

## 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...?<br>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

## Acknowledgements

We wish to thank the following people for their contributions:

- Jason Best, Vianne and Greg Hokin, Joe and Tina Maltese and Terry Martin.
- The neuro oncology research team from Liverpool Hospital: Kylie Wright, Grahame Simpson, Teresa Simpson, Diane Whiting, Eng-Siew Koh, Kathryn Younan, Rachael Rietdijk and Rochelle Firth from Royal North Shore Hospital.
- Members of NSW Cancer Institute – Neuro Oncology Group and other people who have provided reviews including Mark Sabaz and Manal Nasreddine from Liverpool Hospital.

## Apathy / Lack of Motivation

# Can't seem to get yourself going...? Don't seem to care about anything...?

### What is apathy?

Apathy is a lack of interest or concern, most often in relation to matters of general importance or appeal. It can also appear as a lack of initiation in that the person has difficulty starting activities or coming up with ideas. Apathy may seem as if someone just doesn't care about anything anymore.

### How do I know if I am apathetic or lack motivation?

- Finding it hard to get started or show initiative.
- Lack of energy, drive or motivation.
- Know how to do something but need to be prompted.
- Finding it hard to start or finish everyday activities or jobs.
- Less interest in starting activities that were enjoyed before.
- Inactive at home or with leisure activities.
- Finding it hard to make the effort to keep concentrating.
- Not wanting to get out of bed, shower and dress or join in conversations.
- Sit around all day watching television.
- Complain of boredom and be restless and agitated.
- Loss of interest in life.
- Seem not to care about anything.
- Finding it hard to talk with others or think of what to say.
- Giving up easily.

### 'Sue's' Story

'Sue' is in her late fifties and was diagnosed with a meningioma in the right frontal region of her brain. Since her surgery, her son says that she seems

to have lost interest in doing anything. She sits around in her pyjamas all day unless prompted to shower and dress. 'Sue' now finds it hard to start activities, is slow moving and lacks energy. Before the brain tumour, she took great pride in making sure she was perfectly groomed and was very hard working looking after the house and family.

### Strategies

#### For the person with a brain tumour

- Use a weekly timetable and keep it in a place that is easy to see (for example, a whiteboard or timetable pinned to a notice board).
- Write the list the day before or plan the week with someone on a Sunday night.
- Use lists for tasks that need to be done, and then tick off each one as it is done.
- Work with another person to help keep motivation – for example, cook a meal with someone else.
- Plan outings with someone else to ensure you keep up your energy levels and interests

#### For the carer/family member

- Make a routine for the person to follow.
- Use a weekly timetable.
- Write a list of activities and have the person with the brain tumour tick off each item as it is done.
- Ask a doctor if medication can help.
- Give lots of prompts in a positive way that still respects the person.
- Give help to get the person started on activities.

### KEY FACTS

- A survey of people with a brain tumour found that 33% needed frequent prompting, lacked interests and found it hard to finish things.
- Carers of people with a brain tumour who were surveyed found that 27% of their relatives found it hard to get started on anything (problems with initiation).

- Try to let the person do as much of the task as they can – only give as much help as is needed.
- Do things together such as cooking dinner.
- Change tasks often to stop boredom.

### Questions to ask your health professional

- What is the likely cause of the apathy?
- Is it related to the tumour itself?
- Is it related to the treatments given for the tumour or other medications?
- Could the apathy be an unrelated medical condition and does this need treatment in itself?
- Do I/we expect the apathy to get better or worse over time?
- Are there any medications that can help the problem?
- Can a psychologist help to treat this problem?
- Are there any diet or lifestyle factors that can help with the apathy?

**Links to other information:**

- <http://braininjury.org.au/portal/fact-sheets/fatigue-and-lack-of-motivation---fact-sheet.html>
  - [http://www.health.qld.gov.au/abios/documents/behaviour\\_mgt/adynamia\\_motivation.pdf](http://www.health.qld.gov.au/abios/documents/behaviour_mgt/adynamia_motivation.pdf)
- Resource Sheet – Checklist for Getting Ready  
Resource Sheet – Timetable

## Anger

# Are you having trouble with your temper...?

### What is anger?

Anger is a normal human feeling that can range from mild annoyance to intense rage. When we feel angry a number of natural changes occur in our body. Our heart rate and blood pressure rise and stress hormones are released. This can cause a person to shake, become hot and sweaty and feel out of control. When people have angry feelings they can act in ways that are destructive and aggressive. Anger that is out of control can lead to problems in relationships and all other areas of life.

For people living with a brain tumour, outbursts of anger or a general level of irritability can result from injury to parts of the brain that control our impulses. Anger can also result from feelings of frustration at not being able to say what one really wants to say or perform at the level that was possible in the past.

### How do I know if I have a problem with anger?

- Physical aggression including hitting, pinching, punching people or things such as walls, throwing things, making aggressive gestures (e.g. shaking fist) or standing too close to others.
- Verbal aggression such as raising voice, swearing, screaming, making critical or abusive comments, insults, making verbal threats.
- Feeling frustrated and finding it hard to cope with or control yourself.
- Irritability, such as having a 'short fuse'.
- Being more snappy or intolerant.
- Harming yourself, for example, banging your head, hitting oneself.
- Acting in a threatening way, for example

raising voice, staring, or making threats to harm other people.

