

LOOKING AFTER YOURSELF

Common challenges and top tips for carers of stroke survivors



Stroke happens suddenly and there is little that can prepare someone for the role of a carer.

Carers are the unsung heroes of the health system. While the focus is often on the professional health system's response to stroke, it is usually an unpaid carer who carries out the long-term work of caring at home for their whanau member.

Stroke happens suddenly and there is little that can prepare someone for the role of a carer. It is a role that can be rewarding and satisfying, however it can also be physically and emotionally exhausting.

In this guide, you will find common challenges and practical information about how to maintain your own health and wellbeing while you care for a loved one.

COMMON CHALLENGES FACED BY CARERS

Caring can come with its costs. Carers typically face challenges such as:

- confusion about how to manage complex health issues
- grief over the loss of the person they knew before due to the physical, cognitive, emotional and behavioural changes they may have undergone as a result of the stroke
- changes to relationship dynamics
- feeling frustrated by the demands and expectations of the stroke survivor
- the loss of freedom and independence as the stroke survivor's dependence increases
- uncertainty and loss of hope and dreams for the future.



TIPS FOR YOUR CARER JOURNEY

The role of caring for someone who has had a stroke changes as the needs of the stroke survivor change over time. To help you take care of yourself at the same time, it may help to identify practical things you can do as your needs and the needs of the person you care for change:

HOSPITAL BASED CARE

The stroke survivor may be in hospital and receiving intensive rehabilitation. The carer needs to understand the hospital system, work with professionals and make decisions related to the discharge plan. This can be a stressful and uncertain time for carers. The focus is on the care and recovery of the person who has had a stroke. During this phase it is important to:

- find people who can help explain to you what is happening with treatment and what to expect next in a person's rehabilitation, as well as what this means for you as the carer
- build a strong network of family, friends and professionals who can give you practical and emotional support
- be kind to yourself – do not stress about things you cannot change.



LIVING BACK AT HOME

Health service input is significantly reduced when a stroke survivor returns home, and you become the main carer. This stage can be hard work and can continue for a long time. It is easy for your role as a carer to take over your life and to forget about your own wellbeing. During this phase it is important to:

- develop resilience to better take care of your wellbeing (please refer to 'Strategies to Build Resilience' page of this guide)
- reach out for help – you do not have to do it alone. Contact your local Community Stroke Advisor (0800 78 76 53) or talk with other people who are going through similar situations
- take time for yourself and stay connected with friends and family
- be aware of the signs of burn-out – such as poor sleep, irritability, chronic fatigue, increased illness, and anxiety – and take action early
- speak with the person you care for and work out how both of your wellbeing needs can be met
- take advantage of the services and resources available in the community, such as respite care. Talk to your Community Stroke Advisor, family doctor or primary care nurse for further advice
- maintain a healthy lifestyle – regular exercise, eating healthy meals and getting enough sleep are all important ways you can take care of your own wellbeing
- be proud of the job you are doing and the expertise you have developed to be a resourceful and effective problem solver.

YOU HAVE TO BE A STRONG ADVOCATE AND I DON'T THINK YOU CAN BE A STRONG ADVOCATE WITHOUT DOING SOME RESEARCH OR ASKING PEOPLE TO EXPLAIN WHAT IS HAPPENING.

ONCE I LEARNT A BIT MORE ABOUT RESPITE CARE I PURSUED IT, YOU ACTUALLY NEED TO UNWIND AND I FOUND IN MY INSTANCE THAT I WASN'T COMFORTABLE WITH BEING AT HOME, I NEEDED TO GET OUT OF TOWN.

RESIDENTIAL CARE

Sometimes, if the carer needs a break, their health deteriorates or the stroke survivor's needs become too difficult to manage at home, the stroke survivor may need to move to residential care. This could be for temporary respite placements or as a permanent change. This is another difficult period of adjustment and carers can feel a sense of guilt, regret and a loss of purpose. If you reach this point, make sure you:

- plan ahead for this possibility rather than leaving it until there is no choice
- get good information about how to find the right residential placement and what

financial subsidies may be available. Talk to your Community Stroke Advisor, family doctor or primary care nurse for further advice

- recognise that while you may no longer be the primary carer, you still have an important role in providing emotional support and advocacy for your loved one
- acknowledge that this change may enable more personal life choices and time for other relationships
- stay connected with friends and whānau for support throughout this process.

