

SECTION 3.

*Connecting  
with others*





## *Making connections with other people is what we do as human beings.*

When you are facing a challenging situation, it can be helpful to make new connections with people in a similar situation, as well as maintaining good connections with those around you. The first part of this section talks about ways to explain your situation to other people, manage your social life and help your family and friends understand what is going on for you. The second part discusses ways to connect with other people with brain cancer, both in person and remotely. It also explores how to connect with the broader brain cancer community, for information, support and ideas. The last part of this section focuses on family relationships, and provides helpful tips and strategies to get through current and future challenges.

### A PERSONAL EXPERIENCE

#### *Getting family and friends to understand*

*"In the aftermath of treatment this still takes constant communication, because you look so much better than during treatment! Remember they can't relate. Their instinct is to think that you're 'better', because that's what they see and what they really want to believe. So the effects of anti-seizure medications or still getting easily fatigued have to be voiced. Whatever it is, don't hide it for any reason. They want to know, and support you."*

— SHERAN



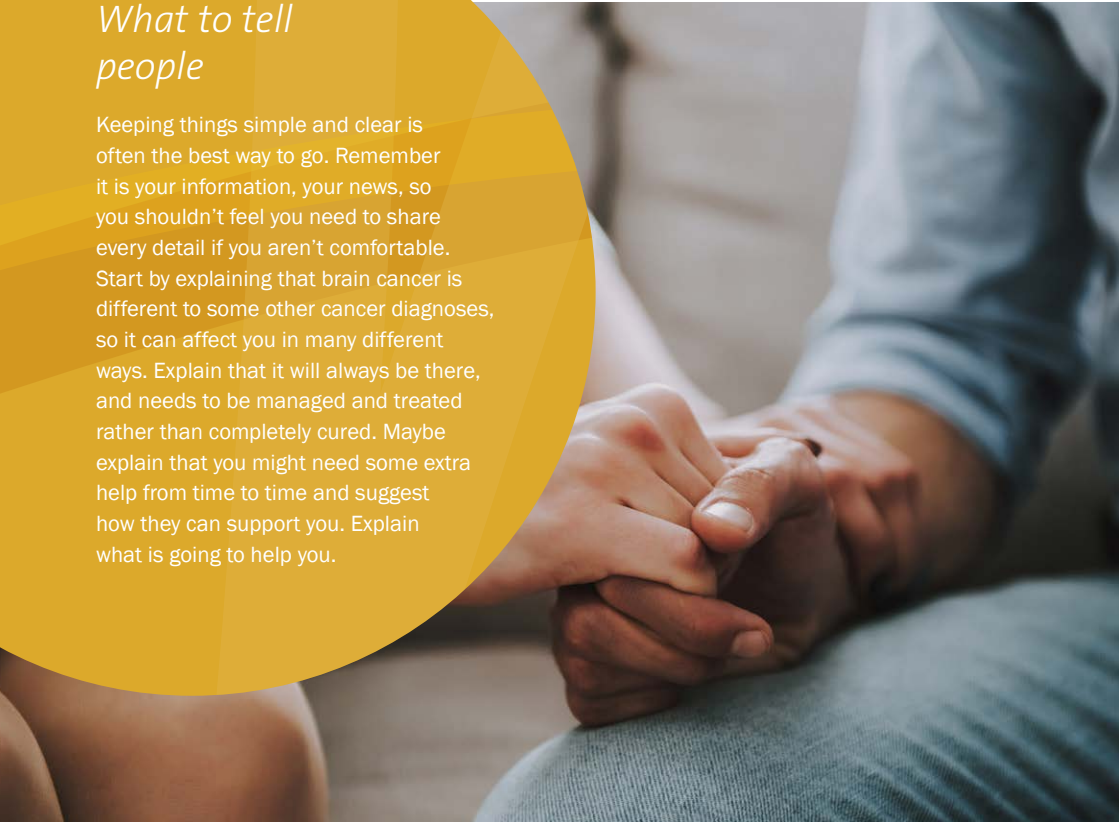
## You are not alone

It's one of the most important messages at this point: you are not alone. Help, support and connection are out there for everyone facing a different kind of life with brain cancer. You may not always feel like you need it or you may seek it early on — everyone is different. However, the value of talking with others who 'get it' cannot be underestimated.

