

OVERVIEW

Managing changes to thinking and behaviour after diagnosis of a brain tumour: A series of fact sheets and information resources for patients and their carers

The NSW Oncology Group, Cancer Institute of NSW has developed 16 fact sheets that provide important information about many of the thinking and behaviour changes people may experience after a brain tumour.

KEY FACTS

Many people experience changes to the way they think and/or the way they behave as the result of a brain tumour.

Each fact sheet is laid out in the same way, and contains:

- A definition of the problem.
- Some statistics about how often the problem occurs among people with brain tumour.
- A list of common symptoms.
- The story of a person living with the problem.
- Strategies that the person with brain tumour can use to manage the problem.
- Strategies that carers or family members can use to support the person.
- Key questions to ask your doctor or other health professionals.
- Links to more information on the web which may also be useful.

In reading the fact sheets keep in mind that:

- Changes to thinking and behaviour can be due to a number of causes including the brain tumour, medication or other treatments such as chemotherapy or radiotherapy.
- The changes can be short term or lifelong.
- The changes may get better or worse over time.
- Different types of tumours in different parts of the brain may result in a number of different symptoms.

Tips for reading the fact sheets

1. Choose the ones that relate to you.
2. Identify the symptoms you might be experiencing.
3. Give the fact sheets to your family members and/or friends to read.
4. Implement any strategies to assist you in managing the changes.
5. Access any additional resources if required.

The resources can be used to increase your knowledge or as a tool to assist you in coping with the changes. They are not to replace professional advice or relevant treatment.

It is not expected that you will experience all of the identified changes. Some people may experience a number of symptoms, some only one or two and others may not experience any changes at all. The goal is for you to access the fact sheet that relates to your particular changes. There is some overlap between the fact sheets and the symptoms you may experience, so you might need to look at more than one in order to fully address your problems.

List of Information Sheets

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| 1. Can't seem to get yourself going...?
Don't seem to care about anything...? | Apathy / Lack of motivation |
| 2. Are you having trouble with your temper...? | Anger |
| 3. Are you feeling tense, nervous and overwhelmed...? | Stress and Anxiety |
| 4. Do you feel exhausted or tired a lot of the time...? | Fatigue |
| 5. Can't seem to think straight...? | High level thinking problems |
| 6. Can't seem to say or do the right thing at the right time...? | Inappropriate social or sexual behaviour |
| 7. Do you feel that you are on an emotional roller coaster...? | Lability |
| 8. Do you keep forgetting things...? | Memory |
| 9. Are you having difficulty staying on task...? | Attention and Concentration |
| 10. Can't find the right word or talk too much...? | Communication |
| 11. Feeling lost, not knowing where you are...? | Disorientation/ Appearing confused |
| 12. Do you repeat yourself or get stuck like a broken record...? | Perseveration |
| 13. Do you only think about yourself and find it hard to see other people's point of view...? | Egocentricity |
| 14. Do you sometimes act without thinking...? | Impulsivity |
| 15. When how you look no longer seems to be important...? | Neglecting personal care/looking after yourself |
| 16. Do you feel sad, tearful, can't seem to enjoy yourself...? | Low mood – Depression |

List of Resource Sheets

1. Anger Management
2. Stress Management and Relaxation Techniques
3. Stress Management
4. Activity Scheduling
5. How to Cope with Depression
6. Mindfulness Exercise
7. Goal Setting
8. Memory Tips
9. Timetable
10. Checklist for Getting Ready
11. Problem Solving

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