



SECTION 6.

References & resources

6

References
& resources

References

GENERAL BRAIN CANCER INFORMATION

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www.thebraintumourcharity.org/understanding-brain-tumours/living-with-a-brain-tumour/side-effects/cognition-and-brain-tumours/
- 2. Caring for a Person with a Brain Tumour or Metastatic Brain Cancer, American Society of Clinical Oncology, 2018**
www.cancer.net/coping-with-cancer/caring-loved-one/caring-person-with-brain-tumor-or-metastatic-brain-cancer
- 3. Cancer Council Victoria: Caring for someone who has a brain tumour fact sheet, 2012** (discontinued publication)
- 4. Cancer Council Queensland: Caring for yourself when caring for someone with a brain tumour, 2016**
<https://cancerqld.org.au/news/brain-tumour-support-service-newsletter/>
- 5. The Brain Tumour Charity: Carers – looking after yourself, 2018**
<https://www.thebraintumourcharity.org/living-with-a-brain-tumour/relationships/being-a-carer/>
- 6. Cancer Council Victoria: Sexuality, Intimacy and Cancer: A guide for people with cancer and their partners, 2018**
<https://www.cancervic.org.au/living-with-cancer/sexuality-and-intimacy/>
- 7. State Trustees: Making a will**
www.statetrustees.com.au/wills/making-a-will/
- 8. Ovarian Cancer Australia: Family and Friends**
<https://ovariancancer.net.au/>

Recommended resources

GENERAL BRAIN CANCER INFORMATION

Cancer Council

The Cancer Council website is a reliable source of information on brain cancer.
www.cancer.org.au/about-cancer/types-of-cancer/brain-cancer.html

The booklet *Understanding Brain Tumours – A guide for people with brain or spinal cord tumours, their families and friends*, is available online or you can call 13 11 20 to order a free printed copy.
<https://cancer.org.au/about-cancer/types-of-cancer/brain-cancer.html>

Brain Tumour Alliance Australia (BTAA)

BTAA is a national brain tumour patient and caregiver organisation in Australia. Their website has resources and links to useful websites, fact sheets and booklets.
www.btaa.org.au/

The Brain Tumour Charity

This is a UK-based charity dedicated to providing support and information for people with a brain tumour, their families and friends.
www.thebraintumourcharity.org/

Cure Brain Cancer Foundation

This foundation is dedicated to improving brain cancer research, advocacy and awareness in Australia.
www.curebraincancer.org.au/

FATIGUE

The Brain Tumour Charity: Fatigue and brain tumours

This can be viewed as a web page or printed fact sheet. It provides information on brain cancer-related fatigue and strategies for coping with this fatigue.
<https://www.thebraintumourcharity.org/living-with-a-brain-tumour/side-effects/fatigue-and-brain-tumours/>

National Brain Tumour Society: Brain Tumours and Fatigue

This two page fact sheet discusses the causes of fatigue in people with brain cancer and strategies that can help manage fatigue.
<https://braintumor.org/brain-tumor-information/>

Braintrust: My Fatigue Book

This 60-page downloadable book helps patients and carers to understand what is meant by fatigue and to self-manage brain cancer-related fatigue.
<https://braintrust.org.uk/brain-tumour-support/quality-of-life/living-well-with-a-brain-tumour/fatigue/>

DEPRESSION AND ANXIETY

Beyond Blue: Brain tumours, anxiety and depression

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

The Brain Tumour Charity: Depression and brain tumours

<https://www.thebraintumourcharity.org/living-with-a-brain-tumour/side-effects/depression-and-brain-tumours/>

NUTRITION

Cancer Council: Nutrition and Cancer Guide

www.cancervic.org.au/living-with-cancer/nutrition

The Brain Tumour Charity: Diet and Brain Tumours

www.thebraintumourcharity.org/living-with-a-brain-tumour/health-fitness/diet/

BC Cancer Agency: Nutrition, Radiation Therapy and Brain Cancer

www.bccancer.bc.ca/health-professionals/clinical-resources/nutrition/nutrition-handouts

EXERCISE

Brainstrust: Exercise and Rest

This fact sheet has 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/>

COMMUNICATION

The Brain Tumour Charity: Communication difficulties

This fact sheet has 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/>

FINANCIAL SUPPORT

BrainLink: Legal and Financial Matters

This fact sheet explains a number of legal and financial matters including making wills, powers of attorney and guardianship, managing finances and financial assistance. <http://www.brainlink.org.au/page/109/living-with-abi-fact-sheets>