### 'Adam's' Story

Adam is a 21-year old man with a high-grade tumour (medulloblastoma) was yelling loudly, breaking and throwing objects when he felt angry. He never said sorry for acting this way. Before his diagnosis, his family said that he was very easy to get along with and was happy most of the time. Though he did not threaten his family, he would explode with anger for little or no reason at all. His family felt they had to 'walk on eggshells' all of the time.

### Strategies

#### For the person with a brain tumour

- Make sure you have a routine in your life.
- Try to lower your stress (see Stress fact sheet).
- Keep a check on your fatigue levels (see Fatigue fact sheet).
- Find someone to talk to who will listen openly.
- If you are starting to feel angry with someone, leave the room before you explode, or go for a walk.
- Try to avoid alcohol.
- Learn Anger Management skills (see Anger Management fact sheet).
- Try to spot triggers that set your anger off and try to avoid those triggers when possible.
- Express your anger, rather than bottling it up. Let off steam with someone you can trust, and seek counselling if you feel this will help.
- Be active in sport, housework or go for a walk. This can help to lower some of the stress that feeling angry can cause.

## KEY FACTS

A survey of people with a brain tumour found that:

- 29% regularly showed significant levels of verbal aggression.
- 17% threw objects, slammed doors or acted in other physically aggressive ways.
- 24% were irritable, easily annoyed or became impatient for no apparent reason.

- Try to think about the reasons why you get angry. The more you know about the reasons, the easier it can be to spot 'danger situations' before they start, and to take steps to avoid those situations from getting worse.
- Following an outburst, forgive yourself, make any repairs or amends you need to make, try to let go and move on.

### For the family member

Anger and frustration are normal feelings for family members living with or caring for someone with a brain tumour. The way people outside the family react can make matters worse, if they do not understand the deeper problems.

- Try to spot the triggers that lead to a loss of temper or irritation. Write them down over a week. Are there any triggers that seem to keep coming up? Is there anything that can be done to avoid or lower the number of times your relative faces these triggers?

- Try to increase the level of routine in the person's day. With more routine, the person with brain tumour is less likely to get angry due to unexpected occurrences.
- Try to gently distract the person from the trigger that is making them upset and focus on something that is enjoyable for them.
- Talk with someone about your own feelings. You may feel hurt, frustrated or feel tired by having to deal with these anger problems.
- Sharing your own feelings with others may help to lower your own level of stress.
- Try to tell yourself that the anger is really not a personal attack on you but is due to the injury that the brain tumour has caused.
- Try not to argue back. If all else fails, leave the room and wait for things to calm down.
- Keeping yourself safe is the first priority – seek help if you get injured.

### **Questions to ask your health professional**

- What is the cause of the anger?
- Is it related to the tumour itself?
- Is it related to the treatments given for the tumour or other medications?
- Could the anger be an unrelated medical condition and does this need treatment in itself?
- Do I/we expect the anger to get better or worse over time?
- Are there any medications that can help the problem?
- Are there any diet or lifestyle factors that can help the anger?
- Will a psychologist be able to help treat this problem?
- Who else could I speak with to help with the anger?

### **Links to other information:**

- [http://www.psychology.org.au/publications/tip\\_sheets/anger/](http://www.psychology.org.au/publications/tip_sheets/anger/)
- <http://www.apa.org/topics/controlanger.html>
- <http://braininjury.org.au/portal/fact-sheets/anger-and-brain-injury---fact-sheet.html>
- Resource Sheet – Anger Management.



## Stress and Anxiety

# Are you feeling tense, nervous and overwhelmed...?

### What is stress and anxiety?

Stress is a natural response to change and coping with major life events. All situations elicit some level of stress but the level and quality of stress we experience will vary. Stress can at times be helpful and motivate us to achieve goals, like when we have to complete work to a deadline. Other types of stress can be upsetting such as anxiety.

Anxiety is a feeling that is often linked with stress. It is defined as a state of apprehension, uncertainty and fear resulting from expecting a threatening event or situation. These threats may be either real or imagined. Anxiety often impairs physical and psychological functioning.

Facing stress triggers a series of chemical changes in our bodies that help us to deal with the stressful situation. This is called the 'flight or fight' response. These changes help us to prepare to face the stressful situation by either escaping from the situation (flight) or knuckling down and tackling the situation (fight). However, if the stress goes on for long periods of time, then these chemical changes can start to harm our health.

### How do I know if I am stressed?

#### Physical signs

- Headaches, heart beating faster than normal, upset stomach, tightness or pain in the chest, poor appetite, butterflies in the stomach, breathlessness, tight muscles particularly in the neck and shoulders, poor sleep, vivid dreams.

#### Feelings associated with stress can include:

- Frustration, nervousness, discouragement, negativity, anxiety, anger or irritability.

### How do I know if I am anxious?

- Feeling uncomfortable and nervous.
- Avoiding situations or people because you feel nervous.
- Feelings of fear or agitation.
- Feeling light headed or any of the physical signs of stress identified above.
- Not being able to sleep.
- Having frequent and worrying thoughts.

### 'John's' Story

'John' is a man in his late thirties who was diagnosed with a glioma. He avoids going out because he has been having seizures and is scared that he will have one in public. As a result he feels very uncertain and worried about his future. He has even had 'panic attacks' when away from home. He says that he always feels stressed and this leads to him being more irritable and aggressive. 'John's' social life has been severely affected because he hardly ever leaves the house. He now feels sad and lonely because of these problems.

