

SECTION 2.

Looking after yourself

2

Looking
after yourself



*Okay, so this is really important: **look after yourself.***

Giving yourself the best possible opportunity to be the best version of yourself is what this section is all about. Looking after your emotional and mental health will help you adjust to life changes and deal with the ups and downs of life (with or without cancer). Looking after yourself will help you connect with a 'new normal': who you are now, living with brain cancer. Looking after your fitness, diet and lifestyle can help you stay strong and do the things that are important to you.

This section will also introduce goal setting/making plans as a way to help you manage challenges and get you back into the activities you want to do.

A PERSONAL EXPERIENCE

Will I ever get back to normal?

"The effort you put into living the kind of life that makes you feel 'normal' is really important. Maybe you won't get back to 'normal' as you knew it, but remember that life goes on. There are lots of other factors that change our lives regardless of cancer, such as changing jobs, having children, getting older, etc."

– SHERAN



Local doctor in your support team

Building your support team is an important part of taking care of your health and wellbeing in the long term. Having a good relationship with your specialist team is important, but having a general practitioner (GP) who knows you and your situation is also vital for your wellbeing. GPs may not be experts on brain cancer but they do have expertise in managing your general health, and being as healthy as possible will help you live your best life and do the things most important to you. If you have a regular GP, they will be getting regular updates from your specialist team, so try to connect with your GP on a regular basis. If you don't have a regular GP, ask around and get

a recommendation from friends or people around you, and give them a road test. GP's will be able to connect you with local health professionals and services that can become important for your health over time.

Depending on what your needs are, you may be eligible for a GP chronic disease management plan. This is the chance to talk with your GP about your health and make plans about things that are important to you. The GP can refer you to a physiotherapist, dietitian, occupational therapist, psychologist or other health professional to help you to work towards achieving your health plan. The GP plan allows you to access Medicare funding to help pay for a limited number of sessions with these health professionals.

A PERSONAL EXPERIENCE

What does all this mean for my future?

One thought that often comes to mind when I think about what might happen to me is one that applies to life even in the absence of this diagnosis, so it comforts me: "Nothing is certain in life; no one knows for sure what is going to happen. The trick is to concentrate on what is happening in the moment and not worry too much about the future, because that only ruins the present."

I also find that thinking about the long-term cancer survivors I know of, always helps to shift my mindset back to being positive.

— MARY



Making sense of what is going on

It is common to find that your worldview shifts after being diagnosed with a life-changing illness. Having brain cancer can take away your feelings of safety and security, and leave you feeling like you don't know how to move forward. Support from a mental health expert, such as psychiatrist, psychologist or counsellor, can help you manage difficult emotions, find ways of coping and see how to move forward. It is common for people to seek mental health support after a brain cancer diagnosis even if they do not have a mental health condition. Connecting with your loved ones and with others who have experienced brain cancer is another great approach.

We all experience illness at some point in our lives. Adjusting to living with an illness is not easy! Changing some of your beliefs, attitudes and ways of thinking can make it easier to accept changes. This might include re-thinking your plans/goals or adjusting some of your roles in life. Thinking about what matters most to you (your core values) can help you steer through these changes. This involves a process of self-discovery, self-renewal and transformation. Adjustment and acceptance is not a passive process, it's about taking action. It's a special kind of action because it is based on what's important to you.

