



Ways Ahead

Improving support for people with brain tumours

Information booklet for patients

Can you help us?

We are conducting research to find out how best to develop a “programme” to help people with brain tumours to manage their health and wellbeing. We would like to interview you about your experiences of living with a brain tumour. We would also like to know what you think would help people to live with this condition.

This booklet describes our research. It explains what is involved in taking part. If you are interested in taking part, please read the information carefully. You can discuss it with other people (such as family and friends) if you wish. You are free to choose whether or not to take part. Your decision will not affect your healthcare.

If you have any questions about the research, please contact the research team using the details below:



07704 300 509



waysahead@newcastle.ac.uk



<https://research.ncl.ac.uk/waysahead>

What is this research about?

The aim of this research is to design a “self-management programme” to support people with brain tumours. Self-management programmes can help people to cope with the challenges of living with a long-term condition. They have been found to improve the quality of life of people living with other types of cancer and other illnesses. We want to develop a new programme that meets the needs of people living with brain tumours.

To do this, we plan to interview people with a brain tumour to find out about their experiences and support needs. We also plan to interview people who support an individual with a brain tumour, for instance spouses, family members or close friends. Finally, we plan to interview healthcare professionals (e.g. oncologists and psychologists) and cancer support professionals (e.g. counsellors and benefits advisors) to get their perspectives on what would help people with brain tumours.

Who is conducting the research?

Researchers at Newcastle University are conducting the research. Ben Rimmer and Lizzie Dutton are co-ordinating the research and undertaking the interviews. The research team is led by Professor Linda Sharp.



Ben Rimmer



Lizzie Dutton

Why am I being asked to take part?

We are asking you to take part in this study because you have been diagnosed and completed primary treatment for a grade II astrocytoma, or a grade II or III oligodendroglioma.

For this research to be successful and produce reliable results, we need as many different people as possible to agree to take part. Therefore, we would greatly appreciate your participation. This study has two Phases. You can take part in either Phase one or Phase two, or both Phases.

What does taking part involve?

If you decide to take part in this research, a researcher will arrange an interview with you at a time and place that is convenient for you. This could be:

- through Zoom or a similar video chat service
- by phone
- at your home (dependent on Covid restrictions)
- at a local meeting place (dependent on Covid restrictions)

The interview is expected to last around 60-90 minutes. The length of the interview can be adjusted to suit your availability or if you are worried that it will be too tiring.

If speech or language difficulties would make an interview difficult, please let us know. We will do our best to find another way to include you in this research.

Before the interview starts you will be asked to read and sign a consent form; this is to indicate that you agree to take part. You

will then be asked a few questions about your personal details and circumstances.

In the interview, the researcher will ask you questions about:

- your experiences of living with a brain tumour
- the impact of the condition on your daily life, including work, relationships and finances.
- the ways in which you manage your health and wellbeing
- the things you think would help other people with a brain tumour manage their health and wellbeing

Examples of the types of questions we might ask include:

- “Have you experienced changes in your physical health?”
- “Can you tell me about your relationships since being diagnosed with a brain tumour?”
- “What do you think have been the biggest challenges you have faced since your treatment ended?”

There are no right or wrong answers to the questions – we just want to know your views and experiences. You won't be expected to answer the questions if you feel uncomfortable doing so.

If you have any travel or other costs (e.g. childcare) associated with being interviewed, please let us know in advance so that we can arrange reimbursement.

Will the research benefit me?

It is unlikely that taking part will benefit you directly. However, it will give you the opportunity to talk about your experiences with an interested, non-judgmental listener who is not involved in your

medical care. You will also have the satisfaction of knowing that you are contributing to research which could help people with brain tumours in the future.

As a thank you for your time, we will also give you a £20 Amazon voucher at the interview.

Are there any disadvantages or risks?

Some people may find it upsetting to talk about their experiences. The interview may bring up difficult or distressing thoughts or memories. You will not be expected to talk about anything you are not comfortable with. You can take a break or stop entirely at any point during the interview. If you want to talk to someone after the interview, contact details of helpful organisations will be provided at the end of the interview.

How will my information be collected and used?

The researcher will ask for your agreement to audio record the interview; if you don't agree they will take written notes instead. The audio recording will be transcribed (typed out word for word). Your name and any identifiable personal details will then be removed so that you cannot be identified. The details of any other people you mention in the interview will also be removed. This anonymous, typed copy of the interview will be used by the research team in their analysis. Your comments may be used in research reports and publications, but your personal details will not be included.