## KEY FACTS

A survey of people with a brain tumour found that:

- 13% were severely or extremely stressed.
- 23% were severely or extremely anxious.

### Strategies

#### For the person with a brain tumour

- Ask for help with your finances, work, family roles and medical decisions.
- Reduce your work load if possible.
- Identify what appears to be causing your stress.
- Look realistically at what you can manage or change.
- Learn positive coping skills such as relaxation (see Resource sheet), positive thinking, meditation, controlled breathing (see Resource sheet), yoga, Tai Chi, mindfulness (see Resource sheet).
- Do some light exercise.
- Spend time with people who help you feel good.
- Do something you enjoy.
- Eat a healthy diet.
- Lower the number of cups of coffee (tea, coke or chocolate) that you drink, because high levels of caffeine also cause similar feelings of stress in the body.
- Avoid people or situations which add to your stress, such as travelling in peak hour traffic.

### **For the carer or family member**

- Manage your own stress so you are better able to assist your family member.
- Don't take things personally.
- Provide support and reassurance when needed.
- Encourage some level of independence.
- Help the person overcome their fears in a controlled and supportive manner.
- Seek assistance if you don't know what to do.

### **Questions to ask your Health Professional**

- What is the cause of the stress/anxiety?
- Is it related to the tumour itself?
- Is it related to the treatments given for the tumour or other medications?
- Could the stress/anxiety be an unrelated medical condition and does this need treatment in itself?
- Do I/we expect the stress/anxiety to get better or worse over time?
- Are there any medications that can help the problem?
- Are there any diet or lifestyle factors that can help the stress/anxiety?
- Who else could I speak with to help with the stress/anxiety?
- Will a psychologist be able to help treat this problem?

### **Links to other information:**

- <http://braininjury.org.au/portal/fact-sheets/stress-and-acquired-brain-injury---fact-sheet.html>
- Resource Sheet – Stress Management
- Resource Sheet – Relaxation
- Resource Sheet – Mindfulness



## Fatigue

# Do you feel exhausted or tired a lot of the time...?

### What is fatigue?

Fatigue is a tiredness or total exhaustion that often doesn't improve with rest. It makes it hard to function and do everyday tasks.

### How do I know if I am fatigued?

- Mild tiredness to total exhaustion.
- A feeling of being 'drained'.
- Resting does not make it better.
- Having no energy or strength.
- Feeling dizzy or light-headed.
- Find it hard to do every day tasks.
- Lacking motivation.
- Find it hard to concentrate.
- Find it hard to think or speak.
- Low sex drive.
- Find it hard to cope with life.
- Difficulty in managing your feelings.

### 'Jenny's Story'

'Jenny' is a 45-year-old mother with a brain tumour who has three young children. Before her diagnosis she had lots of energy. She enjoyed playing netball, coaching the children's sporting teams and she helped out at the local school. Her husband says that she was difficult to keep up with. Since her treatment, 'Jenny' starts the day with some energy but by mid-morning she is struggling to keep going. She feels vague, useless and can't make sense of what she is doing. 'Jenny' wants to keep going but she just can't push herself any further. She feels that she can't achieve anything worthwhile and that she is letting her family down. All 'Jenny' wants to do is sleep.

### Strategies

#### For the person with a brain tumour

- Try to do gentle exercise, such as walking, as this can help to lower fatigue levels.
- Physical therapy may be another option if you are ill or need to be on bed rest.
- Get lots of rest and make set rest times during the day.
- Talk with your doctor or nurse about a plan of regular exercise.
- Eat a well-balanced diet and drink plenty of liquids.
- Limit the number of activities.
- Get help when you need it.
- If you can, ask family, friends, and neighbours to help with daily chores, such as shopping, housework, or driving.
- Get up slowly to help stop dizzy spells after sitting or lying down.
- Speak to your doctor if you are finding it hard to sleep at night.
- Pace your activities, and take lots of rest breaks.
- Each day make a list of your responsibilities, and do the most important ones first while you still have the energy.
- Share tasks with someone else when you can.

#### For the carer/family member

- Give the person more help if it is needed.
- Offer to help, don't wait to be asked.
- Give the person some tasks to do that are not as tiring.
- Support them with a gentle exercise plan. For example, go for a short walk with them.
- Reduce the load and stress on your family member where you can.

### KEY FACTS

A survey of people with a brain tumour found that 28% had considerable problems linked to feeling sleepy through the day and generally feeling tired and listless.

### Questions to ask your health professional

- What is the cause of the fatigue?
- Is it related to the tumour itself?
- Is it related to the treatments given for the tumour or other medications?
- Could the fatigue be an unrelated medical condition and does this need treatment in itself?
- Do I/we expect the fatigue to get better or worse over time?
- Are there any medications that can help the problem?
- Will a psychologist be able to help treat this problem?
- Are there any diet or lifestyle factors that can help with the fatigue?



**Links to other information:**

- <http://braininjury.org.au/portal/fact-sheets/fatigue-and-lack-of-motivation---fact-sheet.html>

## High Level Thinking or Executive Impairments

# Can't seem to think straight...?

### What are executive impairments?

Executive impairments are problems with higher level thinking tasks such as planning, organisation, problem solving, setting priorities, and responding to unexpected situations. It can be very hard to see and accept changes in these areas of thinking and behaviour, that is they do not develop insight into their difficulties.