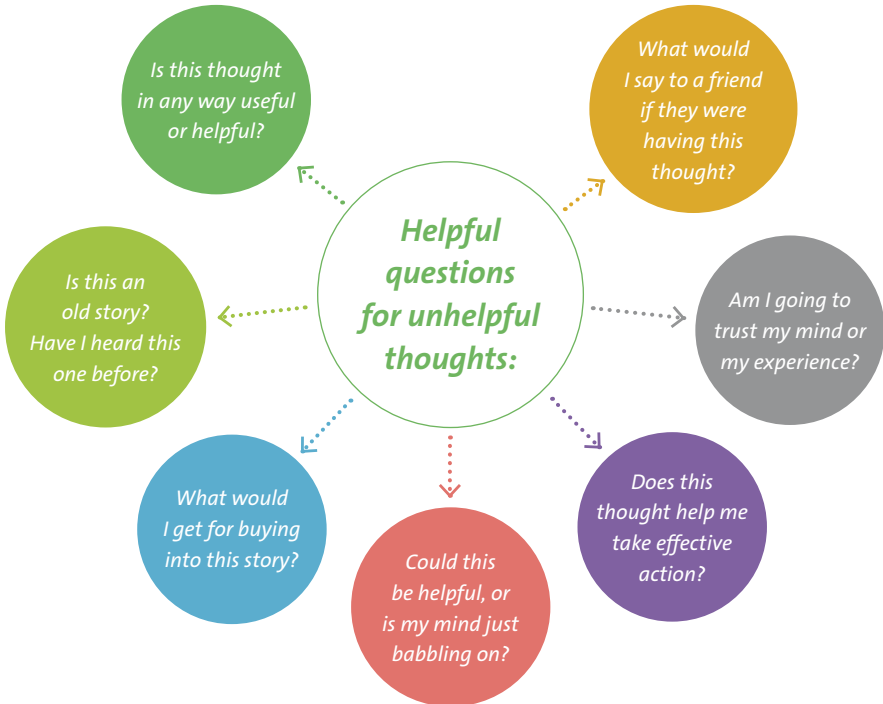
Develop the courage to solve those problems that can be solved, the serenity to accept those problems that can't be solved, and the wisdom to know the difference.

The Serenity Prayer,
Reinhold Niebuhr, 1951

Dealing with unhelpful thoughts

It is very common for people living with an illness to experience painful and/or unhelpful thoughts and unpleasant emotions. Understanding that this can be part of the experience of living with brain cancer and giving yourself permission to ask for support can help. You might find it useful to acknowledge these thoughts and feelings while remembering that feelings pass and that you have the power to change your thoughts. When you change the way

you think, you change the way you feel. Working to be kind to yourself at all times and focusing on living in the moment are powerful ways to reduce the impact of unhelpful thoughts and unpleasant feelings. Other approaches used by psychologists/counsellors, such as cognitive behaviour therapy (CBT), acceptance and commitment therapy (ACT) or mindfulness, can help you change unhelpful or unhealthy ways of thinking, feeling and behaving.



A PERSONAL EXPERIENCE***Feeling emotionally overwhelmed***

I had a number of panic attacks in between diagnosis and surgery because I had not processed what was happening to my life, and I had a terrifying fear of the unknown. Had I known I would eventually get through my treatment, I would have been okay. I was also extremely worried about how my family would cope.

I do not agree that fear of the unknown is the basis of any depression, anxiety, or powerlessness that accompanies this illness. For me, I think the drive to get through treatment successfully is what kept any isolation or sadness at bay. People really rallied around me; there was no opportunity for isolation.

Managing scan anxiety

This supposedly gets better over time, however I find my 'scanxiety' varies a lot. It is often influenced by what I've been exposed to in the lead up to the scan and results. If I hear something scary about cancer that I would ordinarily sweep under the rug, it tends to stick in my mind more in the lead up to a scan. If I happen to be getting headaches, even if paracetamol sorts them out or I know there is a reason to be getting them like hormones, irrationally it makes me anxious about the scan. The antidote may be clearing your mind and listening to your inner voice of reason, or talking to someone who is good at being that voice if you just can't muster positive, reasonable thoughts. And when you get the good news that there is no news, tell all your friends and CELEBRATE! If ever there was something to celebrate, it is that.

– SHERAN

Our mind: the problem-solving machine

Our mind is always trying to 'solve our life', and sees everything as if it were a problem that needs to be solved. However, this is not always a useful approach. A lot of things in life are more like sunsets: what a sunset needs is simply for us to show up, be present and witness it.

What if a lot of the things that cause you struggle in life don't need your attention in

a puzzle-solving sort of way? What if instead they just need you to show up? If that's the case, what you want to do is slow down, look, feel and see what actually shows up in your experience, and learn from that – rather than reacting to what your mind is saying. You may have to slow down, show up, and look a thousand times before doing this becomes more natural.

