

Caring For Yourself Module

Welcome and Module Overview

This summary reviews the key points discussed in the module on caring for yourself when you are caring for a family member with TBI. It includes some tasks for you to work on. This module focused on the physical and emotional and health challenges family members who care for people with TBI can have. Highly stressful situations and reduced support can have a negative impact on family members, and this can lead to poor health, stress, fatigue and mental health concerns such as anxiety and depression.

Your Checklist

Here is a list of the topics we will cover in this summary. Tick these off as you go:

1. What is stress?
2. What are the signs of stress?
3. How to deal with stress
 - a. Active versus Passive Coping
 - b. Your Demands and your Resources
 - c. Maintaining Friendships
 - d. Two Simple Mindfulness Exercises
 - e. Regain Control Over Your Life
4. Getting extra help for Yourself
 - a. What supports do you need?
 - b. Respite Care
 - c. Support Groups
5. Getting Extra Help for Your Family Member
 - a. Self-Advocacy
 - b. Additional Services
6. Summary
7. Your Checklist

1. What is stress?

There are many things in our lives that can cause stress. Looking after a family member with a traumatic brain injury can be one of those things and stress and increase and decrease at different

points of time. Sometimes the pressures of juggling caring for a family with other life roles can become overwhelming. In some cases, these pressures can lead to anxiety disorders and depression.

Stress is a normal human experience and can be useful when dealing with demanding situations. For example, it can help us to perform to the best of our ability when giving a speech or playing sport. But it can also be a problem for us if we are constantly in a state of stress.

Thankfully, stress is very manageable. There are many ways to deal with stress, and simple techniques practiced frequently can really help.

2. What are the Signs of Stress?

The symptoms of stress can vary between different individuals. The most common signs are:

- Sleep disturbances
- Muscle Tension
- Irritability
- Anxiety
- Depression
- Tiredness
- Lack of Motivation
- Difficulty Concentrating
- Change in Eating Habits
- Increased use of alcohol or other drugs
- Unhealthy eating and decreased level of exercise

These symptoms also affect how you deal with the events that cause stress, thereby worsening the stress. For example, if you are tired and irritable, you may respond to your family member differently which may make them more angry or aggressive.

Tick the signs that you have been experiencing in the last couple of weeks. If you have been experiencing more than two or three, it may be helpful to see your local doctor or seek help from a Clinical Psychologist. You and your family may also need more support in the home, including support from additional carers, therapists or respite.



3. How to deal with Stress

You can learn to manage stress by using various techniques, such as monitoring and challenging the way you think about events, slow breathing and solving your problems in a structured way. You can also make changes to your lifestyle to help cope with stress such as exercising, cutting down on drug and alcohol use and doing things you enjoy.

Some of the most **important tips** for carers include:

- ask for help when you need it
- take time for yourself (e.g. respite services)
- exercise, eat healthily and sleep well
- relax regularly
- keep up social contacts
- attend a carers group for support
- access all available services and funding
- acknowledge and deal with feelings.



Active versus Passive Coping

When thinking about managing your stress, it is helpful to distinguish between active and passive coping.

Passive coping involves just waiting and hoping that a situation will get better or go away or simply wallowing. This approach may include not facing the problem, hiding away from it or pretending that the stressful situation isn't important (when it really is). Passive coping might also involve destructive behaviours such as drinking too much alcohol, abusing drugs or comfort eating. For a lot of people, passive coping usually involves a lot of worrying about the problem without actually doing anything to solve it.

Alternatively, **Active coping** is all about doing something to:

- Directly solve the problem
- Get extra help
- Support yourself through the difficult time

Active coping is the type of coping approach that seems to work best. This style helps people to feel more in control and is more likely to lead to problems being dealt with in the most effective way. It's important to note that active coping is not only about trying to solve the problem, sometimes that is not possible. You can, however, learn how to better manage feelings about the situation by changing your thoughts and behaviours.

Your Demands and your Resources

When your demands are greater than your resources, you can feel stressed, pressured and overwhelmed. When your demands and resources are in balance, you are likely to feel much more in control and therefore be able to cope with the stressors in your life.

The first step is identifying your demands (the sources of your stress). Think about areas such as work, family, friends, relationships, health and others. Remember, your role as a carer to your family member with a brain injury may not be your only source of stress.

Next, identify your resources. These can include anything in your life that helps to you manage your stress. Again, think about resources such as supportive relationships, physical resources and supports such as healthy diet, sleep and exercise, personal skills such as sense of humour and a hard-working attitude, or other resources such as money, extra time etc.

So, we want to think of ways we can decrease your demands and increase or enhance your resources.

Maintain your friendships

Maintain an identity of your own separate from the caring role, and keep your links to the world outside caring. Be aware that some friends may tire of you talking about the problems of being a carer. You may become resentful and lose friends by expecting them to provide more support than they are willing to give.

Where possible, seek support from other carers and don't expect too much from friends, even if it means pretending to be interested in things other than your own problems as a carer.

Two Simple Mindfulness Exercises:

These two exercises are simple and easy and will help you to be present in the moment and reduce feelings of distress.

1. Take Ten Breaths

This is a simple exercise to centre yourself and connect with your environment. Practice it throughout the day, especially any time you find yourself getting caught up in your thoughts and feelings.

