

It's **okay** to ask

Questions to ask your healthcare team about
your **brain tumour** and treatment



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A Steering Committee comprising Dr Danette Langbecker (Research Fellow, The University of Queensland), Dianne Legge (Olivia Newton-John Wellness & Research Centre - Austin Health), Dr Jonathan Parkinson (Neurosurgeon & Spinal Surgeon) and Sally Payne (Senior Advisor, IBTA) oversaw the project. It was assisted by a Project Team comprising Patricia Berman, Catherine Hindson, Janet Micallef, Susan Pitt, Rigoula Roussakis, Philip Steel, and Annabelle Wilson.

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Before you read on...

Some people want to know a lot of details. They feel more in control when they know all of the facts.

Other people want only small amounts of information. They get upset when they are told too many details. They may want simple information - for example, what pill to take or what their treatment will be. **Don't be afraid to tell your doctor how much or how little you want to know.**

You may have other questions not listed here. **There is space to write your own questions. You can also write notes.** There are no easy answers to some questions. And it may take time to find answers. Sometimes there may be no answer at all or you will just have to wait and see. Talking to your doctors and nurses can help you deal with your worries.

How to talk to your doctor:

- Take a friend or family member with you to the doctor. They can help you remember things.
- If you have questions, let your doctor know at the start of your visit.
- If you have a lot of questions, ask the receptionist for a longer appointment.
- Everything is new to you. It is important to tell your doctor if you do not understand something they said.
- There is nothing wrong with telling your doctor that you do not understand.
- It is normal to need to hear the same information more than once.
- Your doctor's job is to clear up doubts or worries. It is important to get things straight.
- Ask your doctor who else has useful information.
- Your doctor can refer you to other health professionals in your area.

This booklet is called ***It's okay to ask***. It has questions you can ask your doctors or other staff. People with brain tumours helped to write this booklet. Their families, doctors and nurses also helped.

This booklet will help you get the information and support you need. It is a good **starting point**. It lists questions other patients and doctors found helpful.

The booklet has questions about:

- » diagnosis
- » what you can expect in the future
- » symptoms and changes
- » the healthcare team
- » support
- » treatment and management
- » what to expect after treatment

You may only want to look at these if they affect you right now. **Not all questions will apply to you**. Different tumours have different effects and treatments. It's okay to not want to ask these questions or hear the answers.

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DIAGNOSIS

- Can you write down the name of my tumour?
Are there any other names for my tumour?
- Where is it in my brain? What does that part of the brain do?
- Is it slow- or fast-growing?
- How big is the tumour? How much tumour is there?
- What caused this tumour? Is my family likely to be at greater risk of developing a brain tumour?
- I'm not sure how to tell my family or child(ren) about this – how can I explain it?
- What seems to have worked for others to deal with the stress of this diagnosis? Is there someone I or my family can talk to, to help us cope with this?



TESTS

- What information will this test give us? How will this information affect my treatment or care?
- What is involved with having the test? Will it hurt?
- When will I get the results of my test? Who will tell me my results?
- Can I have a copy of my test results?
- Should I continue my usual activities until we receive the test results? Is there anything I should do or not do?



WHAT TO EXPECT IN THE FUTURE

WHAT TO EXPECT

- How do you think I am going?
- Is my tumour likely to come back after treatment?
- If the tumour is likely to come back, how long before it returns?
- What are the chances of curing my tumour?
- How long do people normally live with this type of tumour? What is the longest you know of?
- What are my chances of surviving this?
- Could my tumour become more aggressive in the future?
- Could my tumour improve by itself? Will it get worse if it is not treated?
- What will you look at to predict what will happen in the future?
- If my tumour cannot be cured, what can I expect in the future? What will my best and worst days be like?



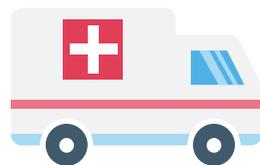
SYMPTOMS & CHANGES

- What symptoms can happen in the future?
- What changes are normal? What changes should I expect?
- Are there any problems that I should look out for? What should I do if I have one of these problems?
- How long will the symptoms last for? Are the symptoms permanent?
- Who should I ask about treatments?
- Who should I ask about side effects?
- What symptoms or changes do I need to tell you about?
- Will my looks change?
- Will I still be able to work?
- Will I be able to do the same things I did before?
- Do I need to rest? Will I still have the same energy?
- Can I still drive? Do I need to tell driving authorities about my tumour?
- Will my sex life be affected?
- What can I do if I am feeling sad, unsettled or angry?



