



Ways Ahead

Improving support for people with brain tumours

Information booklet for healthcare professionals

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 experience of treating people with a brain tumour and your thoughts on what would help people living with a brain tumour.

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 and, if you wish, discuss it with others. You are free to choose whether or not to take part.

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 four groups of people - those living with a brain tumour; their informal carers (e.g. family members); healthcare professionals (like yourself); and other cancer support professionals (e.g. people working for charities) - to get different perspectives on what would help people with brain tumours.

Who is conducting the research?

The study is being led from Newcastle University. 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 are a member of multidisciplinary team, involved in the care of brain tumour patients, including low- and intermediate-grade gliomas.

For this research to be successful and produce reliable results, we need as many different professionals 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 work (dependent on Covid restrictions)
- at a local meeting place (dependent on Covid restrictions)

The interview will last around 30-60 minutes. Before it starts, you will be asked to sign a consent form. During the interview, the researcher will ask you about:

- the issues faced by brain tumour survivors following treatment completion;
- what supports are currently available to survivors; and
- the feasibility of a potential self-management programme for brain tumour survivors.

Will the research benefit me?

No. You will have the satisfaction of knowing that you are contributing to research which could help people with brain tumours in the future.

Your time to participate in the interview has been costed into the study budget and your Trust can be reimbursed.

Are there any disadvantages or risks?

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.

How will my information be collected and used?

The researcher will ask for your consent to audio record the interview; if you don't agree the interviewer will take written notes instead. The audio recording will be transcribed and your name and any other identifying details will be removed before analysis. Quotes from you may be used in research reports and publications, but your personal details will not be included.

Your contact details 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 withdraw from the study at any point; you do not have to give a reason. If you decide to withdraw during the interview, you can ask for your audio-recording to be deleted. If you withdraw after the interview, your audio-recording will be included in the analysis.

Who is organising the research?

This research is funded by the Brain Tumour Charity. It is being led by researchers at Newcastle University. The Newcastle upon Tyne Hospitals NHS Foundation Trust is the sponsor. The 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 email us, we will arrange a suitable time for a telephone conversation during which you can ask any questions and decide whether you would like to go ahead.

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 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 will collect information from you 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.

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 upon study completion.