*"I think having that ability to connect with other people who are in the same situation as you is good because they have an understanding of where you're coming from. There are people out in society who will say to you, 'Yep, you look great' but they don't actually understand what you've gone through, how it's affected you. So I think being able to gather in the support group where you've got people that understand is a bonus."*

### What to tell people

Keeping things simple and clear is often the best way to go. Remember it is your information, your news, so you shouldn't feel you need to share every detail if you aren't comfortable. Start by explaining that brain cancer is different to some other cancer diagnoses, so it can affect you in many different ways. Explain that it will always be there, and needs to be managed and treated rather than completely cured. Maybe explain that you might need some extra help from time to time and suggest how they can support you. Explain what is going to help you.



# Getting family and friends to understand

## Adopting a champion

There is no doubt that a brain cancer diagnosis is shocking, to you and equally to your partner, family and/or friends. It can also get tiring telling a lot of people the same details over and over again. To take away the pressure of communicating to others, including your workplace, from you and your family, 'delegate to a mate.'

- ✔ Think of a friend who is most likely to be happy to take on the challenge of communicating to your friends for you.
- ✔ Put together a list of friends and their email addresses for your champion. They are unlikely to know everyone you want to keep informed.
- ✔ Your friends and neighbours may want to organise meals for you. Your champion can arrange this so meals are delivered to a schedule and there is no waste.
- ✔ Every two weeks or every month, your champion can talk to you about what you want to say, then update everyone in one go.
- ✔ If at any point you feel more comfortable communicating to others yourself, send out a quick 'thank you to my champion' email. This can express your gratitude and let everyone know you're going to be in touch personally from now on.



## Managing a social life

Living with brain cancer means you might not always be able to do the things you did previously. But it is important to maintain a social life. This can be more complicated to manage than before. However, by planning ahead it is possible and can be very rewarding.

Here are some tips for managing a social life, suggested by people living with brain cancer.

- It's easy to forget your new reality when you are around old friends. However, friends can unintentionally expect you to behave like you did before. It is important to maintain a social life, but know your limits and don't exhaust yourself trying to rise to these expectations.
- Before going to an event, such as a wedding or birthday, plan a way to take 'time out'. Sensory overload can happen easily when trying to keep up constant conversation in loud places.
- There can be a lot of pressure to drink when you are out. Hold back if you don't feel comfortable drinking or if you have had seizures and it is a trigger for more.
- Often it won't be obvious to your friends that you are getting tired or overwhelmed. Before an event, have a plan with your partner or a close friend. This way, if you give them a wink or squeeze their arm, they know to get you a chair, go outside for fresh air or take you home.
- Everyone will understand if you are not up to going out! If you get FOMO (fear of missing out), try to ease yourself in with daytime catch ups, or keeping your time at an event short.
- Get some rest during the day if you are going out at night. This will give you more energy for the evening.
- Pace yourself. Don't go out on consecutive nights.
- Try not to have expectations of your friends. Some may be great and accommodating, others not so much. Focus on your recovery; hopefully your friends will come around with time.

*Often, your friends will take their cues from you on how to behave around you.*



## *Connecting with your community*

Support is important for everyone and can be formal or informal. Family and friends provide important informal support. Health professionals, teachers, employers, religious leaders and community organisations are examples of more formal supports. A good point of call for help after a brain cancer

diagnosis is the brain cancer coordinator at your treatment centre. Ask your doctor if you haven't met a coordinator. Not all treatment centres will have a dedicated person available to coordinate your care, so contact the Cancer Council [askanurse@cancervic.org.au](mailto:askanurse@cancervic.org.au) or 13 11 20 and ask them for guidance.

### *Brain cancer support*

Another option for finding support and connecting with others is through a brain tumour/cancer support group. These groups can provide great support to some people, but aren't for everyone. Support groups provide information, help people to cope and allow for sharing of different ways to deal with challenges. There are a number of options to connect with others in a similar situation. These range from face-to-face groups, telephone groups and online forums to Facebook support options. Some groups are run by health professionals and others are run by people with a brain cancer diagnosis. You'll find a full listing of brain cancer support groups on pages 123-125 of this booklet.

Sometimes connecting one-to-one is a better option for you. Cancer Connect is a telephone peer support service offered by the Cancer Council that connects someone who has cancer with a specially trained volunteer who has had a similar cancer

experience. A Connect volunteer can provide practical information, emotional support and hope. For more information call the Cancer Council on 13 11 20 or submit your details online at [www.cancervic.org.au/get-support/connect-and-learn/cancer\\_connect](http://www.cancervic.org.au/get-support/connect-and-learn/cancer_connect).

If a support group or formal cancer services aren't your thing, maybe think about an interest or exercise that will connect you with others, such as yoga classes, local choir, ParkRun or a walking group.