Being present

Unfortunately when we get caught up in day-to-day problem solving, we miss out on enjoying or appreciating life. It's hard to appreciate what we have right now when we're focused on all the things that are bad or wrong, or not quite right, or need

to be fixed and sorted. Part of the work a psychologist can do with you is to help you learn how to shift from puzzle-solving mode to focusing on what's here and now.

Remember, it's hard to get any happiness from your life if you're not actually present to appreciate it.

A PERSONAL EXPERIENCE

When will it come back?

This is a scary question, but it is also like asking, "How long is a piece of string?" I am comforted by the fact that I am under the watchful eye of the team at the hospital, and should this happen at some point, I have support.

I think to feel anxious is a totally natural reaction. I have learned some breathing techniques to help get myself through these moments. I often practice these or meditation while trapped in the MRI tube. Try to focus on what you can control, like making positive changes to your lifestyle. If the fear of recurrence is overwhelming, speak with a counsellor or psychologist. They may be able to teach you some strategies to help you manage your fears and have a more peaceful frame of mind.

Facing your own mortality

Everyone copes with a brain cancer diagnosis in their own way. Your reaction may depend on your age, family situation, cultural background and spiritual beliefs.

Thinking about your mortality is a sure way to bring on negative emotions. Don't be afraid to talk about your fears with a close friend, family member or health professional. Trying to focus on what you have now and appreciating the smaller things can help. Value your heart's desires for what you want to do and how you want to be during your time on this planet. Using that as a guide, it's possible to make plans and take action to change your life for the better. Accepting what is out of your personal control and committing to taking action that enriches your life provides a way forward. Remember, we are all born and therefore we will all die. It's not something we speak about but it is a fact of life.

“The emotional impact of brain cancer and mortality hit me like a sledgehammer. Pandora’s box had been opened! In retrospect, a better analogy would be that it was like being hit by the first wave of a tsunami, which hits you hard again and does damage a few times until, with time, acceptance and getting back to life, it is always present, like waves coming up onto a beach in the back of my mind. There’s nothing that can be done to stop the waves, but I can exercise some control over how strong an impact they have on my wellbeing.”

– Sheran

Recommended Resources

TED TALKS:

Be open to experiencing your emotions – they are part of life and can be useful. Learn strategies for stress reduction by reframing how you view stress.

www.ted.com/talks/kelly_mcgonigal_how_to_make_stress_your_friend

Speak to someone you trust and be vulnerable.

www.ted.com/talks/brene_brown_on_vulnerability

BOOK & EBOOK: THE REALITY SLAP BY DR RUSS HARRIS (2011).

This thoughtful book, based on Acceptance and Commitment Therapy, is about dealing with unexpected changes on life.

BEYOND BLUE: BRAIN TUMOURS, ANXIETY AND DEPRESSION

It's normal to not feel good about having a brain tumour. This fact sheet can help people understand if you need help to manage the emotional and practical impacts of how this might be making you feel.

<https://www.beyondblue.org.au/>

THE BRAIN TUMOUR CHARITY: DEPRESSION AND BRAIN TUMOURS

Brain cancer can affect a person in a number of ways that could potentially lead to some form of short or long-term depression.

www.thebraintumourcharity.org/understanding-brain-tumours/living-with-a-brain-tumour/side-effects/depression-and-brain-tumours/

CENTRE FOR CLINICAL INTERVENTIONS: LOOKING AFTER YOURSELF

This is a helpful research-based online resource on a range of issues including health anxiety, depression and tolerating distress.

www.cci.health.wa.gov.au/Resources/Looking-After-Yourself/

Who can help?