NDIS INFORMATION

NDIS:

Accessing the NDIS

www.youtube.com/watch?v=EM03PSz3Ar8

Reasonable and necessary supports

www.youtube.com/watch?v=TAMD1S-gorM

BrainLink

This resource covers some of the ins and outs about the National Disability Insurance Scheme; the FAQ section is particularly helpful.

www.brainlink.org.au/page/95/national-disability-insurance-scheme-landing

Every Australian Counts

This website has useful information and resources to help navigate the NDIS

www.everyaustraliancounts.com.au/what-is-the-ndis/

RETURN TO WORK

Flinders University: Work after Cancer

This website has information to support work during and after a cancer diagnosis. It provides advice to people diagnosed with cancer, their loved ones, clinicians and employers about their options, rights and responsibilities.

<http://workaftercancer.com.au>

Cancer Council: Cancer, Work & You

This information can be viewed online, PDF download or as a free hard copy booklet.

<https://www.cancervic.org.au/get-support/work/working-after-treatment-ends>

Braintrust: Your Brain Tumour and Work

This page has information on working after treatment, patients' rights, access to work and information for employers.

<https://braintrust.org.uk/%20brain-tumour-support/quality-of-life/practical-help/access-to-work/>

The Brain Tumour Charity: Employment and brain tumours

This page provides useful resources to help you stay in, return to, or look for work.

<https://www.thebraintumourcharity.org/living-with-a-brain-tumour/maintaining-your-independence/employment-and-brain-tumours/>

DRIVING

BrainLink: Driving

This fact sheet discusses specific problems that can affect driving, how to get a driving assessment and how to support a family member who is no longer safe to drive.

<http://www.brainlink.org.au/page/109/living-with-abi-fact-sheets>

VicRoads

Fact sheets:

www.vicroads.vic.gov.au/licences/health-and-driving/medical-forms-and-fact-sheets

Fitness to Drive:

www.vicroads.vic.gov.au/licences/health-and-driving/medical-conditions-and-driving/fitness-to-drive-faqs

Assessing Fitness to Drive:

<https://austroads.com.au/publications/assessing-fitness-to-drive/ap-g56/neurological-conditions>

SEXUALITY AND INTIMACY

Cancer Council: Sexuality, Intimacy and Cancer: A guide for people with cancer and their partners

This guide is a very useful resource.

<https://www.cancervic.org.au/living-with-cancer/sexuality-and-intimacy/sexuality-and-intimacy-overview>

Better Health: Brain injury and sexual issues

This fact sheet discusses causes of sexual problems and resuming sex after brain injury

www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/brain-injury-and-sexual-issues

CHANGES IN COGNITION, THINKING AND BEHAVIOUR

The Brain Tumour Charity

<https://www.thebraintumourcharity.org/living-with-a-brain-tumour/side-effects/cognition-and-brain-tumours/>

The Brain Cancer Group.

This website has information about general brain cancer research and links to a set of factsheets about changes to thinking and behaviour.

<https://braincancergroup.com.au/resources-research/patient-carer-info/>

Cancer Council: Understanding changes in thinking and memory

www.cancervic.org.au/living-with-cancer/common-side-effects/changes-in-thinking

PRACTICAL SUPPORT

Queensland University of Technology: It's okay to ask

This booklet includes questions to ask your healthcare team about your brain cancer. It was written in collaboration with brain cancer survivors, family members and health professionals and is available in 10 languages.

www.btaa.org.au

INFORMATION FOR CARERS, FAMILY AND FRIENDS

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. You can contact them on 1800 242 636 and find more information online at www.carersvictoria.org.au/

The Brain Cancer Group is a group of health professionals based in New South Wales who have compiled some useful information around cognitive changes, coping with emotional changes and fatigue. You'll find online information at <https://braincancergroup.com.au/resources-research/patient-carer-info/>

The Brain Tumour Charity: Supporting a loved one with brain cancer

This page offers useful information and fact sheets for people who support a family member or friend with brain cancer.

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

Peace of Mind Foundation run a series of weekend retreats and opportunities for patients and families to get additional support. For further information visit: www.peaceofmindfoundation.org.au

Support groups

AUSTIN HOSPITAL / OLIVIA NEWTON-JOHN CANCER WELLNESS & RESEARCH CENTRE (ONJ CENTRE) – HEIDELBERG

Brain Space: Brain Space is a group for younger people affected by brain cancer (aged 18-39). The group meets four times a year.