## Support group options

### **Brain Tumour Support**

@ONJ has a number of face-to-face support group options run from the Olivia Newton-John Cancer Centre in Heidelberg. BrainSpace is a support and information program for people 40 years and under. Evening forums are run every 3 months. The Brain Tumour Support Group runs monthly on the second Wednesday and is run by health professionals. More Information: 03 9496 3315 or [btso@austin.org.au](mailto:btso@austin.org.au).

**Brain Tumour Support Group Australia** is a closed Facebook group. It is moderated by people with the direct experience of living with a brain tumour or brain cancer. It's searchable on Facebook via 'Brain Tumour Support Group Australia' or link: [www.facebook.com/groups/198016110233965/](https://www.facebook.com/groups/198016110233965/)

**Brain Tumour Alliance Australia** (1800 857 221) or **Cancer Council** 13 11 20 can connect you with a support group either as an online, telephone or face-to-face option.

**Cabrini Brain Tumour Support Group** is open to anyone living with brain cancer, their friends and families. The group meets monthly (the last Thursday) at Cabrini Malvern. You do not need to be a Cabrini patient to join this group. The group is run by health professionals. Living with Cancer Education Program – Brain Cancer, is hosted annually. More information: 03 9508 1514 or [neurooncology@cabrini.com.au](mailto:neurooncology@cabrini.com.au)



# Connecting with family

## Family relationships

Your diagnosis and treatment have not only touched your life but that of your family. We are not islands on our own, we are people connected to those around us in special ways: we have shared history, plans, love and

friendship. A significant diagnosis can affect our relationships, change expectations or the usual way we relate to each other. This is normal. Sometimes relationships can take some time to adjust to the changes.

### THESE ARE SOME COMMON CHALLENGES FOR FAMILY MEMBERS.

- 1. Not wanting to upset, worry or make demands of you.** With good intentions, this can feel hurtful to you. You might feel like you are being 'left out' or that your feelings and ideas are not being respected. Try to let family members know how you feel, rather than becoming angry or resentful over the situation.
- 2. Feeling like you have changed or you're not the same person.** Family members may need reassurance that while things have changed, they are still important to you – and this is a process along which we can grow and develop together.
- 3. Feeling angry about the situation.** The brain cancer experience can take a lot of your energy and focus, so you may not be able to communicate and respond to others the way you did before. Your family may feel worried about the future, but unable to voice these worries. Maybe they may want to shield you. If family members feel they can't express these emotions, maybe they are being expressed as anger.

## Recommended Resources

### THE BRAIN TUMOUR CHARITY: INFORMATION ABOUT BRAIN TUMOURS AND COMMUNICATION.

This includes information about communication difficulties and tips to improve communication

<https://www.thebraintumourcharity.org/living-with-a-brain-tumour/side-effects/communication-difficulties/>

## *Intimate relationships*

Your roles may have changed within your closest relationship and maybe your partner is taking a greater role in caring for you. What a change this must have been for both of you. How you see yourself as a wife,

husband, partner, girlfriend or boyfriend may feel lost in the impact of your illness. But finding a way to talk, joke and share your feelings for each other can strengthen your relationship.

## *Intimacy and sexual activity*

This may have been off the agenda for some time, but as you engage back in your life, intimacy is important and sex can be part of that. Sexuality and intimacy after diagnosis may be different, but different does not mean better or worse. It just means different and there may be some things you need to consider and manage in another way. Whether you are part of a couple or single, your sexuality and the activities that bring you pleasure or comfort are important.

Working out how to rekindle this part of your life can take some patience and understanding, from you and from the people

in your life. Communication is probably the key to working through this issue and getting back to sexual activities in a way you feel comfortable with. The Cancer Council has a great resource, *Sexuality, Intimacy and Cancer*. This booklet has tips and strategies around challenges such as changes to libido, fatigue, and changes to your appearance. Your medical team, GP, or Cancer Council 13 11 20 can also be good resources for questions. Additional support via a sexual health service or counselling may help you work through these challenges to rekindle intimacy.

