

Questions to ask

Talking to your health team is important - asking questions can help you to understand your condition and allow you to make informed decisions about your treatment and care.

You may want to write down a list of questions, or print this list to take with you when you see your health team.

These questions have been written from the perspective of a patient and are not an exhaustive list.

You may not want to ask them all. Or there may be additional questions that you want to ask that are important to you.

Although some questions may be personal and difficult to ask, your health team will be used to answering these and will be happy to help, so do ask anything you need to.

Don't worry if you don't get to ask all of your questions at once, or if you think of further questions once you leave, you should be appointed a key worker within your health team who'll be your main point of contact. They'll be able to help answer any further questions. They can also refer you to someone else if they find you need more help.

The questions are divided into sections to help you as you go through your experience of a brain tumour.

General questions

These are questions that are useful to ask either the first time you meet one of your health team, or each time you meet afterwards.

- What is your name?

Knowing the names of doctors/nurses will be useful when you need to tell someone who your/your child's doctor is, and will help build a good relationship with them.

- What does that mean?

Sometimes, healthcare professionals can unintentionally use jargon or assume you know what something means. However, if you do not understand any terms or explanations, they'll be more than happy to help – even more than once if you're finding it difficult to remember or wrap your head around it. Brain tumours are so complex, so it's neither surprising nor 'silly' if you do not understand everything.

- How and when can I reach you if I have questions after today?

It's natural to think of other questions after your appointment, or you may get new symptoms or other things may happen which cause you to worry. It's useful to know how to get in touch with your health team, and when they are available, so you can ease your worries or get your questions answered.

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At diagnosis

You may find it overwhelming to ask all these questions when you are first diagnosed, but you should be given a key worker as a point of contact that you can go back to with any questions at a later date or when you are ready.

About your tumour

The answers to these questions may affect your treatment options and also the side-effects you are likely to have.

- What type of brain tumour do I have?
- What grade is my brain tumour? And what does this mean?
- What size is my brain tumour?
- Where is my brain tumour located?
- Is it a primary or secondary tumour? What does this mean?
- Are there any biomarker tests available to me?

Biomarkers can be a change in a tumour's genes which, if your tumour has this change, may be helpful in predicting the growth of your tumour or how well you may respond to certain treatments. Biomarker tests are only available for some types of brain tumour.

About your treatment

- What are the standard treatments for my tumour? What would you recommend? Why?
- What are the risks and benefits of each treatment option?
- Do I qualify for any available clinical trials? Does that include trials outside this hospital/country?

This may be the only way to access some promising new treatments.

Your health team are best placed to know what trials are available and which ones would be best for you.

- Will any treatments prevent me from being able to take part in a clinical trial in the future?

Clinical trials have very strict eligibility criteria, which you must meet to be able to take part. Each clinical trial will have its own criteria, but an example is you must not have had previous treatment.

About possible symptoms and side-effects

- What are the potential symptoms and side-effects that I might experience from the tumour and from treatment – both short-term and long-term?

It's important that you are aware of any possible side-effects of treatments to help you make a well-informed decision on your treatment plan and to prepare for these side-effects.

- What are the options to help manage my symptoms/side-effects?

About the people who will be involved in your care

- Who are the people that make up my health care team, and what do each of them do?
- Who will be in charge of my overall treatment and follow up care?
- Will I have access to a nurse specialist? How do I contact them?

A nurse specialist can help you with so many question from financial help to emotional support. However, they are not available at all neurocentres.

About what happens next

- What happens next? And when? When will I start treatment?
- Where will I be referred to? How often will I have to come to hospital for treatment?

This will be helpful when planning for your travel costs, whether family can stay overnight with you (if needed) or if you need to look into accommodation for them.

- Is there any transport or help with cost of fares to the hospital?
- Can I get a second opinion? How do I do this?
- How do I obtain access to my medical records? Can I get copies or access my electronic files?

This can help when you meet a new specialist or if you'd like another opinion.

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Before surgery

You may not need or be able to have surgery, but if your health team feel it is advisable for you, the following questions may help you understand what is likely to happen.

- What are the risks and benefits of surgery for me?
- Will the treatment impact my ability to enrol in clinical trials in the future?
- Would my brain tumour type be eligible for 5-ALA?

