

Brain Tumour Australia Information © FACT SHEET 54 Help, Care & Support

The Brain- Help, Care & Support

When a brain tumour diagnosis occurs peoples' lives and needs can alter dramatically overnight. Where do you go for help, support and information that may assist in maintaining independence and quality of life.

Each Hospital or Treatment Centre will have Social Workers, Occupational Therapists, Physiotherapists, Speech Pathologists, Dieticians and Psychologists (Allied Health professionals) available to assist.

Some Centres will have Neuro-Nurse Practitioners, or Clinical Nurse Consultants with expertise in neuro-oncology and neuro-psychologists may also be part of the treatment team.

Ask for a referral to the relevant discipline.

If the treatment centre is a great distance from your home you may be eligible for support to offset the travelling/ accommodation expenses. Contact the various state agencies listed for more information.

Support Organisations and Resources

Cancer Councils

Your local Cancer Council may be a source of information and support services for people living with the diagnosis of a brain tumour - all the Cancer Councils use the same phone number.

A call to **13 11 20** will put you through to your State's cancer organisation.

Support - Connect with Others

Attending a support group (or linking to an email group via the Internet) can be a great source of help. Connecting with others who are in similar circumstances can assist in reducing the sense of isolation that may accompany the diagnosis of a brain tumour: people who are experiencing or have encountered the brain tumour journey may have a better understanding of the issues and challenges to be faced.

Support Groups

There may not be a brain tumour specific support group available where you live. However, your regional Cancer Council (phone 13 11 20) may be able to provide information on local general support groups to investigate.

Online & Email Support Groups



Traditional support groups can be great, but their meeting schedule may not be convenient or adequate for your needs. Online support groups may seem more impersonal - however they are available as needed.

Teleconference Support Groups

The Cancer Council New South Wales runs a telephone group counselling service.

For more information about Telephone Support Groups, or any of the Cancer Council NSW support services, call the Cancer Council Helpline 13 11 20 ONLY in NSW - this number directs you to the local Cancer Council outside NSW).

Brain Tumour Specific Support Groups

Because of staff changes, sometimes group details change without notice.

Please check with the social work departments at the listed hospitals

NSW

Newcastle & the Hunter—Calvary Mater Newcastle

Liverpool

 Liverpool Brain Tumour Support Group—Liverpool Cancer Centre

Sydney

- North Shore Private/Royal North Shore Hospitals
- Westmead Hospitals Brain Tumour Support Group

Victoria Melbourne

- Blackburn
- The Alfred Hospital
- Royal Melbourne Hospital

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The Brain- Help, Care & Support cont. Gold Coast

The Gold Coast Brain Tumour Support Group.
 Please the QLD Cancer council or details

South Australia

Adelaide

Please the SA Cancer council for details

Support Groups - Online & Email

This group of lists are NOT run or endorsed

They are just listed here for your convenience.

For those with an interest in Brain Tumours email support groups allow individuals to access a global network of patient support systems.

An online support group - which is also called a "mailing list", is an internet structure for a community of people with a common interest.

People communicate with each other by email.

Each message that is sent to the 'list server' is then forwarded to each member of the list.

If you reply to that message, you have 2 options:

 You can reply directly to the author of the message, if the response is personal,

or

B. reply to the list if you feel your response is important for the entire group.

Australian Online Support Groups

on Yahoo Groups (also called **egroups)** there are two national based groups

OzBrainTumour

- providing a community of support for Australians dealing with brain tumours. This group was established in 2000. It is a area for all aspects of advice on treatment and coping - at all stages, from diagnosis to recovery or to palliative care - or loss..."

To join OzBrainTumour:

Subscribe: OzBrainTumour-subscribe@yahoogroups.com
Post message: OzBrainTumour@yahoogroups.com
List owner: OzBrainTumour-owner@yahoogroups.com

OR you can visit

http://health.groups.yahoo.com/group/OzBrainTumour/.

OzBTCarerplace

"This is a place for carers - and especially former carers, from the OzBrainTumour group, to meet, for quiet, or for support, or for chat, or for helping each other to work their way through issues."

To join OzBT Carerplacer:

Subscribe: OzBTcarerplace-subscribe@yahoogroups.com
Post message: OzBTcarerplace@yahoogroups.com
List owner: OzBTcarerplace-owner@yahoogroups.com