For more information and to attend email btso@austin.org.au or call 9496 3315.

Brain Tumour Support Group (FF): The Brain Tumour Support Group is open to all people diagnosed with a brain tumour, as well as their family, friends and carers. The group meets at the ONJ Wellness Centre and shares lunch together in a safe and relaxed environment. Activities include peer discussion, education sessions and therapeutic activities delivered by health professionals. The group meets on the second Wednesday of every month.

For more information and to attend email btso@austin.org.au or call 9496 3315.

Cabrini Brain Tumour Support Group (FF):

This support group is open to anyone living with brain cancer, their friends and families. The group meets monthly (Last Thursday) at Cabrini Malvern. You do not need to be a Cabrini patient to join this group. The group is facilitated by health professionals. Living with Cancer Education program – Brain Cancer, is hosted annually.

More information: 03 9508 1514 or neurooncology@cabrini.com.au

CANCER COUNCIL AUSTRALIA – NATIONAL

Telephone Support Groups: The Cancer Council hosts Brain Tumour Telephone Support Groups for people diagnosed with a malignant brain tumour. They are held on the first and third Monday of the month throughout the year (1.30 – 2.30pm AEST). Each group has three to seven members and two qualified facilitators.

For more information or to join call the Cancer Council 13 11 20 or email tsg@nswcc.org.au.

Telephone Support Groups (FF): The Cancer Council hosts Telephone Support Groups for people who are providing care for a family member, friend or loved one with a cancer diagnosis. They are held on the second and fourth Monday of the month (1.30 – 2.30pm AEST). Each group has three to seven members and two qualified facilitators. The Cancer Council will connect you to an appropriate group.

For more information or to join call the Cancer Council 13 11 20 or email tsg@nswcc.org.au.

Cancer Connect: Cancer Connect is a telephone peer support service 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.

Family Connect (FF): 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. A Connect volunteer can listen with understanding and share their experiences and ways of coping.

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.

Online Community (FF): The Cancer Council Online Community offers people currently living with cancer, cancer survivors, families, friends, carers and the wider cancer community the opportunity to connect, share experiences and find information and support in a safe forum.

The following link will connect you to the Online Community – www.cancercouncil.com.au/OC.

BRAIN TUMOUR SUPPORT GROUP AUSTRALIA – NATIONAL

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/

GREY MATTERS FOR YOU (FF) – CARLTON NORTH

The Grey Matters Cancer Support Group meets on the third Monday of the month throughout the year at the Carlton North Library. This group welcomes people with benign brain tumours or low-grade brain cancers and their family members and friends. Activities center on peer discussion and social activities but also include relaxation activities and a variety of other events. A gold coin donation is requested, but not compulsory, to attend.

For more information call the Cancer Council on 13 11 20, email thegreymatters01@gmail.com or visit www.greymatters.org.au/calendar

PEACE OF MIND FOUNDATION (FF) – GEELONG AND SURF COAST

The Peace of Mind Foundation runs a monthly Brain Cancer Support Group in Geelong that features a variety of guest speakers (including dietitians, psychologists and researchers). The group welcomes patients, carers, friends and family members living in the Geelong/Surf Coast region, and offers social activities as well as a safe place to discuss feelings and share stories. The group also provides a children's program in conjunction with the support group so adults can attend sessions while their children are being looked after in the room next door.

For more information visit www.peaceofmindfoundation.org.au.

To register as a member phone the group facilitator Bec Picone on 0411 382 457 or email her at bec@peaceofmindfoundation.org.au.

BRICC – BALLARAT REGIONAL INTEGRATED CANCER CENTRE (FF) – BALLARAT

The Wellness Centre at BRICC has a Brain Cancer Support Group open to brain cancer patients, carers, friends and family members. The group meets the first Tuesday of the month throughout the year, at the BRICC Wellness Centre, Ballarat Base Hospital.

To book, contact the Wellness Centre Coordinator, Simone Noelker, on 5320 8614 or Simone.Noelker@bhs.org.au.



Building THE Bridge
to Life with Brain Cancer

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Email buildingthebridge@austin.org.au

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www.buildingthebridge.com.au

www.onjcancercentre.org

www.austin.org.au