	PSYCHIATRIST	PSYCHOLOGIST	COUNSELLOR
Training	Psychiatrists must first graduate from medical school as a doctor and then complete further medical training specialising in psychiatry (the study and treatment of mental disorders.)	Registered psychologists complete a degree with a major in psychology or a four-year Bachelor of Psychology. This is followed by either a two-year postgraduate psychology qualification or two years of supervised experience with a registered psychologist.	To practise informally as a counsellor, there is no mandated education or training. To practise formally as a registered counsellor, a person typically completes two to three years of study, and 12 months of supervised training. The terms 'counsellor' and 'psychotherapist' are self-regulated.
What they offer	Psychiatrists treat mental health conditions like depression and anxiety using medications and/or talking therapies. They use a variety of evidence-based approaches to help people manage difficult emotions and ways of thinking.	Psychologists are more likely to view problems from a behavioural perspective. Psychologists use talking therapies and a variety of evidence-based approaches. They will ask you about your thoughts, behaviour, feelings, and the core reason for your concerns. Psychologists are not permitted to prescribe medication.	Counsellors use talking therapy and typically encourage their clients to direct the session. Through reflecting, listening, and sometimes challenging the statements you make, the counsellor can create an environment where you are able to rebuild your own sense of trust and intuition.
Finding a service	Psychiatrists are specialists, so you need a GP referral to see one. Costs vary and there is a Medicare rebate. Generally an initial consultation is \$360 with a \$221 Medicare rebate, while follow-up consultations are \$180 with a \$113 Medicare rebate.	Psychologists can be approached directly. However, if you would like a Medicare rebate to cover some of the cost, you can ask for a Mental Health Treatment Plan from your GP. Anyone with cancer is eligible for this plan. Rebates range from \$85 to \$125, with fees ranging from bulk billing to \$250 per session.	There is no need for a referral to see a counsellor. Word of mouth recommendations and internet searches may be the best way to find a suitable counsellor. Fees vary and there is no rebate available.

Practical ideas to make life a little easier

Many ideas develop from talking to others about some of the challenges you face. Sometimes talking about these things can really help. Sometimes, though, you need to put strategies into action, and trying something different to deal with a challenge makes more sense. Below are some practical ideas and suggestions from people with brain cancer and those who support them (like support and nurse coordinators).

INFORMATION:

- always get information from someone you trust and seek their guidance about online resources
- try to avoid a Google search; instead go to reputable websites recommended to you
- ask questions of health professionals and your treating team
- don't worry about asking questions twice or asking multiple people.

Recommended Resources

QUEENSLAND UNIVERSITY OF TECHNOLOGY: IT'S OKAY TO ASK BOOKLET

This booklet has questions to ask your healthcare team about your brain cancer. It was written in collaboration with brain cancer survivors, family members and health professionals. It is available in 10 languages. To download the booklet visit the BTAA website

www.btaa.org.au/resources



DAY BY DAY:

- take life one day at a time
- spend time doing things that make you happy, such as coffee with a friend, or a walk in nature.

KINDNESS AND SUPPORT:

- be kind to yourself
- try not to compare your life to your friends' and colleagues'; just acknowledge that they have a different path
- surround yourself with friends and family who are supportive and encouraging.

DEALING WITH STRESS:

- reduce stress where you can
- take the opportunity to focus on what is actually important to you and do the things that best fit with your values.

AT HOME:

- try to create a quiet area within your home that you can retreat to if you need some 'time out'
- busy households can be fun, but tiring. See if a shared understanding of 'quiet time' in the house can be negotiated. It might be a couple of hours each afternoon or early evening, or at some time on the weekend. Even young children can learn to play quietly for a period of time
- save time and energy by sorting your home environment. For example, organising your clothes hanging in the wardrobe by colour can help reduce time and energy spent looking for what you need
- cooking extra meals to freeze can be good for times when you are tired or busy.

“I always stress to patients and family the importance of being kind to themselves. So not beating themselves up when they are forgetful, or have some word finding difficulties, as that only makes it worse and leads to greater frustration.”

– Neuro-oncology nurse

Food and nutrition

It is important to try to eat well and keep your fluids up during and after brain cancer treatment. Sometimes side effects can make it difficult to prepare and eat a balanced diet. Treatments such as radiotherapy, medication and chemotherapy, can cause some people to experience taste changes, fatigue (severe tiredness), increased appetite, nausea or constipation. Below are some tips dietitians recommend to help manage these symptoms.