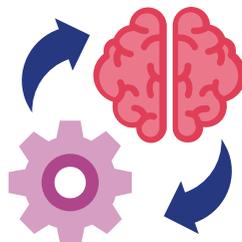
SEIZURES

- Am I likely to have seizures?
- What should my family do if I have a seizure?
- When should I go to hospital or call an ambulance?
- What does it look and feel like to have a seizure?
- Are there warning signs for a seizure?



CHANGES IN THINKING AND PERSONALITY

- How could my thinking, actions or personality change?
- Can you refer me to someone who can check if my thinking is changing?
- How will I know if my thinking or actions change?



THE HEALTHCARE TEAM • • • • •

- Who is in charge of my care?
- What kinds of doctors and staff will care for me?
- When will I meet the people involved in my care?
- How many people like me do you treat each year?
- Who can I talk to if I'm worried about my care?
- Will someone talk with my GP about my tumour?
- Can I get an interpreter to help us?
- Can I talk to a doctor or staff member from my own culture?

MULTIDISCIPLINARY TEAMS

- What is a multidisciplinary team?
- Do you work as part of a multidisciplinary team?
- What does having a multidisciplinary team mean?
- How will the team manage my care?



CONTACTING DOCTORS AND HEALTHCARE TEAM MEMBERS

- Who can I talk to if I receive confusing advice?
- Who is my first point of contact?
- How do I contact my healthcare team?
- What should I talk to my GP about?
- What should I talk to my oncologist about?
- What other services can I get? How do I get them?
- Who can help me with my medicines?
- Who do I talk to when I am not at the hospital?
- How can I get in touch with you out of hours?
- Who do I talk to in an emergency?



DOCTORS' VISITS

- Who will I see next, when and where?
- When will I see you again?
- How often will I see you?



- What services can help me through my illness and treatment?
- How do I get support services when I go home?
- Can you put me in touch with organisations which provide information and support for people like me?
- What should I say to my family and friends?
- How can my family support me?
- Should I tell my children's school about my illness? How can the school help while I'm ill?
- What if I am not coping or feel down?
- Is there someone who can help me cope? Can someone help my family?
- Is there anyone I can speak to about my spiritual needs?
- Who can help me make a Will or Advance Medical Directive?



INFORMATION

- Are there any trustworthy websites with information about my tumour?
- Where can I read more about treatment?
- Where can I get support?
- Do you have more information in other languages?
- Do you have any information I could give my family or children?

PRACTICAL ISSUES

- Who can tell me about government or financial assistance? Can my family also get help?
- Where can I park when I come in for treatment?
- Can I get a disability parking permit? How do I get it?
- Can I get taxi vouchers if I can no longer drive?
- Where can I stay if we have to travel for treatment? Can my family also stay?
- Can I get help at home or in the garden? Can I get home nursing care?
- Is there anyone who can teach my family how to look after me at home?
- Should I track my medications? How should I do this?
- Where can I borrow or hire equipment to help me at home?
- Where can I get a wig or bandana?



PEER SUPPORT

- Can you put me in touch with someone who has been through this?
- Do you know of any support groups? How do support groups work?
- What telephone or online support groups can I use?

FINANCIAL ISSUES

- How much will my appointments cost? What will I get back from Medicare?
- Is treatment different in the public or private system? How do the out-of-pocket costs work?
- What documentation do I need to keep for my health insurance?
- What can I do if my private health insurer refuses to pay for something?
- Is there someone I can talk to about financial matters?
- Can I get cheaper medications?
- Can I get help with the costs of tests or treatments?
- Can I get financial help if I travel for tests or treatment? Can my family get financial help to travel with me?
- Can I access my superannuation to help with the costs of my illness?
- Do any other organisations offer financial help to people in my situation?



TREATMENT & MANAGEMENT

- Is there a guide that you follow in treating people with my kind of tumour?
- How long do I have before I need to decide what treatments to have?
- In your opinion, what treatment is best for me? Why?
- What are my options if my treatment does not work?
- How will you tell how I am doing?
- How will I know if I should stop treatment?
- What is my treatment plan? What happens next?
- What could change my treatment plan?
- Who can make medical decisions for me if I'm unable to make them myself? What do I need to do to help someone else to make medical decisions for me?



SECOND OPINIONS

- Can you refer me to someone you trust for a second opinion?
- Can I get a second opinion, even if I want to stay with you for my treatment?
- How do I get my medical records so that I can show them to another doctor to give a second opinion?