We will also ask for your consent to access your medical records so that we can find out about your brain tumour and the

treatments you have had. Any details obtained from your medical records will be held securely and kept confidential.

The researcher will ask you for your contact details. These will only be used to contact you about this research project (e.g. to let you know about the results of the research). We may ask to contact you about the next stages of the research, when we will be designing the programme. You can choose not to be contacted. Even if you are happy to be contacted this does not mean that you have to participate in later stages of the research.

What will happen to my data?

Your data will be kept safe and secure and treated with strict confidence. Your identifiable data will be stored in a safe place on a secure computer database provided by the Newcastle-upon-Tyne NHS Foundation Trust. Any physical copies of your contact details will be stored in a locked cabinet in a secure part of Newcastle University.

The audio files and anonymous transcripts (typed out copies of the interviews) will be stored on secure Newcastle University systems. These will not be stored under your name. The audio files will be destroyed after analysis, and the transcripts will be destroyed after five years.

Your data will be kept in accordance with the General Data Protection Regulation (GDPR). Further details can be found in the privacy notice at the end of this document.

What if I want to stop taking part?

You can decide not to take part at any point, before, during or after the interview. You do not have to give a reason. It will not affect your health care.

If you decide during the interview that you do not want to continue in the study, then you can ask for the audio recording to be deleted. Once the audio-recording has been transcribed it will not be possible to withdraw it from the research.

Who is organising the research?

This research is funded by the Brain Tumour Charity. It is being undertaken by researchers at Newcastle University. The Newcastle upon Tyne Hospitals NHS Foundation Trust is sponsoring this research. Several other hospital trusts will also help us to recruit participants.

All research supported by the NHS is reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Wales Research Ethics Committee.

How can I take part?

To take part or to find out more, please contact:

Ben Rimmer on 07704 300 509

email: waysahead@newcastle.ac.uk

If you are interested in taking part, you can call or email us, or tell one of the staff at the hospital clinic.

We will arrange a suitable time for a telephone conversation. You can then ask any questions you have. We will also ask you a few questions. After this, you can decide whether you want to take part. You can choose not to take part at this point or at any point during the interview.

Concerns or complaints

We do not anticipate any problems arising during this study. However, if you do have a concern or a complaint, please contact Professor Linda Sharp, by email at linda.sharp@newcastle.ac.uk, or by post to: Linda Sharp, Institute of Health and Society, Newcastle University, Sir James Spence Institute, Royal Victoria Infirmary, Queen Victoria Road, Newcastle, NE1 7RU.

If you prefer to raise your concerns with someone not involved in your care, you can contact the Patient Advice and Liaison Service (PALS). This service is confidential and can be contacted on Freephone: 0800 032 0202

Alternatively, if you wish to make a formal complaint you can contact the Patient Relations Department through any of the details below:

Telephone: 0191 223 1382 or 0191 223 1454

Email: patient.relations@nuth.nhs.uk

Address: Patient Relations Department, The Newcastle upon Tyne Hospitals NHS Foundation Trust, The Freeman Hospital, Newcastle upon Tyne, NE7 7DN

Privacy notice

You may have read or heard about the General Data Protection Regulation (GDPR) which came into law in the UK in May 2018. The GDPR aims to protect your personal data and because of this we need to be clear with you about how we will use your personal data, and what your rights are.

Newcastle upon Tyne Hospitals NHS Foundation Trust (NuTH) is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that NuTH are responsible for looking after your information and using it properly. NuTH will keep identifiable information about you for up to five years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how NuTH use your information by contacting the Data Protection Officer for NuTH via email at nuth.dpo@nhs.net.

Newcastle University and your hospital trust will collect information from you and your medical records for this research study in accordance with our instructions.

Newcastle University will keep your name and contact details confidential and will not pass this information to NuTH. Newcastle University will use this information as needed, to

contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from NuTH and regulatory organisations may look at your medical and research records to check the accuracy of the research study. NuTH will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

NuTH will collect information about you for this research study from your medical records. This information will include your name, contact details, Medical Record Number and health information, which is regarded as a special category of information. We will use this information for the purpose of undertaking the study.

The research team will only retain personal details about you from this study for the purpose of sharing a summary of the study findings. If you do not want a copy of the summary of findings, your personal details will be destroyed once the details of your brain tumour diagnosis and treatment have been abstracted from your medical records.