



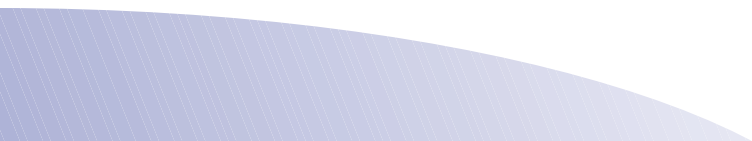
INFORMATION FOR CARERS OF PEOPLE WITH STROKE

*'Flatter me and I may not believe you.
Criticize me and I may not like you.
Ignore me and I may not forgive you.
Encourage me and I may not forget you!'*

William Arth



OF NEW ZEALAND INC



INDEX

- 01** INDEX
- 02** INFORMATION FOR CARERS OF PEOPLE WITH STROKE
- 07** PRIOR TO DISCHARGE
- 12** NOW THAT MY STROKE PERSON IS HOME
- 14** COMMONLY ASKED QUESTIONS AND ANSWERS
- 19** ACKNOWLEDGEMENTS
- 21** USEFUL NAMES AND PHONE NUMBERS

INFORMATION FOR CARERS OF PEOPLE WITH STROKE

HOW CAN THE STROKE FOUNDATION HELP ME?

The Stroke Foundation has community based Field Officers in your area. They are available to answer any questions you have about Stroke Services. They can help you to understand how things work in the hospital system and how to go about accessing things you may need in the community. They offer support and can provide you with information about Stroke Foundation Services. You can access your local Stroke Foundation Field Officer by calling 0800 - 78 76 53, or by looking in the phone book under Stroke Foundation for your local office.

The Stroke Foundation has some excellent written material (including this pamphlet) available at no charge. Ring us on 0800 - 78 76 53 or ask your Stroke Foundation Field Officer.

The Life After Stroke Guidebook is an excellent book written by New Zealand stroke experts for stroke survivors and their families. It is available for a small charge from the Stroke Foundation. You may also receive a Diary, which enables your stroke person to keep track of their progress over time.

‘Treat people as if they were what they ought to be and you help them become what they are capable of being!’

-unknown

IN HOSPITAL - WHAT DO I NEED TO KNOW?

Who do I talk to, to find out information now that my stroke person is in hospital?

- **Interpreters**

In some hospitals you will find interpreters to help those whose first language is not English. Ask when you first arrive at the hospital if you require this service.

- **Doctor**

The Doctor is responsible for medical care and deciding on the best options for medical management of your stroke person.

- **Key Worker**

Ask who your Key Worker is who has been designated to be responsible for co-ordinating your stroke person care.

- **Nurses**

Ask at the Ward office for an introduction to the Nurse in charge of your stroke person.

- **Social Worker/ Needs Assessor**

The Social Worker can talk through issues that have come up for you and your stroke person and can help you to arrange things like benefits or residential care if required.

- **Counsellor**

The Counsellor is there to help both the stroke person and the

Carer through this difficult and often life changing experience. There are many issues/changes both physically and psychologically to deal with. It may help you to be able to talk these through with someone experienced.

WHO ELSE MIGHT BE INVOLVED IN MY STROKE PERSON'S CARE WHILE THEY ARE IN HOSPITAL?

- **The Physiotherapist (P/ T)**

The P/ T is responsible for physical rehabilitation programmes and needs.

- **The Occupational Therapist (O/ T)**

The O/ T is responsible for assessing and providing aids and training in day-to-day activities.

- **The Speech Language Therapist (SLT)**

The SLT is responsible for communication, speech and swallowing problems.

- **The Needs Assessor**

The Needs Assessor is responsible for assessing and approving you for services needed on discharge e.g. Home care, personal care, carer support funding, residential care eligibility etc.

- **The Dietician**

The Dietician is responsible for dietary needs such as special foods and nutrition.

- **The Continence Nurse**

The Continence Nurse is responsible for issues relating to bladder and bowel control and management.

- **Spiritual and Cultural Health Liaison**

Many hospitals provide specific support to meet the spiritual and cultural needs of your stroke person carer the family/whanau.

WHAT IS A FAMILY MEETING?

(Called Discharge Planning Meetings by some hospitals).

- At a family meeting you can directly ask the staff questions about treatment rehabilitation programmes, progress, and the goals you as carer for the stroke person would like to aim for.
- You can request a Family Meeting through the Key Worker/ Social Worker or Charge Nurse. In some hospitals this is a routine procedure. Check with the staff to see if the hospital holds a Family Meeting or if you need to ask to arrange one.
- The hospital staff may ask the carer family and the stroke person, where appropriate, who they would like to have at the meeting.
- Family can make their own notes.
- After the meeting a written summary of the meeting should be given to the family member.

