



**University  
Hospitals Sussex**  
NHS Foundation Trust

# Finishing treatment - what`s next?

Patient information

# Your Recovery Care Plan

“When I am a patient, I am dependent.  
When I am a person, I am resourceful”.

When treatment has been completed, we sometimes find people feel lost and wonder what will happen next. The Neuro-oncology team would like you to continue feeling informed and supported. This plan has been put together with that very much in mind and can be used in conjunction with copies of your clinic letters. It is to be used how you wish. We hope that you will find it helpful.

<b>My diagnosis and treatment:</b>	
<b>My oncologist:</b>	
<b>My neurosurgeon:</b>	
<b>My clinical nurse specialist:</b>	

<p><b>What happens next?</b></p>	<p>Initially 3 monthly MRI scans will be arranged by your oncologist followed by a clinic appointment for the results at The Hurstwood Park Centre, Princess Royal Hospital, Haywards Heath with your oncologist, a consultant neurosurgeon and a clinical nurse specialist (CNS). The scan appointment will be approximately a week before and the details of the appointments will be sent to you. Clinic appointments will be either by telephone, video link or face to face.</p> <p>If you have any concerns about scan/ appointment dates or times please contact our support worker.</p>
<p><b>Who is now in charge of my care?</b></p>	<p>You are still under the care of your oncologist and neurosurgeon for your brain tumour. However, your GP is now the key person for everything else, for example prescribing your medication and any other health related issues.</p> <p>Your CNS will act as a link between the hospital and the community teams.</p>
<p><b>What if I feel unwell between my scans?</b></p>	<p>Keep the contacts of your clinical nurse specialist somewhere safe. They remain your key contact and will be happy to discuss any questions that you may have by telephone or email.</p> <p>It is important to talk to your team if you have any worries or concerns.</p> <p>Scans can always be rearranged if necessary.</p>

<b>When the tumour regrows what signs and symptoms should I look out for?</b>	Due to the nature of the tumour this can be unpredictable however you may find the symptoms you originally had come back. If you notice something different or have any new concerns, you should discuss this with your CNS.
<b>What are the long-term side effects of my treatment?</b>	Your oncologist will have discussed the long-term side effects of radiotherapy when they first met you and we recommend using your clinic letters as a reminder. However, radiotherapy to the brain can cause premature aging (the aging process is brought forward) meaning you may notice the following: <ul style="list-style-type: none"><li>• a worsening of your short-term memory</li><li>• increasing unsteadiness, you are more at risk of falling over or your mobility is not as good as it was.</li></ul>

<p><b>What can I do to remain as healthy as possible?</b></p>	<p>Walking is an excellent form of exercise that can be managed within your capabilities.</p> <p>Always remember that however far you walk, you have to get back.</p> <p>We suggest that you follow a general healthy diet, avoiding anything too extreme. Please ask for advice if you are unsure.</p> <p>We would also encourage you to discuss reintroducing your regular sporting activities with the team.</p> <p>The health and wellbeing service at the Macmillan Horizon Centre is also available to sign post you to other activities and advice.</p>
<p><b>Can I still be referred to a physiotherapist or speech therapist even though I am no longer having treatment?</b></p>	<p>Of course! You may even notice that you need more input than before.</p> <p>Please contact your CNS who will refer you to the appropriate team in your local area.</p>
<p><b>When can I return to work and what should I do if I have employment issues?</b></p>	<p>Discuss this with your team. Returning to work is very much decided on an individual basis and what your job involves.</p>

<p><b>What if I have emotional concerns such as depression or anxiety?</b></p>	<p>There are many different ways of providing emotional and psychological support including counselling, reviewing your medication and support groups. If you have any concerns at all about your mental health, we would encourage you to discuss this with your CNS and they can refer you to the appropriate support services.</p>
<p><b>What can I do if my family and friends are struggling?</b></p>	<p>Your family's mental health is equally as important as yours. There are several services available for your family members and your CNS can look into what they feel is the most appropriate. This includes your children who we would encourage to be involved in your diagnosis and treatment.</p>
<p><b>Where can I find help with financial issues?</b></p>	<p>We can recommend contacting the following number for welfare benefits advice:  <b>East Sussex – 01323 635989</b>  <b>West Sussex – 01903 532234</b></p>

<p><b>Useful contacts</b> (add additional numbers you feel will be useful here):</p>	<p><b>Nurse specialists</b> <b>01444 441881 Ext. 68466</b> Email <a href="mailto:uhsussex.neuro.oncology.nurses@nhs.net">uhsussex.neuro.oncology.nurses@nhs.net</a></p> <p><b>Imaging booking dept</b> (patient dedicated line for scan appointments) – <b>01273 523040</b></p> <p><b>Carer support West Sussex – 0300 028 8888</b></p> <p><b>Macmillan Horizon Centre</b> Telephone number - <b>01273 468770</b> (Mon–Fri 9am – 4.30pm). Email address <a href="mailto:Horizoncentre@macmillan.org.uk">Horizoncentre@macmillan.org.uk</a> Website <a href="http://www.macmillan.org.uk/horizoncentre">www.macmillan.org.uk/horizoncentre</a></p>
<p><b>Useful websites:</b></p>	<p><b>The Brain Tumour Charity</b> <a href="https://www.thebraintumourcharity.org/">https://www.thebraintumourcharity.org/</a></p> <p><b>Brainstrust</b> <a href="https://brainstrust.org.uk/">https://brainstrust.org.uk/</a></p> <p><b>Macmillan Cancer Support</b> <a href="https://www.macmillan.org.uk/">https://www.macmillan.org.uk/</a></p>

# Notes

Ref. number: 2092

Publication date: 11/2021

Review date: 11/2024

© University Hospitals Sussex NHS Foundation Trust Disclaimer:  
The information in this leaflet is for guidance purposes only and is in no way  
intended to replace professional clinical advice by a qualified practitioner.