5-ALA (otherwise known as the 'pink drink') is a surgical tool, which is taken as a drink prior to surgery. It works by illuminating the tumour cells, making it easier for the neurosurgeon to see and therefore remove.

Not all tumour types are eligible, but it can be beneficial during surgery to help surgeons remove as much tumour as possible, especially if your tumour was expected to be a high grade.

- Can I have a sample of my tumour tissue frozen, so I can be a candidate for a clinical trials in the future and have genetic (biomarker) tests?
- Is there anything that will need to be done/any tests to have before treatment?

Occasionally you may find that prior to surgery, scans may need to be undertaken. It's important to check all this with your doctor to help book in any other tests before treatment to prevent any delays.

- What happens if I become ill before my treatment/surgery?

Often, doctors will not operate or let you undergo treatment if you have come down with a chest infection, cold etc. It's important to find out what the procedure for this will be, should you fall ill.

About the surgery procedure

- What happens during surgery?
- Where and how big will the incision be? Will you have to shave my head?
- Will I be awake during surgery?
- Would surgery whilst awake benefit me?

This is very dependent on your age, tumour type, and physiology, so it is something only your neuro-oncologist can answer.

- How will you protect against damage to the brain?

About what happens after surgery

- What can I expect when I wake up from surgery? Who will be involved with care for my recovery? How long for?
- How long will I be in hospital after surgery?
- What can my family and friends bring to the hospital as gifts?
Hospitals no longer allow some gifts, such as flowers, due to health and safety protocol. It is worth speaking to the hospital staff to check what your family and friends can and cannot bring.
- I've heard about steroids. Should I be on them?
Steroids can help lessen symptoms, but speak to your GP about this for more information.
- How will tumour location affect my outcome and your strategy?
- Will I experience different symptoms or cognitive problems after surgery?
- When and who should I call for immediate help? With which side-effects?
- If I need extra support or care at home, who should I contact?
Speak to your key worker in your health team. They should be able to give you advice and put you in touch with relevant organisations, such as adult services in your local council or authority.
- Can I go on an airplane after surgery?
Generally not for six weeks. The change in pressure and oxygen levels pose a risk to your health and can cause a seizure. Speak to your medical team to find out when you could be allowed to fly again.

About the follow-up

- What additional treatments might I need?
- What is the plan for long-term follow-up care and appointments?
- What will happen at my follow-up appointments?
- How often will I need to have a scan?
- What should I do if I am worried between my appointments?
- What is the likelihood of my tumour recurring? If this happens what treatment options will be available to me?

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Before other treatments

e.g. radiotherapy, chemotherapy

For each type of treatment you may receive, the following questions are useful to ask:

- What is the aim of the treatment for me?
- What are the risks and benefits of the treatment for me?
- Am I eligible for any clinical trial- and when? What is the goal of the trial(s)?
- Will the treatment impact my ability to enrol in clinical trials in the future?
- What can I do to prepare for treatment?

About the treatment procedure

- What happens during the treatment?
- How long will my treatment last?
- How am I likely to feel?

About what happens after the treatment

- What are the possible side-effects of each treatment option?
- What can I do to manage my side-effects? What can I do to feel better?
- Will I need rehabilitation services, like speech therapy or physiotherapy?
- Could treatment affect my fertility? If so, should I speak to a fertility specialist before it begins?
- When and who should I call for immediate help? With which side-effects?

About the follow-up

- What additional treatments might I need?
- What is the plan for long-term follow-up care and appointments?
- What will happen at my follow-up appointments?
- How often will I need to have a scan?
- What should I do if I am worried between my appointments?

- What if this treatment doesn't produce the expected results? What would be the next steps?
- What is the likelihood the tumour will return after this treatment?

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Before immunotherapy

- What can you tell me about immunotherapy?
- Can I have immunotherapy? Is there a reason why it is not suitable for me?

Immunotherapy for brain tumours is still only available in clinical trials for certain tumours and with strict eligibility criteria, which you must meet to take part.

- How might I feel during immunotherapy treatment?
- What are the possible side-effects of immunotherapy?
- Are there any immunotherapy clinical trials for my brain tumour type? If yes, how can I request to be part of a clinical trial?
- Is it possible to access immunotherapy privately, and where?
- How much does immunotherapy cost (privately)?

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During treatment

- How will my brain tumour and treatments affect my daily life? Will I still be able to work, do housework, play sports etc?
- Can I return to work/education?
- Who is responsible for sick notes and repeat prescriptions?

