



**University  
Hospitals Sussex**  
NHS Foundation Trust

# Decisions about having palliative chemotherapy for my brain tumour

Patient information

Your oncologist is considering a course of drug treatment to try to control the growth of your brain tumour and minimise any effects on your wellbeing.

Your team will have explained the likelihood of your tumour returning when you were first diagnosed. It can be a real shock to find out your tumour has regrown and making the decision to have further treatment might be challenging. However, you will need to consider how additional treatment will impact on your quality of life in addition to the impact on your survival.

### **There are several reasons why you may not receive palliative chemotherapy:**

- Your oncologist does not think it will help;
- You do not want it;
- You are not well enough to tolerate potential side-effects.

This aid is designed to help you to make an informed choice about treatment suitable for your brain tumour. We recommend that you discuss your choice with your oncologist or nurse specialist before making a final decision. Keep in mind, the right decision for you may change over time. The decision aid aims to help you make the right decision for now but you could have a further conversation with your oncologist as your illness changes.

# Decision aid about whether or not to have palliative chemotherapy.

Shown below is information regarding each of the two options. The table allows you compare three options, side-by-side.

Frequently asked questions	Chemotherapy palliative care	Palliative care only
<b>What is it?</b>	Chemotherapy is a drug(s) given to try to slow or shrink your tumour by killing cancer cells.	Palliative care includes giving medications to relieve symptoms such as headache, sickness or fatigue.
<b>How could chemotherapy improve my symptoms? or How could palliative care improve my symptoms?</b>	Chemotherapy is intended to improve symptoms by shrinking the tumour or stopping it growing, temporarily. This usually helps to reduce symptoms.	Palliative care will be provided by the community team based at your local hospice. They use their knowledge and expertise to control your symptoms with a variety of medications. The team also has other support services they can offer to improve your quality of life.

<p><b>What could be the the effect on the growth of my tumour?</b></p>	<p>Chemotherapy may temporarily stop the tumour growing and may even cause it to shrink. However, this cannot be guaranteed.</p>	<p>Palliative care will not affect the growth of the tumour.</p>
<p><b>Will chemotherapy help me live longer?</b></p>	<p>Chemotherapy can sometimes help people to live longer, but each individual's response is different.</p>	<p>Palliative care is unlikely to allow you to live longer. It aims to enhance quality of life, not quantity.</p>
<p><b>What about the side-effects or complications of treatment?</b></p>	<p>Chemotherapy may cause side-effects of which some could be severe or even life-threatening. There are medications to help manage side-effects but these can take time.</p>	<p>Palliative care aims to improve your quality of life by helping control and minimise any symptoms.</p>
<p><b>What is the effect on my quality of life?</b></p>	<p>Your quality of life may improve if your tumour symptoms are reduced. However, the side-effects of chemotherapy could have a negative impact on your day-to-day life. You may live longer but still with significant symptoms from your tumour.</p>	<p>Palliative care is intended to maximise your quality of life but will have no impact on tumour growth.</p>

<b>Where will I have my treatment?</b>	Intravenous chemotherapy treatment is given at the Oncology Day Unit or, if in tablet form, can be taken at home.	People receiving palliative care usually have this at home. Occasionally you might be seen as an out-patient at the hospice or as an in-patient when experiencing difficult symptoms.
<b>Who will be involved in my care alongside my GP and district nurse?</b>	Your oncologist. Your specialist nurse. The hospital oncology team. The supportive and palliative care team.	The palliative care team.

## What matters most to you?

Your personal feelings are just as important as the medical facts. Think about what matters to you most in this decision and indicate how you feel about the following statements:

Option	How do I rate this option?				
	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
I would like a treatment that gives me the best chance of a longer life.					
I would like the best quality of life in the time I have left. I do not want to have to cope with the side effects of chemotherapy just for a longer life.					
Avoiding side-effects is very important to me.					
I want to spend as little time as possible at the hospital.					
I do not want the treatment to affect my life in general.					

## Some thoughts people may have when considering the two options might include:

“I’ve decided to attempt a course of chemotherapy to see if this will slow down the growth of my tumour and improve my symptoms. I hope to feel better but I accept that while I am on chemotherapy, I may experience side effects which could affect how I feel”.

“I want to have the treatment that gives me the best chance of surviving longest. I understand there is no guarantee that my treatment will work but my progress will be monitored. I know that I can stop my treatment at any time”.

“ I do not want chemotherapy. I am worried about possible side-effects and I have been told that the treatment might only prolong my life for a few months. So I have decided to choose palliative care only”.

**Further reading:** [www.macmillan.org.uk/information-and-support](http://www.macmillan.org.uk/information-and-support)

# Notes

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