Participant Information and Consent (Patient)

Long-term Survivors of High-grade glioma

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Living with a brain tumor
Living with a brain tumor causes changes in everyday life. We know from other patients that the disease is associated with new challenges and thoughts. We would like to know more about how the situation is experienced by patients who have lived with a brain tumor for 3 years or longer. We will use your experience to become even better at helping patients and their relatives who are in the same situation as you and your relatives.

Your relatives
When a person is diagnosed with a brain tumor, we know that the diagnosis also affects the relatives, and especially the person (s) closest to you. Your relatives' experience is also important to us. Therefore, your immediate relatives will also be asked to be included in the investigation. If your relatives do not want to participate, you can attend anyway. Your relatives can also attend without you attending. It is you who decides who is your closest relative (the person must be over 18) and several of your relatives are allowed to enter.

What does that mean for you?
Your participation means that I interview you once. The interview takes place at a time that fits into your everyday life. At about the same times as the telephone interviews, you will receive some questionnaires by mail, which you please complete and return to me.

What does it mean for your relatives?
Your relatives will also be asked to attend an interview at about the same times as our interviews. The interviews will be about how your relatives experience everyday life after you become ill. At the same time, we will try to find out what needs the relatives have and how we can help them.

The interview questions
My questions are about how you feel physically, mentally and socially and how to best help you.

The questionnaires
The questionnaires are about how you experience your everyday life after falling ill. For example, if you are experiencing problems that others are not aware of. Please complete the questionnaires within 1 week of receiving them. It is important that your answer is a picture of the situation at certain times of your illness and treatment. It takes approx. 10 minutes to answer the forms. The participation will not incur any expenses for you as you will be provided with postage answered envelopes so you can send the answer directly to me.

I would like to request access to your journal so that I can obtain data on your medical history that may have an impact on your answer.

What should it be used for?
Data will be used for part of my research, ie. academic articles, oral presentation and referred to in future research. Once the results have been compiled and published, you have the opportunity to receive results from the project either by saying it now or by contacting me at a later date.

Voluntarily and confidentially
You can withdraw your consent at any time by calling me. Withdrawing your consent will not have consequences for you. All information from your answer will be treated strictly confidential. Any information acquired through this project that may reveal your identity will remain confidential in any publication. Data is stored in a locked cabinet at Rigshospitalet during the project. Electronic data will be stored in a closed folder on the researcher's computer. Only I have access to data. The project is reported to the Data Inspectorate. Data will be destroyed in the year 2025.

The Research team
The study is carried out by nurse and PhD. Karin Piil, University Hospitals Center for Health Research (UCSF), Neurocenter and in collaboration with the oncology clinic at the Copenhagen University Hospital and senior researcher Mary Jarden from UCSF. The project is supported by the Novo Nordisk Foundation.

If you have any questions, please contact Karin Piil by email at Karin.piil@regionh.dk or phone 35 45 73 45.

This page should be signed and sent to project manager Karin Piil

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If you sign the consent statement below, it means that you wish to participate in the project and that you accept the conditions described.

Signed (block letters):_____

Declaration of consent

I hereby give my consent to participate in the survey. I am informed that the purpose of the research project is to investigate my life situation and needs.

- I am informed that my identity, personal data and health and illness content are not disclosed, as all personal information will be encoded.
- I am informed that Karin Piil will gain insight into my journal.
- At my request, I will be sent the results of the research project.
- I have read and been provided with participant information and accept the conditions regarding my participation.

Signature of patient

_____Date:_____2017

I will like to achieve the results of the research project.: ____(Yes) _____(No) at this

address_____ or e-mail:

_____

Statement from the person submitting the information: I declare that the individual has received oral and written information about the trial. In my opinion, sufficient information has been provided to enable participation in the trial:

Signature

_____Date:_____2017