INCREASED APPETITE:

Some medications, such as steroids, can increase your appetite. To curb weight gain due to steroids, the same strategies used to control weight in general are recommended. Fill up on high-fibre (wholegrain breads and cereals) and low-energy (fruits and vegetables) foods. Include a source of low-fat protein at each meal (such as lean meat, chicken, fish, beans and tofu). Limit foods high in sugar as often they do not satisfy hunger.

STEROID INDUCED WEIGHT GAIN:

Steroids can affect your metabolism and how your body deposits fat. It can be very difficult to lose weight while taking steroids. It is generally advised to try maintain your weight while on steroids. If necessary, focus on weight loss once the steroids are stopped and your body readjusts.

CONSTIPATION:

Eat high-fibre foods, such as wholegrain breads, unpeeled fruits and vegetables, nuts, seeds and legumes (peas, beans etc.). Aim for 8–10 glasses of fluid a day (e.g. water and prune juice). Ask your doctor or nurse about using a laxative, stool softener or fibre supplement.

TASTE CHANGES:

Rinse your mouth frequently, experiment with different foods and add extra flavour to food if it tastes bland, such as herbs, honey or chilli.

LOSS OF APPETITE AND FATIGUE:

Eat small, frequent meals and snacks. Small portions are more easily finished and they help give you energy and nutrients without the burden of a large meal. Nourishing drinks, such as milk drinks, smoothies, and juices, can also be a good way to get the nutrients you need. Ask for and accept offers of help with shopping and cooking from family and friends.

NAUSEA (FEELING SICK):

Eat and drink slowly and avoid foods that are overly sweet, oily, spicy or that have a strong smell. Try small meals consisting of dry, bland and/or cold foods such as crackers. Not eating for long periods can make nausea worse. Ginger and peppermint products or anti-nausea medication can help ease nausea.

Nausea is not a usual symptom. If you experience unexplained nausea speak to your treating team. Do not assume cancer means you should feel 'sick'.

DIARRHOEA:

Drink plenty of fluids such as water and diluted cordials. Choose low-fibre foods such as mashed potato, yogurt and white bread. Avoid alcohol, raw fruit, vegetable skins and spicy, fatty or oily foods.

Diarrhoea is not a usual symptom. If the diarrhoea persists beyond a few days, or if you have signs of dehydration, seek medical advice.

Are you taking steroids?

Steroid use (such as dexamethasone) can decrease your body's ability to move sugar from the blood into your cells. This can cause high blood sugar and increase your risk of diabetes.

Important symptoms to look out for include: Blurry vision, dry mouth, frequent thirst and increased urination (needing to pass water). Difficulties with sleep, changes in attention, feeling irritated and fatigue can also be side effects of steroids. If you experience these symptoms it is important to discuss them with your treating team. This condition may go away after you stop taking steroids.



Fluids

It is important to stay hydrated (drink plenty of fluids). Aim to drink around eight glasses of liquid each day (approximately two litres).

If you have diarrhoea or vomiting, you lose fluid rapidly. It is important to replace the fluid and minerals lost. If required, talk to a health professional about special rehydration drinks.

Can a diet help in managing brain cancer?

There is no clear evidence that a specific diet can cure or slow brain cancer.

However a balanced diet can:

- ✓ help keep your strength and energy up
- ✓ improve wellbeing
- ✓ prevent malnutrition and dehydration
- ✓ help manage side effects
- ✓ support treatment recovery

Who can I see for diet and nutrition advice?

With the range of professionals available, it can be difficult to choose who is best to help with your nutrition needs. You may have come across the titles dietitian, nutritionist, wellness coach and naturopath. If you have brain cancer and are experiencing problems with your diet or weight, an accredited dietitian is best qualified to assist you. Dietitians work within hospitals, community health centres and privately. They are recognised by Medicare and most private health funds. Your GP may be able to organise a team care arrangement (Chronic Disease Management Plan) so you can use Medicare funding to see a dietitian.

For further information about eating well and brain cancer

Ask your oncologist or care coordinator refer you to a Dietitian. Most treatment centres will have access to a dietitian.