### How do I know if I have executive impairments?

- Poor problem solving skills.
- Very rigid in your thinking style, have a 'one track' mind that is hard to shift.
- If faced with a problem, find it hard to think 'outside the box'.
- Find it hard to organise information, ideas, or activities.
- Lack of insight, that is, see yourself as the same as before the brain tumour.
- Are not aware that you have any current problems.
- May deny that you have any problems with your thinking or argue with others about the problems.
- Do not cope well with changes in routine or anything unexpected.
- Have problems with judgement.
- Lack awareness of the way you act and as a result, seem tactless or rude.
- Cannot understand you are unable to do things such as work, drive or manage your own finances.
- May not be willing to undertake therapy or refuse help with tasks even when it is needed.
- Being unable to finish an activity or follow through.
- 'Scattered' in your approach about how to do the most important tasks first.

### 'Julie's' Story

'Julie' is a woman in her late forties who was diagnosed with a Meningioma. She now finds that she is so disorganised that it can take her up to three hours to get ready to go out. 'Julie' was also having problems planning and preparing meals. This gets worse when she is distracted by other people or the TV. 'Julie' needs many prompts from her family to help her live from day to day. She often feels overwhelmed by having to complete tasks that used to be easy and automatic.

### Strategies

#### For the person with a brain tumour

- Use a diary, whiteboard or planner to map out your day and week.
- Write out a daily timetable or list of tasks to complete.
- Once you have a list, circle the tasks that are most important and complete them first. Number them in the order you wish to complete them and preferably re-write your list in the right order.
- Reduce noise and other distractions when taking on hard tasks.
- Do harder tasks when you are fresh.
- Don't make big decisions on the spot – wait until you have had a chance to talk to someone that you trust about the issue.
- Take regular rest breaks.
- Have your family member help you if it is needed.
- Try to do only one thing at a time.

### KEY FACTS

- A survey of people with a brain tumour found that 39% frequently had difficulties with higher level thinking tasks such as planning or problem solving.
- Carers of people with a brain tumour who were surveyed said that 15% of relatives had limited insight into these difficulties.

#### For the carer or family member

- Give lots of clear and simple reasons about why a problem is being treated or why the person is unable to do something.
- People can learn a simple five-step process for solving problems. Speak to a psychologist about this. (See Resource sheet - Problem Solving).
- Help your relative to develop a daily routine.
- Keep an eye out for anything that comes up that is not part of that routine – the person may have problems knowing what to do.
- If the person is stuck on one idea, don't argue – it will not change their minds and it will only make you more upset. Find other ways to get around the problem.
- The person may deny that their tumour is changing their life in any way. They may have unrealistic ideas about what they are still able to do. If the person goes on denying the problem or keeps finding reasons to explain it away, then change the subject.



- If a person wants to try something you know they cannot do, let them go ahead and try (as long as it is safe). Sometimes failing at something can help a person to learn about their problems.
- In a gentle manner, you can point out the problems that a person is having when they are finding it hard to do something.
- Encourage the person to join a support group for people with a brain tumour. Talking with other people 'in the same boat' can help to improve awareness of their own difficulties.
- If you can, show the person results from the reports on any tests of their thinking. This may help them learn about the problems that they are now facing.
- It may help to know that insight can get better (perhaps slowly) over a long time.
- Know the reason why they are having problems, and know what to do, but when they are in the problem-situation, they can't use this knowledge to change their actions.

### **For more detailed strategies, also see other fact sheets in the series**

Executive functioning refers to higher level thinking. It involves a number of different parts of our thinking abilities (for example, see list below) working together. The result is that we are able to act in an effective goal-directed manner. For this reason, some of the following fact sheets also have ideas that will help a person who is having problems in this area.

- Attention and concentration
- Confusion and disorientation
- Impulsivity
- Memory
- Lack of motivation/ apathy

### **Questions to ask your Health Professional**

- What is the cause of the thinking problems?
- Is it related to the tumour itself?
- Is it related to the treatments given for the tumour or other medications?
- Could the thinking problems be an unrelated medical condition and does this need treatment in itself?
- Do I/we expect the thinking problems to get better or worse over time?
- Are there any medications that can help the problem?
- Will a psychologist be able to help treat this problem?
- Are there any diet or lifestyle factors that can help the thinking problems?
- Who else could I speak with to help with the thinking problems?

### **Links to other information:**

- <http://braininjury.org.au/portal/fact-sheets/getting-your-life-organised---fact-sheet.html>
- <http://braininjury.org.au/portal/fact-sheets/impaired-self-awareness---fact-sheet.html>
- Resource sheet – Problem Solving

## Inappropriate social behaviour / Inappropriate sexual behaviour

# Can't seem to say or do the right thing at the right time...?

### What is inappropriate behaviour?

Inappropriate social behaviour is acting or talking in an awkward, embarrassing or socially unacceptable way. This is sometimes called 'stepping over the line'. When someone acts in this way, it is very embarrassing for families or partners. Generally this behaviour was not present before the brain tumour or if it was, it has worsened.

Inappropriate sexual behaviour is acting in a way that does not meet with community standards of behaviour. This can include talking about sex too much or touching people when they don't want you to.