RECOMMENDATIONS:

- Make a list before the family meeting of the subjects you would like discussed.
- It is recommended a spokesperson be appointed.
- Don't be afraid to ask lots of questions. This meeting is for the benefit of you and your stroke person.
- Don't worry if you don't remember everything from this meeting. Remember that you can always ask for clarification or for more information at a later date.
- Ensure you have received enough information about how the stroke has affected your stroke person. Ask this at the family meeting if need be.
- Request that the decisions of the meeting are given to you in writing.
- Take this opportunity to talk about your needs as a carer.
- Ensure you have talked about your stroke person's probable recovery to your satisfaction.

PRIOR TO DISCHARGE

Home Trial

Often the hospital will work towards your stroke person coming home for a visit overnight or for a weekend before being discharged. This will give you an opportunity to see how you both cope with the changes.

Transitional Care

Some Hospitals provide this service. If available this service can offer a discharge plan with a hospital team comprising all disciplines needed (Doctor, Nurse, Occupational Therapist, Physiotherapist, Social Worker) attending your stroke person's own home. The stroke person will have goals to achieve within this time and have the input of the Therapists. The therapy is usually not as intensive as it would be within the hospital.

Residential Care

If your stroke person is being discharged to Residential Care (Rest Home or Private Hospital) this should be discussed at your Family Meeting. As this can be a difficult time, you may wish to speak with the needs Assessor/ Social Worker or your local Stroke Foundation Field Officer.

WILL MY STROKE PERSON RECEIVE REHABILITATION?

This should be covered at the family meeting. You might like to write it down on your list of questions.

What do I need to arrange before my stroke person is discharged?

Have you discussed your person's probable recovery to your satisfaction? If not take the opportunity to clarify this while they are still in hospital.

Care in the Community

There will generally be some continuing care facilities available for your stroke person. There is a range of community services available. Talk to your Social Worker, Needs Assessor or Stroke Foundation Field Officer about your needs.

OTHER MATTERS TO CONSIDER:

- **Home Care Service** is a service to provide home care support to the stroke person who wishes to live independently at home or to give support to a caregiver.
- **Drug Charges.** Find out how much the drugs that the hospital is recommending for your stroke person cost. If they are too expensive ask for alternatives. Check if your person's prescription form is included with their discharge summary and, on discharge, remember to pick up any needed medication.
- **Community Services Card.** Your stroke person might be eligible to apply through WINZ.

- **Respite Care** is a scheme in which a stroke person assessed as having a higher level of need can be temporarily cared for in a rest home or private hospital. There is a range of people who are qualified to make the assessment and pass the request on to the decision makers who are the Needs Assessment Service in your area. Some of the people who are able to do the assessment are your GP, the nurse at your GP practice, District Nurses to name a few.
- **Carer Support Subsidy** is a scheme for carer relief in which a stroke person can be temporarily looked after in a hospital, rest home or at home.
- **Activities.** Speak to your Stroke Foundation Field Officer for information about local Stroke Groups and other activities in the community.
- **Talking Books and large Print Books.** These are often available through your local library; there might be a small charge for them. The Royal Foundation of the Blind does not give out books to stroke survivors who do not meet their criteria.
- **Financial Assistance.** You may be entitled to additional benefits through WINZ. Speak to the Social Worker about this or call WINZ directly. Many stroke persons are eligible for Disability related benefits through WINZ. Information is available in a range of languages.

- **Driving.** It is very important you speak to the Doctor at the hospital or your GP regarding this. After a stroke there is a mandatory minimum stand down period of one month. This period may be longer, as determined by the Doctor/ GP. Where there is doubt about fitness to drive after the stand down period a driving assessment must be undertaken by a trained assessor. Generally there is a charge for the driving assessment. Speak to the Occupational Therapist or your Doctor about this.
- **Transport Assistance.** Your stroke person may be eligible to access half price taxi fares. Speak to your Stroke Foundation Field Officer. In smaller towns and rural areas transport can be a huge problem. Ring your local Citizen Advice Bureau to ascertain what transport assistance is available in your area.
- **Disability Parking Sticker.** Contact your local CCS Branch, or speak to your Social Worker or Stroke Foundation Field Officer.
- **Medical Alarm?** Your Stroke Foundation Field Officer can give you information on alarms.
- **Employment issues for you or your stroke person.** Visit your local Work and Income office (WINZ) to discuss your options about returning to or staying in paid employment.
- **Support Services.** Check that the services you will need at home have been put in place before discharge.

WHAT CAN I DO IF I AM UNHAPPY WITH ANY ASPECT OF MY STROKE PERSON'S HOSPITAL STAY?