Cancer Council – Nutrition and Cancer Guide: www.cancervic.org.au/living-with-cancer/nutrition/nutrition-overview

The Brain Tumour Charity – Diet and Brain Tumours fact sheet: www.thebraintumourcharity.org/living-with-a-brain-tumour/health-fitness/

BC Cancer Agency – Nutrition, Radiation Therapy and Brain Cancer fact sheet: www.bccancer.bc.ca/health-professionals/clinical-resources/nutrition/nutrition-handouts

Exercising after treatment

Getting back to exercise can be an important part of getting back to life. However, things may be different now; your mobility may have changed or you may not be as strong. Finding support from an exercise physiologist, physiotherapist or discussing this issue with your treating team will be a good way to start the process of getting back to exercise.

Research has shown that exercise may help reduce treatment side effects such as tiredness, thinking and memory problems, and anxiety and depression. It is recommended that all patients exercise during and after a cancer diagnosis as set out in the table below. These guidelines are something to aim for and not necessarily a starting point.

Aerobic Exercise	Resistance Exercise	Flexibility	Physical Activity
3 - 5 sessions/ week Moderate to vigorous intensity 20 - 30 minutes duration	2 - 3 sessions/week Moderate to vigorous intensity 6 - 10 Exercises 6 - 12 Repetitions 1 - 4 Sets	1 - 3 sessions/week When required	Stay as active as physically possible during treatment

Clinical Oncology Society of Australia, COSA Position Statement on Exercise in Cancer Care 2018: Level 14, 477 Pitt St, Sydney NSW 2000

Doing a little bit every day is more important than doing a lot on one day.



Getting started can be a scary prospect, so here are a few tips to get you on your way. If you are unsure what to do or what is safe, you should seek out an exercise oncology specialist such as a physiotherapist or exercise physiologist.

Setting exercise goals

When looking at starting to exercise again, set yourself some SMART goals:

- S Specific:** what do you want to achieve? Do you want to climb a flight of stairs without help or do the shopping without getting short of breath?
- M Measurable:** so you can see if you are progressing towards your goal.

- A Achievable:** if you haven't run in 10 years, a marathon next week is not the best place to start.
- R Relevant:** is this goal something you really want to achieve? If the goal is not that important to you, there may be better goals to set.
- T Timely:** how long will it take you to achieve this goal? Can you commit to that time and is it realistic?

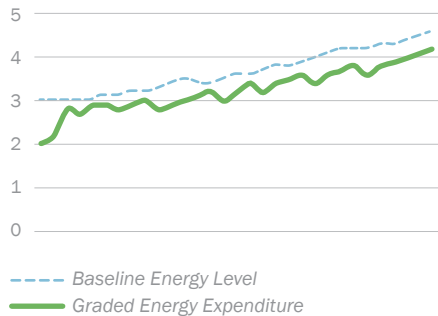
Getting started

Once you have a goal in mind, you need to set a starting point based on your current health and fitness. Taking a step by step approach can reduce your risk of experiencing increased tiredness because of your exercise.

To do this, set a starting point just below what you believe you can achieve. If a 20 minute walk leaves you feeling 'crashed' (exhausted) afterwards, start at 15 minutes so you avoid crashing. Walk every day for 15 minutes and after two weeks, look to increase the time period or intensity by 10-20%. Over time, your energy and exercise tolerance will increase and you will avoid crashing. A stepped approach to exercise

is shown in the graph below. Your ability to complete a task or exercise without crashing is called your 'Baseline Energy Level'.