QUESTIONS TO ASK ABOUT DIFFERENT TREATMENTS

- How will this treatment affect my symptoms and chances of survival?
- What will the treatment involve? What will I experience?
- How long until I see if the treatment is working?
- What tests will I need during or after treatment?
- Where will I have the treatment? Can I have it somewhere closer to home? Can I have it as an outpatient?
- Who will give me the treatment? Will this be a specialist?
- How will having this treatment affect my everyday activities? Will I be able to work, travel and drive?
- Will this treatment impact on my fertility? How can I manage my fertility?
- What will I see or feel during or after treatment?
- How long will the effects last? Will they continue after I finish treatment?
- Can we prevent the side effects of treatment? What can we do to manage side effects?



SURGERY

- Are you planning to take out the whole tumour?
- How will you do the surgery?
- Will I be awake during the surgery?
- Where will you make the cut? How big will it be?
- Is there anything that could change your plan for my surgery?
- Will this surgery cure me? Will the surgery help control my symptoms?
- What do I need to take into hospital with me?
- What will I feel when I wake up after the surgery? What tubes or drips will I have in?
- How long will I be in hospital after surgery?
- How long until we know if the surgery worked?



AFTER SURGERY

- Did you take out the entire tumour? Why or why not?
- How much tumour is left? Where is it?

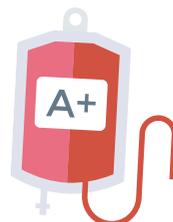
ORAL MEDICATIONS

- What are these tablets for?
- What can I do if I have problems taking my tablets?
- What do I do if I miss a dose or vomit it back up?
- What do I do if I take too many pills?
- How long do I keep taking these medications?
- Should I keep taking my existing medicines whilst I am on these?
- Will these medications have any effect on my existing medical conditions?
- Can I get these tablets from my usual chemist?
- Should I buy all the repeats up front? Could my prescription or dose change?
- Should I keep taking my seizure medication if I have a seizure? Should I change the dose?



CHEMOTHERAPY

- What drugs will I get during chemotherapy? In what doses?
- How will my chemotherapy be given?
- Will I need to do anything to protect myself during or after my chemotherapy? What about other people?
- Do I need to use birth control when on chemotherapy?



RADIOTHERAPY

- What type of radiotherapy will I get?
- What sort of procedures will I have to undergo before radiotherapy?
- Will I need to wear a mask during radiotherapy?
- Can you teach me relaxation to help me during my treatment?
- How can I care for my skin during radiotherapy?
- Will radiotherapy affect my thinking?

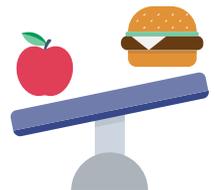


OTHER TREATMENTS

- Are there any new treatments or clinical trials that might help me? Are they here or at other hospitals?
- I have heard of new cancer treatments. What are they? Could they help me?

HEALTHY LIVING DURING TREATMENT

- Can I keep working during treatment? How can I manage symptoms and side effects at work?
- Are there any supplements or changes to diet to help me stay healthy during treatment?



- Can I drive while I'm having treatment?
- What should I do if I start feeling tired? Should I rest more? Could exercise help?
- Is there anything else I can do to stay healthy during treatment?



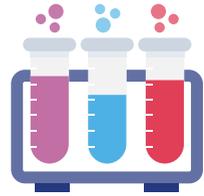
COMPLEMENTARY AND ALTERNATIVE MEDICINES

- What are complementary and alternative medicines?
- Are there any complementary medicines that may help me? Are there any that I should avoid?
- How do I know if an alternative medicine is safe?
- Can you recommend any trustworthy information or websites about alternative medicines?
- Can I take my usual vitamins or herbal medicines during my treatments?
- Could any of the other medicines I use cause problems with my medical treatment?
- Do I need to tell you about other medicines I am using?
- Can my alternative therapist contact you to discuss my care?



CLINICAL TRIALS

- What are clinical trials?
- Are there any clinical trials that might work for me?
- What does being in the trial mean?
- What would I have to pay if I went in the trial?
- Who do I contact if I have problems while I'm in a trial?



PALLIATIVE CARE

- What is palliative care?
- What can palliative care offer me?
- Can I get help from the palliative care team at home?



AFTER TREATMENT

- Will I need to have more treatments in the future? What for?
- What can I do to help me get better?
- What tests will I need to have in the future? What for? How often will I need to have them?
- Who will I see after finishing treatment? How often will I see them?
- What should I do if I am worried about my tumour coming back?
- What treatments can I have if my tumour comes back?



GETTING BACK TO NORMAL

- What will happen during my recovery?
- How long will it take for me to get back to normal?
- Will any of the symptoms or changes be permanent?
- Who can I talk to about coping with the changes in my life?
- What should I think about before returning to work?
- Can you refer me to someone to help me to get back to work?
- What should I tell my employer about my illness?
- When will I be able to start driving again?
- Can I travel again?





BRAIN TUMOUR
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