- Speak to the Nursing Staff, Charge Nurse or Doctor.
- Follow the Hospital Complaints Procedure - pamphlets are available in most Wards.
- Get a copy of your stroke person's notes from the hospital.
- Speak with the Key Worker.
- Phone the Health & Disability Commissioner on 0800 -11 22 33 to get their advice (their pamphlets will generally be available on the Ward).
- Call your local Stroke Foundation Field Officer.

NOW THAT MY STROKE PERSON IS HOME

WHAT CAN I EXPECT NOW WE ARE HOME?

- Ensure services as discussed in hospital are in place, eg: personal care or home care
- You may need a review of the services you are receiving or to put in place some activities for your stroke person. Speak to your local Doctor or Stroke Foundation Field Officer.
- Support from your local Stroke Foundation Field Officer. If you need some advice call the local Stroke Foundation number or 0800 - 78 76 53.

WILL MY STROKE PERSON GET REHABILITATION NOW THAT THEY ARE HOME?

- Upon discharge your stroke person should have received a Discharge Summary. This will indicate if your person has been referred for further rehabilitation.
- Discuss with your doctor and rehabilitation therapists relevant timeframes of how long the rehabilitation will go on for.
- It is common for stroke persons to continue with outpatient rehabilitation after they are discharged. This might include Physiotherapy, Occupational Therapy, Speech Language Therapy or a range of other services. Generally these services are

available only for a limited time. You are encouraged to learn the exercises from the Therapist and be prepared to encourage your stroke person to do their own exercises regularly.

ARE THERE COMMUNITY ACTIVITIES IN WHICH MY STROKE PERSON CAN PARTICIPATE?

Some of the local activities may include:

- Local stroke clubs
- Day activity centres
- Local marae
- Local church
- Exercise groups
- Gym programmes
- Other community-run groups

Your Stroke Foundation Field Officer may be able to assist you in locating suitable activities if required. You can also ring your local Citizen Advice Bureau, Community Centre or Marae.

ARE THERE ANY SUPPORT GROUPS FOR ME AS A CARER?

Many areas have specific support groups for Carers. Ask your Stroke Foundation Field Officer if there is one near you. Some local maraes and churches also provide support services.

COMMONLY ASKED QUESTIONS AND ANSWERS

IS IT NORMAL THAT STROKE PERSONS ARE VERY TIRED?

Fatigue is very common after a stroke. Ask your Stroke Foundation Field Officer for more information about fatigue and stroke.

WHEN WILL THEY BE ABLE TO DRIVE AGAIN?

Speak to your local Doctor. They may be required to have a driving assessment. There is a minimum stand down period of 1 month.

OTHER ISSUES

- Personality/Behaviour changes
- Change to income
- Employment issues
- Psychological issues
- Sexuality issues
- Role changes
- Financial
- Driving
- Household chores
- Gardening

- Employment
- Enduring Power of Attorney - talk to your lawyer
- A Will - talk to your lawyer

Talk to your Doctor or Stroke Foundation Field Officer regarding any of these issues.

RECOMMENDATIONS

- Don't be afraid to ask for extra help
- Plan your days. Assign priorities.
- Allow for a rest period or time out each day.

Remember to observe your stroke person's rest times. This is important for their recovery and for you to have time out. You need to stay strong and well yourself, so you are able to take care of your stroke person.

- Consider obtaining a Personal Medical Alarm if your stroke person will be alone or if they are at risk of falling.
- Don't take on too much.
- Be careful not to take away the independence of your stroke person.
- Build a support system around you if possible.

Feedback from Carers indicates that at times you might experience some of these feelings:

- Being worried about not doing the right thing for the stroke person.
- Feelings of failure.
- Feeling criticized by others.
- A sense of grief, sadness or anger.
- Feelings of being alone or socially isolated.
- Financial worries.

It is normal to experience a range of feelings during this time.

WHO DO I GO TO FOR HELP?

There are a range of people you can talk to for advice and assistance

- Your Doctor.
- Your Stroke Foundation Field Officer.
- Your Social Worker.
- The Needs Assessor.
- Work and Income NZ (WINZ).
- An Accountant or Lawyer - did you know that many Citizens Advice Bureau (CAB) have a Lawyer who will talk to you without charge for a short session.
- A counsellor.

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 - even though the person I am caring for may object.
- To recognize my own limits - without feeling I have failed.
- To keep 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 other person.
- To experience feelings of anger or depression - and to express these and other difficult feelings.
- To reject any attempts by the person to manipulate me - through guilt, anger, self-pity or depression.
- To be entitled to receive consideration - affection, acceptance, forgiveness.
- To take pride in my accomplishments - including the effort and courage it sometimes takes to meet needs.
- To preserve my individuality.
- To expect to be supported as a caregiver - by medical staff and others just as much as the person with stroke is supported.
- To feel content with myself and what I am doing - even without direct feedback, acknowledgement or praise.