1. Take ten slow, deep breaths. Focus on breathing out as slowly as possible until the lungs are completely empty—and then allow them to refill by themselves.
2. Notice the sensations of your lungs emptying. Notice them refilling. Notice your rib cage rising and falling. Notice the gentle rise and fall of your shoulders.
3. See if you can let your thoughts come and go as if they're just passing cars, driving past outside your house.
4. Expand your awareness: simultaneously notice your breathing and your body. Then look around the room and notice what you can see, hear, smell, touch, and feel.

2. Notice Five Things

This is another simple exercise to centre yourself and engage with your environment. Practice it throughout the day, especially any time you find yourself getting caught up in your thoughts and feelings.

1. Pause for a moment
2. Look around and notice five things that you can see.
3. Listen carefully and notice five things that you can hear.
4. Notice five things that you can feel in contact with your body (for example, your watch against your wrist, your trousers against your legs, the air on your face, your feet upon the floor, your back against the chair).
5. Finally, do all of the above simultaneously

Regaining control of your life

In the aftermath of a brain injury, a family tends to put life on hold and focus everything on the person with the brain injury. However, in the long term families often find this never changes, and the whole family begins to suffer.

Carers need to establish a balance in life that allows enough self-care to be effective over the long term. Respite care is an important part of this, but it also means good time management and priorities to allow everyone's lives to return to normal as much as possible. Make time for your usual hobbies and interests as much as possible.

4. Getting Extra Help for Yourself

It is crucial to get extra help if you feel that your stress is leading to clinical anxiety or depression. Guilt, anger, resentment, fear, stress, anxiety, depression and grief are some of the emotions that will be encountered while caring for someone with a brain injury. With time, the worst of these feelings will go. It is normal to feel as if you are going crazy at times, and it does not help to try to suppress or deny what you are feeling.

The best way to deal with your feelings is to accept them, but make sure you can talk about your feelings with someone who understands, whether it is a family member, friend, counsellor or support group. Depression is always a potential concern for carers, and you should seek professional help if it becomes a serious issue.

Clinical depression involves ongoing low mood or lack of pleasure and interest in most of your daily activities. It persists for two or more weeks and is accompanied by other symptoms such as trouble sleeping, difficulty concentrating, fatigue and weight and appetite changes. A lot of people also have thoughts of suicide and hopelessness. **Clinical anxiety** involves frequent and excessive worry and feelings of anxiety that persist and interfere with your work or social life. Clinical anxiety may lead you to avoid situations, people and everyday tasks, or make it quite difficult to do your normal activities.

Respite care

Long-term carers find that taking time out for themselves is vital for survival. It can be provided at home or in a variety of other settings, for just a few hours or even a week to allow a holiday. Make sure you have a regular schedule of breaks using respite care. Initially families may dislike a stranger caring for their family member but there are plenty of good quality services around that can make a big difference to helping you care more effectively.

Support groups

You can meet others in a similar position, have a break, find information and get support from others who know what your situation is like. Sharing ideas, feelings and concerns can help you feel less isolated. Sometimes friends won't understand your situation, but a support group will. If there are no support groups in your area, consider joining an online brain injury support group.

5. Getting Extra Help for Your Family Member: Additional Services

It is easy to fall into the role of 'super carer', thinking you can work, look after the rest of the family, and care for your injured family member all by yourself indefinitely!

An essential aspect to managing stress is knowing when and how to access extra help. Where possible, try to delegate. For example, Ann might be able to get some extra carer time for John so that he is able to engage in fun activities which will reduce his own stress as well as give Ann some more time for herself. Jenny might be able to get some of Tran's friends to take him to football games on the weekend so that she is not the only person trying to motivate him to engage in activities.

Self-advocacy

At some point, carers will find themselves unhappy with the level of support from a particular hospital, health professional or welfare association. You have the right to expect appropriate support or treatment, and should be assertive in claiming what you want. There are grievance procedures and appeal processes in most cases. Your Brain Injury Association may be able to assist, or link you with advocacy organizations.

Additional Services

For crisis and support:

- Lifeline: <https://www.lifeline.org.au/> phone: 13 11 11

Support for family and Carers:

- Icare NSW: <https://www.icare.nsw.gov.au/treatment-and-care/services-and-support/families-and-carers/#gref>
- In NSW – Carers NSW: <https://www.carersnsw.org.au/>

For information about Mood, Anxiety and Stress Disorders:

- Beyondblue: <https://www.beyondblue.org.au/>
- Black Dog Institute: <https://www.blackdoginstitute.org.au/>

- Australian Psychological Society: <https://www.psychology.org.au/for-the-public/Psychology-topics/Stress>

Peak Bodies and Advocacy Services for Brain injury

- In NSW and Qld: Synapse: <http://synapse.org.au/>
- Brain Injury Australia: <https://www.braininjuryaustralia.org.au/>

6. Your Checklist

Your tasks to do following this module are:

- Review the Caring for Yourself module again
- Re-read and print out this module summary (it won't take long!)
- Assess your own level of coping
- Identify any areas of stress
- Complete the stress symptom checklist
- Practice the two helpful mindfulness exercises
- Implement any helpful coping strategies from Section 3.
- Explore the frequently asked questions and extra resources sections on the website
- Reward yourself for completing this module.

Summary

Congratulations on completing the Self-Care module. In this summary we discussed stress and how it affects our thinking, behaviour and emotions. We also identified different types of coping and how to implement coping strategies. Two mindfulness exercises were provided for you to practice in your own time. The importance of taking time for yourself, asking for help and seeking additional services and respite were also discussed.