what is presently required. Helpers may enjoy a change of job, or people with different aptitudes or available time-slots can be added to the roster.

Sometimes a workmate or other acquaintance may have a particular interest in medical aspects and would welcome the chance to take part in a recovery programme and befriend the person with stroke: for example, they might spend a couple of hours a week visiting for a chat combined with practising speech-language exercises.

## TAKING REGULAR BREAKS

Whatever the level of help, the primary caregiver needs adequate time off. A day each week is a reasonable break: time to recharge emotional batteries, catch up with friends and activities outside the home, have a rest. Taking a regular day off may mean a bit of extra effort, planning and help, but is vital to the long-term wellbeing of the caregiver and household. Don't skip

**Every day you learn something more. Each month you realise you're slightly better off than the month before.**



some weeks or feel guilty about handing over responsibility.

Arranging for the person to attend a day-care centre on a regular basis can achieve time off for the caregiver. Respite care (where the person spends a short period in a rest home) is also available. A Community Stroke Advisor will be able to give you information on respite care options and refer to the Needs Assessment Service Coordination (NASC).

Between days off, aim for some time to be set aside each day which the caregiver can call their 'own', with the understanding that during this time they will not take phone calls, not answer the door, not help to find anything, not make a quick cup of tea for anybody or be called on for any other reason. (see page 65).

## MAINTAINING A HEALTHY LIFESTYLE

When you are very busy and somewhat stressed, it is easy to let healthy living habits slip, and after a time this adds to stress and tiredness.

### What helps

- Eat mostly whole foods with plenty of vegetables and fruits, not just what's easiest and quickest to make (see page 45).
- Plan meals that you will enjoy, even if you have to prepare separate food for the person you are looking after.
- Stop for meals – a banana eaten on the way to the letterbox is better than no lunch, but a 20-minute break with a delicious sandwich will do more for you.
- Move more every day, outside whenever possible. Go for a walk, do some yoga, try gardening or dancing, swim if you have the opportunity, go for a bike ride or even do some housework. Spending energy on exercise makes more energy.
- Keep up your own interests: go to concerts, the bridge club, even join a new group that interests you – the stimulation will benefit both you and the person you are caring for.



## LEARNING ON THE JOB

Helping the person with stroke is an ongoing learning process, much of it to do with the individual stroke and the special needs of the person you are looking after. Many solutions and strategies will have to be 'invented' by the caregiver to fit the unique requirements of their situation. Some aspects can be taught by health professionals, e.g. how to transfer from bed to chair, maintaining a catheter, eating and drinking techniques for a person who has swallowing difficulties.

Caregivers are a vital part of the rehabilitation team, both in hospital and at home. Talk to staff about how to be involved from early on. If the caregiver learns exactly what is involved in rehabilitation therapy they will feel much more confident about encouraging and supervising the person in practising exercises at home, and will be able to adapt home routines to enhance the effects of therapy.

Observation and common sense lead to excellent solutions to everyday problems, e.g. using a cart instead of a wheelbarrow in the garden, replacing fiddly fasteners on clothing with velcro or large buttons. Being in contact with a stroke club means that inventive ideas can be shared, solutions to difficult problems can be brainstormed, and a wide variety of experience is instantly available.

### AS A CAREGIVER, I MUST REMEMBER...

**To take good care of myself** – this is not selfish, but will enable me to take better care of the person I am looking after.

**To ask for help from others whenever I think I need it** – even though the person I am caring for may object.

**To recognise the limits of my own endurance and strength** without feeling I have failed to measure up.

**To keep up my own interests and activities** just as I would if the person I am caring for was healthy.

**To do some things for myself alone**, while doing everything I reasonably can for the person.

**To feel it is normal to experience anger or depression occasionally** and to express these and other difficult feelings.

**To reject any attempts by the person to manipulate me** (consciously or subconsciously) through guilt, anger, self-pity or depression.

**To feel entitled to receive consideration** – affection, acceptance, forgiveness – for what I do, as long as I am offering these qualities.

**To take pride in what I am accomplishing**, including the effort and courage it sometimes takes to meet needs.

**To preserve my individuality and right to live my own life** in preparation for the time when the person will need less care.