Create your own Haven/ Space

This could be an area within your home set-aside just for you, the caregiver. It is your space alone. It can be your bedroom, an office, a bench outside in the garden or on the porch. It's a place where you can relax, recharge and take a break.

A FINAL WORD...

Caregiving can be a demanding and lonely job. It is our hope that by you reading this pamphlet we have helped you in some small way in this journey. It is impossible to answer all your questions in a small pamphlet. There are a lot of books written about this subject, which you could get through your local library. There are Carer Support Groups set up around NZ, not only by our organisation, but also by others in your local community. If there is any other way we can help you, please do not hesitate to contact the Stroke Foundation on 0800-78 76 53.

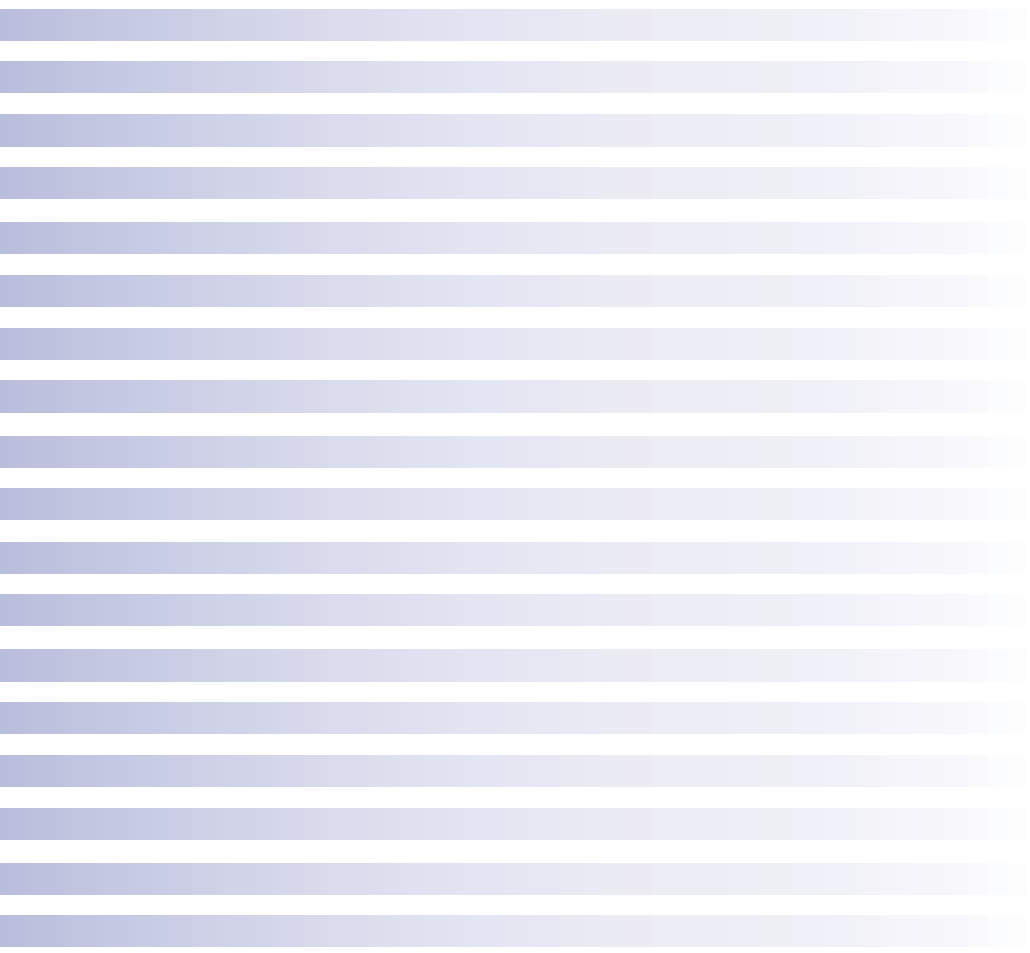
‘By perseverance, the snail reached the ark.’

- unknown



We gratefully acknowledge the Lion Foundation Trust for their support in the printing of this pamphlet.

Our thanks goes to the Stroke Foundation Northern Region Field Officers, whose initiative it was to put together this resource and who laid down the groundwork for it.



USEFUL NAMES AND PHONE NUMBERS:

Stroke Foundation :

Stroke Foundation Field Officer :

GP :

Pharmacy :

Hospital :

Specialist :

Key Worker in Hospital :

Social Worker :

Physiotherapist :

Occupational Therapist :

Speech Language Therapist :

Dietician :

Needs Assessor :

Contenance nurse :

WINZ :

CAB :

Others :



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