

Caring for someone who has a brain tumour

Caring for someone with a brain tumour can present many challenges. This information sheet explains some of the difficulties you may have and useful strategies for coping.

Caring for yourself

Accepting the role of carer may be one of the first changes you face when someone in your life is diagnosed with a brain tumour. Sometimes the demands of care-giving combined with the stress of everyday life can be overwhelming. In order to provide care and support for someone else, you need to look after your own needs as well.

- Recognise signs of stress in yourself, earlier rather than later.
- Seek help and accept it from family, friends and neighbours or from a social worker, who can tell you about practical and emotional supports available.
- Make time to do things that you enjoy.
- Maintain your contact with others and try not to give up your hobbies and interests.
- Share your feelings with a supportive person such as a family member, close friend, health professional or members of a support group.
- Ask your doctor for information so you understand what is happening. If you don't understand what the doctor says, ask him or her to explain again. Having answers to your questions can help to reduce your stress.

- Look after your own health needs by making sure you eat a healthy balanced diet, exercise, sleep regularly and find time to relax. Don't put off your own medical appointments.

If possible, share the care of the person with a brain tumour with trusted family members or friends. This will help you to receive adequate rest.

You may find it helpful to read our booklet *Caring for Someone with Cancer*. Visit www.cancervic.org.au or call the Cancer Council Helpline on **13 11 20**.

Coping with behavioural and personality changes

The person's behaviour and personality may be affected, depending on where the tumour is in the brain. Effects from the tumour may include confusion, short temper, forgetfulness, anxiety, depression, sadness and, rarely, aggression. The person may become more or less emotional than usual and may become quite withdrawn. Their senses may also be affected – vision, taste and smell. As a support person or carer, the following strategies may be helpful to manage these changes.

- Talk to your doctor about any changes you see in the person you are caring for. Your doctor will help you to better understand what is going on.
- Reduce demands made on the individual without taking away independence and control – too many demands or too much stimulation can add to confusion and frustration.
- Try to set achievable goals, limitations and boundaries.

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- People may show behaviour change during the course of treatment – with increasing awareness can come anger, frustration, anxiety, depressed mood, etc.
- Try not to take angry outbursts and words personally – try to remain calm.
- Gently remind the person of the changes/limitations that have occurred and why they might need help.
- Be reassuring and encourage them about how well they are doing.
- Use written daily schedules to create routine.
- Keep family members informed of any changes, which will help reduce confusion, tension or potential embarrassment.
- Encourage physical activity as an outlet.
- Don't pretend to know what another person is feeling – ask them.
- If the person becomes agitated about something, try to redirect their attention to another topic.

Tips for communication problems

A brain tumour may lead to difficulties in talking, reading, writing, concentrating and remembering. See a speech pathologist and/or occupational therapist at the hospital or community health centre to find out how these difficulties can be managed. Here are some general tips that may be helpful:

- Talk in short, clear sentences.
- One idea or concept at a time helps. Fatigue, memory loss, etc. can make it difficult to consider several concepts at a time.
- Allow a reasonable amount of time for a response to occur during conversation – avoid rushing the person or finishing their sentences.

- Check to see if the person has understood you – rephrase or simplify your point if needed.
- Encourage communication, even if it is slow, and maintain eye contact.
- Acknowledge difficulties if the person is getting upset or frustrated.

Information and support services

Remember that you can only care for a person successfully if you also care for yourself. It can be helpful to identify and discuss your thoughts, feelings and needs with the person you are caring for and with others (e.g. family, friends, support group members or health professionals).

- Call the Cancer Council Helpline on **13 11 20** to speak to an experienced cancer nurse and find out about support groups and practical services that may assist you.
- Carers Victoria (1800 242 636) can provide useful information for carers.
- Brain Tumour Australia (www.bta.org.au) has lots of helpful information about brain tumours.

References

Acknowledgment is made of resource material produced by:

American Brain Tumour Association (2001) *Living with a Brain Tumour: A Guide for Brain Tumour Patients*.

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