### How do I know if my behaviour is inappropriate?

- Changes in the way you behave, for example acting before thinking, swearing, telling off-colour jokes, or acting recklessly.
- Telling strangers too much private information, for example walking up to a stranger and telling them about personal matters such as your brain tumour.
- Being too friendly with people that you do not know well, such as hospital staff or people that you meet for the first time in a shop or on the train.
- Withdrawn, not being as social with other people.
- Flirting and making unwanted sexual suggestions.
- Embarrassing or difficult behaviour.
- Not showing the right feeling for the situation, for example laughing when something sad has happened.
- Saying lewd or sexual remarks.
- Standing too close to other people, making them feel uncomfortable.

- Touching someone that you do not know well.
- Touching yourself in public or in the company of others.
- Exposing yourself in public, for example flashing genital area.

### 'Lewis' Story

'Lewis' is a 56-year-old father with adult children who was diagnosed with a frontal glioma. His close friends report he is normally shy, quiet and polite. However, since his brain tumour he has changed. 'Lewis' has been asking personal questions of newcomers to the church. He sometimes makes crude or sexually inappropriate comments to these total strangers. Normally a private person he is now over-familiar with strangers and shares personal details upon meeting new people.

### Strategies

#### For the person with a brain tumour

- Try to keep a check on the way you act. Look for clues or reactions from others so you know if you have stepped over the line.
- If you are told to stop acting in a way that is not enjoyed by other people, try not to get upset. Look at how you can act better next time.
- Think about how you would like to be treated by others and use this as a guide for the way you act. This is like the saying 'do unto others what you would have others do unto you'.
- Look around for people that you want to be like and try to act the same way.
- Use controlled breathing (see Resource sheet) to keep yourself in check.

### KEY FACTS

- A survey of people with a brain tumour found that 37% showed inappropriate sexual and social behaviour such as laughing too easily or talking too much about sex.
- Carers of people with a brain tumour said that 12% of their relatives showed inappropriate social behaviour that was different to the way they acted before the brain tumour.

### For the carer/family member

- Be consistent with the way you act and the rules you set.
- Make clear rules for behaviour that is 'out'.
- Be clear when someone is acting in ways that are not okay. Make sure your relative knows what rules of behaviour are okay at the family home and when going out.
- If your relative asks rude or embarrassing questions, provide a guide for more appropriate way to act.
- Do not laugh or show disgust when your relative acts in ways that step over the line. Rather, tell the person in a firm tone that such comments, questions or behaviours are 'not on'.
- In a calm manner, let the person know how to act correctly.
- Encourage the person to change the way they act.
- Do not ignore behaviour that breaks the rules as this may encourage the person to keep on going.
- Make sure you praise the person when they act well and stick to the rules you have set.



## Questions to ask your health professional

- What is the cause of the inappropriate behaviour?
- Is it related to the tumour itself?
- Is it related to the treatments given for the tumour or other medications?
- Could the inappropriate behaviour due to an unrelated medical condition and does this need treatment in itself?
- Do I/we expect the impulsivity to get better or worse over time?
- Are there any medications that can help the problem?
- Can a psychologist help to treat this problem?
- Are there any diet or lifestyle factors that can help with the inappropriate behaviour?

## Links to other information

- [http://www.birt.co.uk/images/BIRT06\\_Sexualproblems.pdf](http://www.birt.co.uk/images/BIRT06_Sexualproblems.pdf)
- Resource sheet – Stress Management & Relaxation Techniques



## Lability

# Do you feel that you are on an emotional roller coaster...?

### What is lability?

Lability is a quick and extreme change in a person's feelings, often for no apparent reason. A person may cry over nothing or laugh about things that are not funny. Sometimes the person may know inside that their tears or laughter are not the right response but may be unable to stop.

### How do I know if I am emotionally labile?

- Giggling or laughing, even in sad situations such as hearing bad news.
- Crying or being tearful, even when you are not sad.
- Crying for very little reason.
- Being irritable and snappy.
- May feel that you are being 'picked on'.
- Brief crying spells or anger outbursts and then quickly going back to being calm again.
- You may seem 'over the top' for the situation.

### 'Debbie's' Story

'Debbie' is a 27-year-old woman with a high-grade brain tumour (Glioblastoma) in her frontal lobe. After surgery her family found that one minute she was very snappy and the next smiling. They also said that she cried for no clear reason at all. When given the devastating news about her diagnosis, 'Debbie' did not show much sadness or distress at all. Her family were more upset about the news than she was. The family felt that they were overwhelmed trying to cope with the diagnosis and not knowing how 'Debbie' was going to react at any given moment.

### Strategies

#### For the person with a brain tumour

- Use anger management strategies (see Resource sheet – Anger management).
- Make sure you keep yourself calm and quiet and avoid stressful situations.
- Try taking four deep breaths (Resource sheet – Stress Management).
- Walk away when your feelings are out of control.
- Try to distract yourself by doing something that you know makes you feel calm (for example, going out into the garden).
- If you are laughing or crying, take the tip of your finger and place it on your lips. This will help to bring your feelings back under control.

#### For the family member

- Try to ignore the behaviour.
- Be positive when the person is able to control their feelings - help them talk about how they were able to do it.
- Try to act calmly yourself.
- Look for triggers which may cause the laughing, crying or anger - avoid them if you can.
- Try to limit the number of stress factors that the person is facing.
- Try to avoid criticism, as this may even make things worse.
- Encourage the person to use their strategies such as walking away, controlled breathing or distraction.