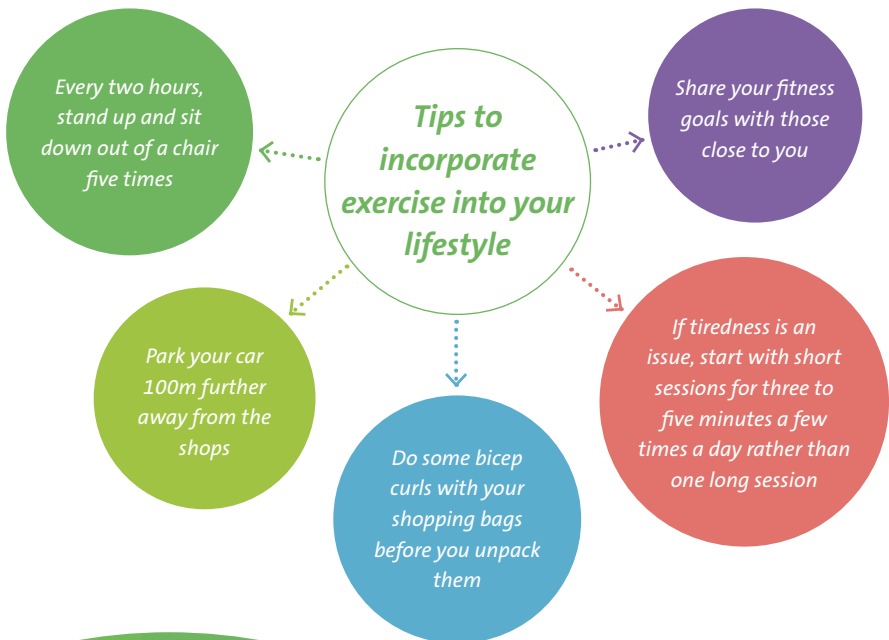
GRADED EXERCISE THERAPY APPROACH



What to look out for

When exercising and dealing with ongoing tiredness, it is important to avoid causing exhaustion (crashing). If you often exercise to the point where you crash, you may be experiencing a 'boom-bust' cycle. This typically occurs when you feel good and energetic, so you overdo your activities

and this causes you to crash later. The boom-bust cycle can result in larger crashes and longer recovery periods. By avoiding overdoing it you will improve your long-term results. It is also important to accept that there may be days where you do not meet your exercise goals.



Recommended Resources

BRAINSTRUST: INFORMATION ABOUT EXERCISE WHEN LIVING WITH BRAIN CANCER

<https://brainstrust.org.uk/brain-tumour-support/quality-of-life/living-well-with-a-brain-tumour/exercise/>

FAMILY, FRIENDS AND CARERS INFORMATION:

Caring for yourself

Caring can be rewarding, but it can also be mentally, emotionally and even physically challenging. Sometimes the demands of caring for someone else, combined with the stress of everyday life, can be overwhelming. To care for someone well, you need to look after yourself first. Here are some tips, recommended by carers and health professionals, to help you stay on top of your own needs.

PRIORITISE YOUR HEALTH AND WELLBEING

Make time for yourself to make sure you still meet your own needs. Try to make this a part of your routine from the beginning. Exercising, sleeping and eating well can help you to cope with stress, maintain your energy and manage fatigue. It is also important to make time to relax and do the things you enjoy. Take breaks to go for a walk, have coffee with a friend, watch a movie, read a book or listen to music, are small steps that can support your wellbeing.⁴ Sometimes, you may feel you need a longer break. This does not necessarily mean leaving home. It could be that the person you are caring for goes on a holiday and you stay home.⁵

RECOGNISE YOUR FEELINGS

There is personal satisfaction to gain from being a carer. However, feelings of anxiety, stress, frustration, fear, anger, isolation and loneliness are also common. If there have been significant changes to a relationship or the person you are caring for has changed a lot, you may feel grief or sadness. These are natural emotions as you adjust to a new reality. If these feelings last or you find yourself quick tempered and unable to control your feelings or reactions, you may need extra support. Be honest with yourself: if everyday activities are becoming overwhelming, if you lack motivation or if things that used to bring you enjoyment no longer do, these could be signs of depression. Talk to your GP or other health professional if you feel any of these things. Remember that your emotional health is very important; if you are not in a good space and that feeling does not go away, there is strength in reaching out.



