

Brain tumours at relapse and looking to the future



Information for patients

Weston Park Cancer Centre



PROUD TO MAKE A DIFFERENCE

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Introduction

Brain tumours can occur at any age and affect people from all walks of life. They can be classed as low grade or high grade tumours. The most common brain tumours are called astrocytomas, oligodendrogliomas or glioblastomas.

Some of these brain tumours have a shorter life expectancy than others and unfortunately, the tumour almost always re-grows at some point in the future.

This often prompts patients to look to the future and ask lots of questions. This booklet is aimed at giving you more information about what the future may hold and answering some of those questions to help you make some important decisions.

The timing of a brain tumour growing back is different for every person and depends on many things. This uncertainty can be very difficult for you to live with but there are people who can help with this. If you feel that you need more support, then speak to us and we will try to direct you to the most appropriate help.

Some people find this uncertainty can be helped by making plans for the future. This may be as early as at diagnosis but some wait until their tumour re-grows. There are lots of decisions that can be made in advance which allow you to keep some control in your life. These include power of attorney, living wills, advanced directives and wishes for the end of your life. These will be discussed later.

One of the most difficult things for healthcare professionals is the difference in the amount of information individual patients want to receive. Some wish to know lots of detail and some very little. This booklet is designed to help by splitting information into small chunks that means you can read the bits that are helpful to you but you can miss parts you feel are in too much detail for you presently. However, as a team we believe it is important that you understand what the future

may hold and can discuss this with your family and friends while you are well.

Important goals for you and your family

Probably the most important first step is to identify the most important goals and wishes for you. For some people this is to live as long as possible regardless of what treatments or interventions you may have. These may include surgeries, painful procedures or treatments that have unpleasant side effects.

For other people, the most important wish may be to reach a specific point or goal such as a family wedding. Some people may decide that feeling well and their quality of life is so important they do not wish to have any further treatment and some opt to never receive any.

We will always try to give you as much information as you need to help guide you in making these decisions. If you feel you would like more information please ask us and we will do our best to explain things further.

Once you have made these initial important decisions, it is also very important that you discuss these decisions with those closest to you and make sure they are aware of your wishes. There are also official ways of recording these decisions such as advanced directives and living wills. These would be appropriate when you decide you no longer wish to receive any treatment for your brain tumour.

What sort of decisions are important?

The important decisions will vary from person to person, but there are some issues that are common for many. Some people find it useful to discuss when they would refuse treatment. For some people this may be when the only treatments available have less chance of working against the tumour than they do of causing side effects, some of which may be severe. Others find it useful to discuss what they would like to happen if they suddenly become less well. It may be that if you become poorly

due to the tumour, you would wish to be kept comfortable. However, if you had an infection or heart attack you would want more treatment.

We also feel it is important that you tell us if you change your mind as we realise that as situations can alter, some people would want their choices to change too, and this is perfectly natural.

Power of Attorney

As tumours progress and you become less well, it is important that you have someone you trust who can make decisions for you if needed.

This is also important as sometimes you can become suddenly and unexpectedly unwell. It is then very important that we know who you would like us to discuss your treatment with. Often this is your next of kin, but we realise that some family situations are very complicated. Therefore it can be very useful for this to be formalised so that decisions can be made on your behalf, even if you are too unwell to make them yourself. This is called a Power of Attorney and is a legal document.

There are two different Power of Attorney documents; one for 'wealth', giving someone control of your finances should you become unable to do this yourself, and one for 'health'. Your Attorney for health can make decisions about your medical care. These documents are very important, especially in people with brain tumours. This is because both the tumours themselves, and the treatments for them, can affect a person's ability to make decisions and remember things, even when they appear outwardly quite well.

You will need to fill in some forms to complete this process which can be done online or can be done through a solicitor. You can have more than one person as each type of Power of Attorney to help share decision making. You may also have different people for each type of Power of Attorney. It is important that this step is completed before you suffer any problems with your memory or thought processes.

What might the future hold?

As a team we are frequently asked what will happen in the future. In this section we explain what happens to most people, but you may prefer to not read about this yet.

Brain tumours usually re-grow and then can start to cause symptoms again. These can be very varied and people may suffer none of the symptoms. Symptoms may include physical weaknesses, speech problems, seizures and confusion. Apart from the side effects of treatments, people typically also become more tired and sleepy as the tumour progresses. The overwhelming number of people spend more and more time in bed as time passes, and become unconscious as the end approaches. They usually die in a very peaceful way.

We are often asked how long people have to live. This can be easier to predict in some situations than others, however we will try and give you an idea if we can.

Some people have a very strong opinion on where they want to die. This is another decision that can be made in advance and plans can be drawn up to help make this possible. You may wish to be in hospital or you may wish to be in a hospice or other palliative care environment. Some people would prefer to be at home. This is a very personal decision. Some families find it very hard to discuss, but when they do it often makes all involved feel calmer and more in control of the situation.

We can help you when discussing this and when you are trying to make a decision. You might like to visit a hospice or other place of care before making this decision. This decision is often referred to as 'preferred place of dying' and may be discussed with you by your GP and community team.

What do I tell my children?

Some of our patients have young children and this can be a very difficult time for all involved. There are agencies available that can help explain the situation to children. Some children may be helped by doing activities such as art therapy, counselling and memory boxes to name a few. It may also be necessary to make future plans for the care of any children when a parent dies.

There are specialist agencies that can help children before and after a loved one's death. We can put you in touch with these groups so tell us if you think this would help. How much children understand, and what their reaction may be will very much depend on their age, but also on each individual child. It may be that older children will find counselling or sessions without family members more helpful, whereas a younger child is less likely to benefit from this.

Resuscitation (trying to restart someone's heart when it stops)

Inevitably as people become less well there may be discussions regarding resuscitation, or trying to restart the heart and breathing when they stop.

Resuscitation is something that should be used when someone's heart or breathing stops suddenly, for instance in a heart attack, accident, sudden severe reversible illness (such as sepsis) or choking. It was developed to be used in people who are otherwise well, and in cases where healthcare professionals believe the outcome would be successful in restarting the heart and breathing. It is fundamentally for when the heart and breathing are the first organs in the body to stop working.

For people in the late stages of a brain tumour, this is generally not the case, as they are no longer fit and well. If the heart does stop, it is

because the rest of the body has stopped working properly, and it is part of the ordinary dying process.

As a team we feel this is an important decision to make with your family while you are still well. These discussions should ideally not be left until you are very poorly as at this point in your life you may not feel well enough to discuss these decisions. The decisions may then be left to your closest family or friends.

As a team we will aim to offer you all the treatments that are likely to work, but avoid the ones that won't. Resuscitation in an end of life situation is usually futile, and can be distressing and painful. If you make a decision to not have resuscitation performed, a form can be filled in and the hospital and GP informed, so all are aware. If you think more information is needed to help you make your decision, then please talk to us.

Finally

We understand that many of the points raised in this book may not yet feel relevant to you. However, we feel that it is never too early to discuss these issues and have plans in place. We also understand that some people find these topics very distressing to discuss, but in our experience, patients feel more worried about the unknown and how they are going to make these decisions. By having plans in place, people may feel that they can put the worrying aspects of the future to one side and carry on living.

We hope the information has been useful to you. It would be very helpful to your care team if you tell us your decisions so we can document them in your notes. This means all your team are aware and you won't be asked difficult questions when you feel most poorly. If you have any concerns, contact a team member and we will try to help you further.



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