## KEY FACTS

- A survey of people with a brain tumour found that 10% found it hard to manage their feelings.
- Carers of people with a brain tumour who were surveyed said that:
- 24% of their relatives showed frequent lability.
- 19% of their relatives laughed or cried too easily.

### Questions to ask your health professional

- What is the cause of the emotional changes?
- Is it related to the tumour itself?
- Is it related to the treatments given for the tumour or other medications?
- Could the emotional changes be an unrelated medical condition and does this need treatment in itself?
- Do I/we expect the emotional changes to get better or worse over time?
- Are there any medications that can help the problem?
- Will a psychologist be able to help treat this problem?
- Are there any diet or lifestyle factors that can help the emotional changes?
- Who else could I speak with to help with the emotional changes?





**Links to other information:**

- <http://braininjury.org.au/portal/fact-sheets/emotional-lability---fact-sheet.html>
- [http://www.health.qld.gov.au/abios/documents/behaviour\\_mgt/lability.pdf](http://www.health.qld.gov.au/abios/documents/behaviour_mgt/lability.pdf)
- [http://www.chw.edu.au/rehab/brain\\_injury/information\\_sheets/behaviour/emotions.htm](http://www.chw.edu.au/rehab/brain_injury/information_sheets/behaviour/emotions.htm)
- Resource Sheet – Anger Management
- Resource Sheet – Stress Management & Relaxation Techniques

## Memory

# Do you keep forgetting things... ?

### What is memory?

Memory includes the ability to store, retain and recall past experiences and information. It also includes the ability to lay down new memories and later recall them when required.

### How do I know if I have problems with my memory?

- Find it hard to learn and remember new things such as names.
- Forget appointments or what has been said.
- Losing things like your glasses or keys.
- Not able to read a book or sit through a movie as memory problems make it difficult to follow.
- Forget instructions or what you are supposed to do for the day.
- Not able to find the way to somewhere familiar.
- Forget what the doctor says.
- Forget what you did yesterday but able to remember things from a long time ago.
- Forget to pass on phone messages, or even that someone has phoned.
- Forget words, feeling that the word is on the tip of the tongue.
- Find it hard to keep track of conversations.

### 'Alice's' Story

'Alice' is a 52-year-old lady with a Glioblastoma (high grade tumour) in her left temporal lobe. Her family found that she is forgetting more and more. She can't recall what day it is, what she has been told and even forgets that she has a brain tumour. This is placing growing stress on her husband who feels overwhelmed with trying to keep track of her medical appointments and

taking on managing the house. 'Alice's' daughters find that they have to spend more time with their parents to lower their father's stress and support Alice who is needing more and more help in everyday activities because of her growing memory problems.

### Strategies

#### For the person with a brain tumour

- Write everything down straight away using a diary, notebooks, lists, and a whiteboard.
- Use a 'to do' list for each day.
- Number the jobs to help with remembering which jobs to do but keep the list short.
- Keep the list to five items. Only add another item when one has been finished.
- Write a timetable for the week or use a wall calendar to note appointments.
- When you have to go to an important appointment (for example, the doctor), write down any questions you might want to ask.
- Take a notebook to write down the answers, take someone with you, or ask the doctor if you can record what he says on a mini tape recorder or your phone.
- Always leave your keys, purse, wallet or glasses in the same place.
- Keep a daily journal or diary of your activities.
- Keep yourself calm and give yourself plenty of time.
- Keep a routine.
- Repeat back to someone important information that you need to remember; this will check that you have

## KEY FACTS

A survey of people with a brain tumour found that:

- 50% used memory strategies such as writing notes.
- 25% forget to do things but will remember when prompted.

heard it correctly and will help you remember for later.

- If you have something hard to learn, try to break it down into small pieces and then learn each one a little bit at a time.
- Learning to remember something new by breaking it down into little 'chunks' of information is called 'chunking'. For example, breaking long phone numbers into smaller groups of three or four numbers.

### For the carer/family member

- Encourage the use of diaries and post-it-notes.
- Use notice-boards or calendars placed in central places around the home.
- Use maps or write out the steps to help get to people and services.
- Use prompts as a way to trigger the memory (i.e. reminders that trigger familiar or regular thoughts eg. names of pets, lunch at 12 noon, mailman always comes in the afternoon).
- Break tasks into smaller steps so there is not so much to remember.
- Give information slowly, one thing at a time.
- Use short simple sentences and simple direct language.



- Reduce distractions in the home/work environment.
- Change home/work situations to fit to an individual's level of coping.
- Schedule more demanding tasks when the person is at their best (often mornings).
- Do things in short bursts, allow for lots of breaks.
- Set realistic goals for reading activities (eg. short stories, and magazines instead of longer books).
- Find new interests for the person, which need less concentration if past hobbies can no longer be done.
- Label household items (e.g. drawers or kitchen cutlery) or even rooms if needed. Use words or symbols.

### **Questions to ask your health professional**

- What is the likely cause of the memory problems?
- Is it related to the tumour itself?
- Is it related to the treatments given for the tumour or other medications?
- Could the memory problems be an unrelated medical condition and does this need treatment in itself?
- Do I/we expect the memory problems to get better or worse over time?
- Are there any medications that can help the problem?
- Can a psychologist help to treat this problem?
- Are there any diet or lifestyle factors that can help with the memory?