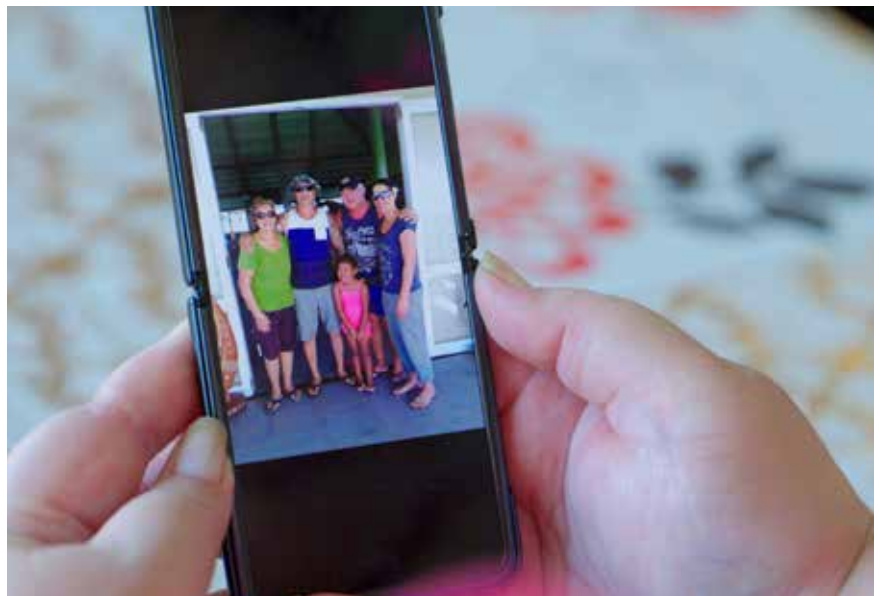


THINGS ARE DIFFERENT. THIS IS LIFE-CHANGING. YOU NEED TO BUILD A NEW RELATIONSHIP WITH A NEW PERSON AS THEY ARE NOT HOW THEY USED TO BE.

BUILDING RESILIENCE TO ACHIEVE WELLBEING

Resilience is the ability to bounce back – and move forward – during periods of change, adversity and stress. There is no rule book for building resilience. It is a skill that can be learned and cultivated over time, building on the unique strengths we already have. It can decrease the burden and distress that can be associated with the carer role and helps us maintain our optimum wellbeing.

YOU NEED SUPPORT FROM PEOPLE IN THE SAME POSITION – PEOPLE WHO CAN UNDERSTAND YOUR LOSS OF FREEDOM, LOSS OF DREAMS AND YOUR PLANS FOR THE FUTURE.



I SPOKE WITH HEALTH PROFESSIONALS SO I WAS AWARE OF WHAT HAD HAPPENED AND WHAT WAS GOING TO HAPPEN IN THE FUTURE – IT MEANT THAT I WAS ABLE TO PREPARE NOT ONLY OUR HOME BUT OUR NEW WAY OF LIFE.

STRATEGIES TO BUILD RESILIENCE



GAIN THE KNOWLEDGE YOU NEED TO MAKE GOOD DECISIONS AND SOLVE PROBLEMS

- Find out as much as you can about stroke, recovery and what resources are available to support you. Community Stroke Advisors (0800 78 76 53) can help you with this.
- Building your knowledge about stroke can help you gain a sense of control and better equip you to solve problems.
- Over time, you become your own expert. You develop unique skills and strengths that work for your situation.



EMBRACE HEALTHY THOUGHTS TO HELP YOU COPE EMOTIONALLY

- Accept the new reality. This decreases stress and gives you strength to take action. This involves accepting what you have lost.
- Practice gratitude. Acknowledge and celebrate the good things in your life. Developing habits such as keeping a gratitude diary, cherishing your friendships and noticing the natural world around you can help bring back a sense of control to your life.



REACH OUT FOR HELP AND BUILD POSITIVE SUPPORT NETWORKS

- Be honest about your own limits of ability to care. Recognise your strengths but be prepared to ask for advice and support.
- Create positive support networks with whānau, friends, and professionals. Ask for specific help. People often want to help but are unsure what will be most useful.
- Take advantage of respite care, day programmes or companion services.

Learning to let go and take time for yourself helps everyone.

- Community Stroke Advisors can tell you about where and how you can access relevant services available in your community. There may be local support groups you could join, or you could be connected with others who have found themselves in a similar situation.



NEGOTIATE YOUR RELATIONSHIP WITH THE PERSON YOU CARE FOR SO THAT YOUR ROLE AND NEEDS ARE RESPECTED

- Communicate clearly with the person you are caring for so you understand each other's needs to maintain wellbeing. It is okay to review and revise what your needs are over time – the nature of your relationship changes due to the stroke survivor being dependent on you for everyday activities. The stroke survivor may not always understand how demanding caregiving can be. This is often because of the effects of the stroke.





WHERE TO FIND HELP AND INFORMATION

Stroke Foundation of New Zealand

The Stroke Foundation Community Stroke Advisor service can help carers by providing support, information and advice to build knowledge and skills. Our Community Stroke Advisor team work to ensure stroke survivors and their family and/or carers are receiving the right services.

Phone: 0800 78 76 53

Our website: stroke.org.nz is a useful source of information.

Facebook: search for @StrokeFoundationNZ or 'Stroke Foundation Life After Stroke Group' and join our community of stroke survivors and carers.

OTHER HELPFUL LINKS

Carers New Zealand
Carers.net.nz

Ministry of Health
Search for 'carer support':
health.govt.nz

Mental Health Foundation
Search for 'wellbeing':
mentalhealth.org.nz