SEEK AND ACCEPT HELP

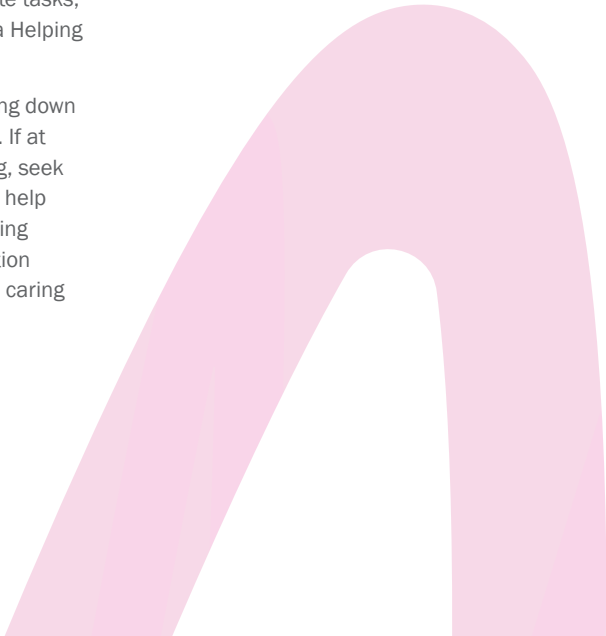
Some carers find it difficult to accept or ask for help. Some are concerned about burdening friends and family and others feel it is their job alone to care for their loved one. There does not need to be only one carer; if possible, share the care with one or more family members or friends.

Some friends, relatives and even work colleagues want to help and be useful, you just need to tell them what you need. Write a list of tasks that need to be done or draw up a calendar that includes times you would like some help or to have to yourself. Organise a network of people who can help you and show them this list when they ask what they can do. Some carers create an email thread, shared documents (such as Google Docs or Dropbox), or use social media or specific phone apps to communicate tasks, visits and schedules (such as Lotsa Helping Hands).

It is normal to have periods of feeling down as you adjust to what is happening. If at any stage you feel you're not coping, seek professional help. A counsellor can help by suggesting strategies for managing relationships, keeping communication channels open, and balancing your caring role with your own needs.

STAY CONNECTED TO YOURSELF AND OTHERS

Sometimes when caring for someone else, you can lose your sense of identity and your previous roles and interests might take a back seat. Keeping up some of your usual hobbies and interests can provide a refreshing break and help you retain a sense of self. Continuing your contact with others is also very important as an outlet for you to talk about your needs and prevent feelings of loneliness and isolation. Take a few minutes every day to consider how you are looking after yourself. Some people set aside a few minutes in the morning or before going to bed to do this. Others use a diary to write what is going on for them or to reflect on their feelings and how they are coping.



SHARE YOUR FEELINGS

Spend time with people who you are comfortable being honest with. This can help you lighten your load and make sense of your feelings. They could be friends or family members, a counsellor or health professionals, a religious or spiritual person, or someone else who is going through the same thing, for example via a support group. Friends and family often want to support you and have you open up and talk to them. However, they may be worried about upsetting you by bringing up the topic, so it might be helpful for you to start the conversation. On the other hand, sometimes it may be hard to be honest with those close to you as they might get upset. In these circumstances consider external options. There are organisations you can approach that specifically support carers with resources, support groups and counselling.

Many cancer support groups and education programs are also open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share feelings, experiences and ways of coping.⁵ See pages 123-125 for a list of support groups open to carers.

“In carers' group, you can speak honestly and it was so reassuring to have somebody else say, ‘I also feel like that, you're not being disloyal by saying that or thinking that’. It was nice having it expressed by other people that you weren't the only one.”

– Focus group participant

Recommended Resources

CARERS VICTORIA:

This is an organization specifically for people in caring roles. There are resources, support, and information about a range of issues. Carers Victoria also has a counselling service for carers.

www.carersvictoria.org.au

THE BRAIN TUMOUR CHARITY: SUPPORTING A LOVED ONE WITH BRAIN CANCER

Useful information and fact sheets for people who provide support for a family member or friend with brain cancer.

<https://www.thebraintumourcharity.org/living-with-a-brain-tumour/relationships/being-a-carer/>



Building THE Bridge
to Life with Brain Cancer

Phone 03 9496 3315

Email buildingthebridge@austin.org.au

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