### **Links to other resources:**

- <http://www.headinjury.com/memorystrat.html>
  - <http://www.tbiguide.com/memory.html>
- Resource Sheet – Timetable  
Resource Sheet – Memory Tips

## Attention and Concentration

# Are you having difficulty staying on task...?

### What is attention and concentration?

Attention is not just one type of mental process. There are thought to be three basic types of attention: selective attention, sustained attention and complex attention.

Selective attention is the ability to focus on one part of the world while ignoring other aspects of the environment that are not important for the task at hand. For example, listening carefully to what someone is saying while blocking out other noise in a room.

Sustained attention is the ability to focus on the task at hand for a sustained or relatively lengthy period of time.

Finally, complex attention is the ability to flexibly control attention by either switching or dividing attention between more than one thing. This could include carrying on with a conversation whilst driving a car or bringing one's attention back to cooking a meal after you were momentarily distracted by a child's cry for attention. Complex attention is important when we want to multi-task.

Not all types of attention will necessarily be equally impaired if you have a problem with attention.

### How will I know if I having a problem with attention?

- Having a short concentration span, jumping from one idea to the next.
- Finding it hard to focus on and finish a task.
- Finding it hard to plan a set of steps that are needed to complete a task (for example cooking a meal) and then finishing them in the right order.

- Difficulty with problem solving.
- Loss of concentration.
- Finding it hard to keep attention focused for a long period of time, for example watching a movie, reading a book.
- Being easily distracted.
- Can't sit still for long - being agitated or restless, getting up and down and walking around all of the time.
- Unable to do two things at a time, for example, talk while making a cup of tea.
- Not appearing to listen or maintain a conversation.

### 'Liz's' Story

'Liz' is woman in her early fifties who was diagnosed with a right temporal meningioma. She returned to her part-time clerical job, but found that she was finding it hard to stay focused and was easily distracted. 'Liz' tried using 'to do' lists to keep on track. She found that she was much slower in finishing tasks. 'Liz' said that she could only focus on one task at a time. There were times when she was working on task and was interrupted by the phone, when the call had ended she found it hard to pick up where she had left off. 'Liz' said that everyone at work was very supportive. However, she was unable to work at the same pace or complexity as she could before her brain tumour.

### Strategies

#### For the person with a brain tumour

- Break the task into smaller parts to make it simpler to do.
- Reduce outside noise and distractions when trying to do a task, for example,

## KEY FACTS

A survey of people with a brain tumour found that:

- 21% had problems paying attention or concentrating.
- 13% were disorganised.
- 29% could not do two things at the same time such as talk and prepare a meal.

turn off the television when cooking or eating a meal.

- Write a list for any tasks you need to do and tick off the list as it is finished.
- Use a whiteboard or notice board to write down any tasks you need to do.
- Work on harder tasks when you are not feeling tired.
- Use cues and reminders to help you return your focus to the task.
- Focus on tasks for a short time, then allow a rest break, take a walk or do something you find enjoyable.
- Use self-talk to keep yourself on task, for example tell yourself "I need to get milk when I am at the shop".
- Use lists to remind yourself what you need to buy when shopping – remember to look at the list.
- Work on tasks with a 'buddy', for example, prepare a meal together, share the housework (while one is dusting the other person can vacuum).

### **For the carer**

- When giving instructions for a task that has a number of steps, only give the person one step at a time.
- Use reminders to keep the person on track.
- Help them by working on tasks together.
- Limit other sources of noise or distraction when talking to them, such as the television.
- When giving them important information to remember, make sure they are not being distracted and have heard what you are telling them.

### **Questions to ask your health professional**

- What is the cause of the concentration or attention difficulties?
- Is it related to the tumour itself?
- Is it related to the treatments given for the tumour or other medications?
- Could the poor concentration/attention be an unrelated medical condition and does this need treatment in itself?
- Do I/we expect the poor concentration/attention to get better or worse over time?
- Are there any medications that can help the problem?
- Are there any diet or lifestyle factors that can help the poor concentration/attention?
- Will a psychologist be able to help treat this problem?
- Who else could I speak with to help with the poor concentration/attention?

### **Links to other resources:**

- <http://braininjury.org.au/portal/fact-sheets/attention-and-concentration---fact-sheet.html>
- [http://www.health.qld.gov.au/abios/documents/behaviour\\_mgt/attent\\_concentrate.pdf](http://www.health.qld.gov.au/abios/documents/behaviour_mgt/attent_concentrate.pdf)
- [http://www.chw.edu.au/rehab/brain\\_injury/information\\_sheets/thinking\\_skills/attention\\_and\\_concentration.htm](http://www.chw.edu.au/rehab/brain_injury/information_sheets/thinking_skills/attention_and_concentration.htm)

## Communication

# Can't find the right word or talk too much...?

### What is communication?

Communication is the ability to talk to others in a way that they can understand. It is also about understanding what other people say to us. Communication is about when we talk, who we talk to, how long we talk for, what we say and what we don't say.

Communication needs a number of skills that involve different areas of the brain. The location of the tumour in the brain will affect the sorts of communication difficulties a person may experience.