This is your GPs responsibility, always speak to them for repeat prescriptions and sick notes. Your hospital can provide you with a sick note to cover your admission period, but anything beyond that is up to your GP to prescribe.
- What are my financial rights?

Your nurse specialist can help with this, but in the meantime it is best to set up a phone call to our Benefits Clinic. Our expert adviser, from the Citizens Advice has a wealth of experience with people affected by brain tumours.
- When should I inform my child's school of my/my child's brain tumour?

The early the better when it comes to inform your child's school, but should you need guidance on how to tell them, your GP or neuro-oncologist can help you with this
- Is a special diet advised?

Whilst there is no proof and limited benefits highlighted for undertaking a special diet when you have a brain tumour, if this is something you want to try speak to your GP first, as you would with any diet.
- Can I have alcohol?

Alcohol should always be drunk responsibly and only within the legal driving limits. However, it can have an effect on anti-seizure medications and steroids, so it is best to speak to your GP or specialist nurse about this.
- Does my tumour put me at risk of a seizure? If so, are there treatments to prevent this and at what point would I receive it?

Seizures are not always frequent for those with a brain tumour, it depends on the location of your tumour. Medication can be provided to help with seizures should they occur regularly. Your health team will be able to advise you more on this.
- What support services are available to me and my family?
- Where is a local, good hospice?

Although this may not be relevant for everyone, knowledge of local hospices can be very useful. Many people assume that hospices are only for 'final days', but this is not the case and some people will return home. Many hospices provide a respite service between hospital stays, rather than 'final days' care. Your GP will be able to help you with finding a hospice, should you need to.
- Do you have any reading materials that will help me understand my condition, treatments and the support available to me?

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After treatment

About follow-up

- After treatment what follow-up tests will I need? And how often?
- How often will I need to have a scan?
- What will happen at my follow-up appointments?
- What should I do if I am worried between my appointments?
- What is the likelihood that my tumour will recur? What factors contribute toward that?
- What happens if my tumour does recur? What symptoms should I be mindful of?

About quality of life

- What are the side-effects of my short-term medication and treatments (chemotherapy, radiotherapy)?
- What are the side-effects of my long-term medication (steroids, seizure medications)?
- Will I have long-term or permanent side-effects from my brain tumour or treatment? If so, can you help me create a management plan?
- Will I be able to return to work/education? When? How do I go about this?

It can be difficult to decide whether you're ready and able to go back to work, or whether you/your child is ready to go back into education, and even harder to figure out how to do this. Speak to your health team, they may be able to give you advice and point you in the right direction for getting this sorted.

Also see the **Employment resources** and the **Education resources** on The Brain Tumour Charity website.

- If I can't return to work, how can I apply for long-term disability benefits?
- Can you tell me about any financial support services that my family and I can use to help with any hardships we may be facing related to my brain tumour?

The Brain Tumour Charity runs a telephone benefits clinic in partnership with Rushmoor Borough Council on Tuesdays with a benefits expert from Citizens Advice. Call the Information and Support team, Monday-Friday 9.00am-5.00pm, on 0808 800 0004 to make an appointment.

- Can I drive? Will I be able to drive eventually?

- If so, what do I need to do to be cleared to drive again?
- If not, can you recommend any local transport assistance schemes?
- Where relevant, will my sense of taste return? Will my hair grow back?

About support

- Do you know of support groups in the area or online that I can attend?
- Do you know of organisations who can help me financially?
- What is the contact information for my long-term care team?
- What should my partner and loved ones expect?
- Where can my partner/carer go for support?

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At recurrence

If your tumour recurs, questions from previous sections apply, but in addition, you may like to ask:

- How will the treatment for my recurrence be different from the treatment for the original tumour?
- Is there different financial support that my family and I can use to help with any hardships we may be facing related to my brain tumour?

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- Should I be planning financially for long-term medical care, such as a nursing home or hospice?

At end of life

- Is there a counsellor or someone that I can talk with to help me cope with my prognosis?
- Can you give me information about home or hospice care?
- Can you give me information about palliative care?
- At what point should we shift focus from trying to treat the tumour (curative treatment) to treating me (palliative treatment)?
- You can also ask about a DNAR (Do Not Attempt Resuscitation form), advance statements or living will.
- Can I donate my tumour tissue to research?