**To expect to be supported as a caregiver** by medical staff and others just as much as the person affected by stroke is supported through their illness.

**To feel content with myself and what I am doing**, even without direct feedback, acknowledgement or praise.

# STROKE IN YOUNGER PEOPLE

Although stroke is much less common in younger people it does occur, even in children. Many of the recovery processes described elsewhere in this book apply, though inevitably some things are different.

## CHILDREN

- Parental and family/whanau support is particularly important when stroke occurs in the youngest age group.
- Emphasis should be placed on explaining the stroke and its consequences in a way that is appropriate and easily understood. With young children, hopeful matter-of-factness (no matter what the parents are feeling) will help to reassure – the child will take their cue from how adults are responding to the situation.
- Therapy may need to continue for a long time. Try to find ways to make therapy more appealing, more ‘fun’, and to integrate it in as normal a lifestyle as possible, e.g. swimming practice could be part of belonging to a swimming club with parallel participation in club social activities.
- Ensure that teachers and schoolmates have adequate information about the stroke and its effects, so they can be supportive. Teasing, shunning and misplaced disciplining are the result of ignorance, so make a point of identifying problem areas and ask a social worker or Stroke Foundation Community Stroke Advisor to provide enough explanation so that the child’s classmates and teachers have an understanding of how the stroke is affecting daily life.
- It is also helpful to advise the child how to respond directly to questions or taunts about their disabilities (and to explain how their schoolmates might be motivated by fear rather than malice).
- At the same time, don’t be overprotective. A stroke is going to present difficulties and these must be overcome rather than avoided.
- Brothers and sisters of the child may feel ‘left out’, especially in the early days, or have unexpressed worries about the stroke. Make time to give siblings special attention and reassurance, repeating information as often as necessary.
- Contact with other families in a similar position is beneficial for the whole family.
- A Stroke Foundation Community Stroke Advisor can liaise with the school, and link you up with families who can provide support and advice from their own experience with stroke.



## TEENAGERS

The psychological implications of stroke have particular importance in this age group. Most healthy teenagers find it hard to cope with feeling 'different' and the differences that a stroke makes can seem especially difficult.

- Altered body image and perception of attractiveness are issues that can present more problems than physical disability; counselling can be of great value.
- Family/whanau support is essential, but peer-group support may be more crucial at this age. Contacting and sharing experience with other teenage stroke patients should be encouraged (ask a Stroke Foundation Community Stroke Advisor to help arrange contact), as well as participation in a normal social life.
- Education and work training are of vital importance, for both self-esteem and successful rehabilitation. Teachers and employers should be given a thorough background to stroke, as well as explanation of the particular problems and needs of the young person (a Stroke Foundation Community Stroke Advisor will undertake this if you wish).
- The demands of entering relationships, establishing a career, encountering the challenges of adult life impose special needs. Teenagers with a stroke may need to actively seek 'bursts' of additional therapy or specialised counselling as indicated by life situations.

## YOUNG ADULTS

When a younger adult has a stroke, problems of family, finances and social implications may be accentuated.

- Childcare in particular may present difficulties for women. A specific rehabilitation programme and enough support should allow a mother to breastfeed, bond with and care for a baby.
- The children of a parent who has had a stroke need ongoing explanation and reassurance. It may take some time for them to come to terms with the new situation, and initially they may reject the parent. 0800 What's up – run by Barnardos – is a free, nationally-available counselling helpline and webchat for children and teenagers. They offer support and tools to deal with a situation (**0800 942 8787 or [whatsup.co.nz](https://www.whatsup.co.nz)**).
- For both partners, seeking information about intimacy and sexuality at an early stage can avoid unnecessary fears and psychological complications.
- Interaction with other families in a similar position is very helpful for information sharing, practical advice and support, but it is also important to keep up former contacts and to lead as normal a social life as possible.
- Some stroke clubs cater more to the needs of younger people (enquire at the Stroke Foundation).
- When the partner of a younger stroke patient is the caregiver, having adequate 'time off' and opportunity to pursue their own life interests becomes especially important.