### How will I know if I have a problem with communication?

Communication problems can include difficulties with:

- Being able to think of particular words.
- Understanding more complicated or abstract language.
- Slowed or slurred speech that is hard to understand.
- Focusing during conversations, not listening.
- Following information given in a conversation.
- Recalling conversations after they have happened.
- Organising your ideas in a conversation.
- Keeping a conversation going.
- Talking too much.
- Keeping the tone or volume of your voice at a normal level.
- Picking up on social cues from others (for example when the person you are talking to is bored or upset).
- Making comments or asking questions which could be considered rude.
- Talking about topics which may not be appropriate for the situation.
- Problems with reading or writing.

- Making things up.
- Picking up when other people are making a joke or are being sarcastic.

### 'Helen's' Story

'Helen' has shown a number of problems with her communication since her brain tumour diagnosis. She tends to put too much detail in her stories and does not notice when people are bored. Though 'Helen' is able to listen to others and remember what they say she does not pick up when people are being sarcastic or seems unable to detect lies. She also tends to talk non-stop and not give the other person a chance to talk. 'Helen' rarely asks questions and has a tendency to interrupt when other people are talking, often talking over the top of them. People try to avoid her in social situations and she tends to latch onto people, especially new people, who are often at a loss in how to deal with 'Helen's' non-stop talking.

### Strategies

Successful communication will need the person with a brain tumour and their family and friends to work together. You can talk about these strategies together.

#### To think of words or names:

- Describe the word you are unable to think of in a different way. This will help the other person to know what you are talking about. It may also help you to think of the word yourself.
- Family and friends can help by saying the correct word as part of the conversation if you are unable to think of it.
- Link the names of people you meet

## KEY FACTS

In a survey, the carers of people with a brain tumour found that:

- 26% of their relatives 'sometimes or frequently' interrupted the conversation or talked out of turn.
- 21% had some difficulties with communication, such as trouble finding words or having a tendency to ramble.

with another person of the same name or with a word that sounds the same as their name (Mr Jones – phones).

#### To follow people who use complicated words or ideas:

- Let the other person know if you did not understand (e.g. Can you break that down for me? Could you write it down?)
- If in a group setting (e.g. work meeting or class), write down questions that you can ask the person at a later time.
- Family members and friends should aim to talk in a way that is easy to follow (for example, break down information into smaller chunks, using examples to explain what you mean).

#### Difficulty speaking clearly:

- Have conversations in a quiet place.
- Tell people up front the topic that you want to talk about – giving the big picture will make it easier to follow the smaller details.
- If someone doesn't understand a word, try to explain it in a different way. If needed, try another way - spelling the word or writing it down.





### **Getting distracted while speaking to someone:**

- Aim to have any important conversations in a quiet place.
- Prompt yourself to keep focused on the conversation. Ask yourself, "Am I really listening?"
- Think of questions you can use which follow on from what the person is saying. This will help to keep you focussed.
- Spell out the reason for the conversation at the start. This can help you to keep track until the end.

### **To follow what the other person has told you:**

- Don't be afraid to check with people to make sure you understand what they are saying (for example, ask 'So what you are saying is...?').
- Family and friends can sum up what has been said at the end to make sure you have got the important points.

### **To recall a conversation after it has happened:**

- Write down the important points. You can then look back to it at the end of the conversation.
- Use a diary to help you keep track of appointments or things to do that people tell you about. Family and friends can help by reminding you to put information in your diary, if you have a problem remembering to do this.
- Family and friends may need to tell you the information again after the conversation has ended. This way, you do not have to try to remember it all.

### **Difficulty organising your ideas in a conversation:**

- Ask others to let you know whether you are getting your message across clearly (for example, ask 'Does that make sense?').

### **Links to other information:**

- <http://braininjury.org.au/portal/fact-sheets/communication-disorders---fact-sheet.html>

- Family and friends can help by organising the conversation using their questions as "subheadings" (For example, asking 'What do you want to do this weekend? Who will you go with?').
- Solve problems by talking them through with family or friends, as it may be hard to come up with an answer on your own.

### **To keep a conversation going:**

- Listen to the news and make a note of interesting topics that you can talk about with others.
- Plan before social events the topics you can use in talking with the people who will be there. Family and friends can also help you come up with ideas.
- Aim to keep conversations going by using follow-up questions or comments.

### **Talking too much in a conversation:**

- Aim to have a two-way conversation. If you have been talking more than the other person, use a question or stop talking for a bit so that they can have their turn.
- Family and friends can also help when they need to have a turn in the conversation (For example, by saying 'Hang on, I just wanted to add in what I think about...').

### **Making comments or asking questions, which could be considered rude or talking about topics that may not be appropriate for the situation:**

- Check whether what you are about to say is the right thing for the situation. If it isn't right, you can think it, but don't say it.
- Family and friends can help with working out the right sort of questions to ask before social situations.

- Use a short phrase to help yourself communicate successfully (for example, 'Stay in control, Hang in there, Be serious'). If needed, your family or friends can use it to remind you.

### **Questions to ask your health professional**

- What is the cause of the communication difficulties?
- Is it related to the tumour itself?
- Is it related to the treatments given for the tumour or other medications?
- Could the communication difficulties be an unrelated medical condition and does this need treatment in itself?
- Do I/we expect the communication difficulties to get better or worse over time?
- Are there any medications that can help the problem?
- Are there any diet or lifestyle factors that can help the communication difficulties?
- Will a psychologist or a speech therapist be able to help treat this problem?
- Who else could I speak with to help with the communication difficulties?