## ***Recommended Resources***

**CANCER COUNCIL: SEXUALITY, INTIMACY AND CANCER: A GUIDE FOR PEOPLE WITH CANCER AND THEIR PARTNERS**

[www.cancervic.org.au/living-with-cancer/sexuality-and-intimacy](http://www.cancervic.org.au/living-with-cancer/sexuality-and-intimacy)

**A TOUCHY SUBJECT: THE RESOURCES TAB ON THIS SITE LISTS A RANGE OF CANCER AND SEXUALITY RESOURCES**

[www.atouchysubject.com/resources](http://www.atouchysubject.com/resources)

**BETTER HEALTH: BRAIN INJURY AND SEXUAL ISSUES**

[www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/brain-injury-and-sexual-issues](http://www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/brain-injury-and-sexual-issues)

## Children

Brain cancer can be difficult for children to fully understand, particularly when you are back home and getting on with the routine of life and family. Children may immediately think you are better. They may behave differently or protectively around you; this can trigger new feelings. Again, keeping things simple and clear is often the best way forward. Children often sense that something is not right, so being upfront, honest and simple is the best way to open the conversation. Educate them about what you've been through, listen to them and try to answer their questions honestly.

You know your children best, and have a better understanding of behaviours that might indicate stress or worry in this situation. Children can sometimes feel responsible, while others appear disengaged as a way to manage their emotions. It is important they have an open opportunity to ask questions, to express their worries and to talk to someone they trust. A trusted adult may be you, but it also may be their teacher, a mate's mum, a family friend or an uncle. Canteen is a great organisation to support children and adolescents on their terms.

## Recommended Resources

### **CANCER COUNCIL: TALKING TO KIDS ABOUT CANCER**

This is an important resource for parents and grandparents. It gives tips and strategies for talking to children and teens about cancer considering their different levels of understanding and stage of development.

[www.cancervic.org.au/cancer-information/children-teens-and-young-adults/talking-to-kids-about-cancer](http://www.cancervic.org.au/cancer-information/children-teens-and-young-adults/talking-to-kids-about-cancer)

### **MUMMY'S WISH: DEALING WITH CANCER: A GUIDE FOR MUMS**

This booklet provides mums with some of the basic information they need to know, including telling children about a cancer diagnosis, how to ask for help, and ways to enjoy time with the family.

[www.mummyswish.org.au/guide-for-mums-with-cancer/](http://www.mummyswish.org.au/guide-for-mums-with-cancer/)

[www.nowwhat.org.au](http://www.nowwhat.org.au)

[www.canteen.org.au/young-people/my-parent-has-cancer/](http://www.canteen.org.au/young-people/my-parent-has-cancer/)

**FAMILY, FRIENDS AND CARERS INFORMATION:**

## *Connecting with others*

Spending quality time with family or friends can help you see a life outside and beyond the brain cancer diagnosis.

It is important to stay in contact with friends and family when someone you care about has brain cancer. Having a strong support network can help you cope and spending time with others can give you a much-needed break from the focus on brain cancer. Connecting with others and sharing your feelings can also help lighten your load and make sense of any emotions you may be experiencing.

Another way to connect with others is through the Cancer Council Family Connect program. Family Connect is a telephone peer support service that connects family and friends of someone with a cancer diagnosis with a specially trained volunteer who has had a similar cancer experience. For more information call the Cancer Council on 13 11 20 or submit your details online at [www.cancervic.org.au/get-support/connect-and-learn/cancer\\_connect](http://www.cancervic.org.au/get-support/connect-and-learn/cancer_connect).



## RECOMMENDED RESOURCES

Carers Victoria is an organisation that focuses on the needs of people in a caring role. The Carer Advisory Line can provide some short-term counselling options, referral information and support. Contact them on 1800 242 636.

## INTIMACY AND SEXUAL ACTIVITY

When you take on the role of carer for your partner, it can be tricky to switch back to a role of lover. Thinking about the activities and interests you shared together before the diagnosis can be a good way of reconnecting with each other as partners, which can help focus your relationship beyond what is going on medically. Some people find that changing the setting (e.g. having a date night) can help you return to the role of partner and focus on things other than cancer. If your partner is not ready for sexual contact, try other ways of showing you love them, such as touching, hugging and massaging.<sup>6</sup>

## SUPPORT PROGRAMS

Many organisations run cancer support groups and education programs that are open to carers, family members and friends. These groups and programs can give you support and resources. They offer you the opportunity to share your feelings and experiences, and get answers to questions. What is spoken about in each group is confidential so you can feel comfortable to discuss personal situations.

Groups are free and often meet regularly in public places, such as a community hall or hospital. If you cannot attend in person, many groups also offer telephone support or online forums.

You'll find a list of Victorian brain cancer support groups that family and friends can attend on pages 123-125 of this booklet.















**Building THE Bridge**  
*to Life with Brain Cancer*

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[www.onjcancercentre.org](http://www.onjcancercentre.org)

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