Thinking Ahead: Exploring and Understanding Experiences and Decisions in End of Life Care

Patient Information Leaflet

Study Title
Thinking Ahead: Exploring and Understanding Experiences and Decisions in End of Life Care

Invitation
We are a team of researchers at LOROS Hospice in Leicester and we would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please feel free to talk to your family and friends about the study and please ask us about anything that is unclear.

Why are we doing the study?
We want to find out about the experiences of people from diverse ethnic backgrounds who are living with serious illness. We also want to speak to family or friends who care for them and the doctor or nurse who supports them. The information we collect will help us improve the training of doctors and nurses and the care they provide for patients and their families.

Why have I been invited?
You have been invited to take part in this study because you are affected by a serious illness. You have been identified by a health care professional who provides care for you, as someone who may be interested in taking part in this study.

Do I have to take part?
No, it is up to you to decide whether or not to take part. If you do decide to take part you are free to withdraw from the study at any time, without giving a reason. If you decide not to take part this will not affect your medical care or legal rights

What happens if I take part?
If after reading this information leaflet or watching the study video in a language that you understand and discussing it with a member of the research team, you decide to take part in the study you will be asked to sign a consent form.
You will then be invited to have an interview with a researcher. After that you will be invited to have one or two more interviews over the next few months. All interviews will be recorded.

Interviews are informal discussions usually lasting about 45 minutes and they can take place in your home, at LOROS Hospice or at a suitable location of your choice. The length of the interviews are flexible, depending on your interest in the study and how you are feeling at the time. Interviews will be arranged

entirely at your convenience. The interview can be in a language other than English if you prefer. We will provide an interpreter to help the researcher if this is needed.

The interviews will be about your experience of living with a serious illness and the care that you have received from health care professionals managing your care. We would like to find out:

- How you approach living with a serious illness and thinking about the future
- About your experience of talking with health care professionals about your illness and any discussions that you have had about your choices and your decisions about end of life care and treatments
- What you have found most and least helpful in the kind of support and information health care professionals have provided for you about living with a serious illness and if there are any ways in which this could be improved

With your permission we will later access relevant parts of your medical records to find out more about your illness and end of life care and treatments.

We will also ask you to nominate a member of your family or a friend and a health care professional who support you to be interviewed. This will help us find out about their perspective about your illness and your care.

With your permission we may use the anonymised data collected in this study to support other ethically approved research in the future. This may mean that the anonymised data may be shared with other researchers.

What are the possible benefits of taking part?
The study may not help you directly but some people find it helpful to have the chance to share their experience of illness, treatment and care with someone who is not directly involved. The information that we collect may help health care professionals to better understand the experiences of patients and their families from diverse ethnic backgrounds. This should help to improve the care and support provided to families in the future.

What are the possible disadvantages of taking part?
We understand that talking about issues relating to your illness may be difficult and might be upsetting during the interview. We ask you to consider this carefully, please remember that you will never be under any pressure to answer any questions or talk about any topics that you prefer not to discuss. You can stop the interview at any time or withdraw from the study at any time by letting the researcher know that this is your wish.

Will I receive any payments for taking part?
You will be given a £20 voucher after each interview as a "Thank You" for your time. If you incur any travel expenses as a result of your participation these may be reimbursed on production of a receipt for public transport or as a claim for mileage which would be reimbursed at the LOROS standard rate up to a maximum of £20.

Will my information be kept confidential?
Yes this is very important to us. The study will be conducted in accordance with current data protection regulations. All information which is collected will be kept strictly confidential and will be stored in a locked cabinet within a locked office at LOROS Hospice. All information that is stored on a computer will be kept in password protected files with restricted access.

The interview tapes will be sent securely to a qualified professional (transcriber) who will listen to them and turn them into a written document (transcript). Your name and identifying details will be removed from interview transcripts and replaced with a study identification number so that you cannot be recognised (anonymised). All interview recordings will be deleted from the recorder after having been transferred to the secure LOROS computers.

We will let your GP know that you are taking part in this study so that they can document this in your medical records.

The study data will only be accessed by authorised members of the research team but may also be looked at by authorised representatives of the Sponsor, Regulatory Authorities or Host NHS organisations for the purpose of monitoring and audit.

The only circumstances under which confidentiality may be broken would be if the researchers were made aware of actions or situations resulting in serious risk or harm to yourself or others. In this case the researchers would discuss this with you and consider the need to raise the matter with managers of the service involved.

All study data will be stored securely for the duration of the study and will be kept for seven years before being disposed of securely.

Data Protection and General Data Protection Regulations
The University Hospitals of Leicester NHS Trust (UHL) is the Sponsor for this study based in the UK. LOROS and UHL will be using information from you in order to undertake this study and UHL will act as the data controller for the study. This means that we are responsible for looking after your information and using it properly.

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.

The Legal Basis for collecting your data for the purposes of this research is specific consent.
The data we will be collecting, processing and storing about you for this research is listed below:

- Your name and personal contact details
- The interview transcripts
- Information collected from your medical notes to find out more about your illness and end of life care and treatments

For further information about the way the University Hospitals of Leicester NHS Trust use data for research please see the Privacy Statement at the Trust's public website:
http://www.leicestershospitals.nhs.uk/aboutus/about-this-website/fair-processing-notice/

More information from the Health Research Authority can be found here: https://www.hra.nhs.uk/information-about-patients/

What will happen if I don't want to carry on with the study?
Your participation in the study is voluntary and you are free to withdraw at any time by contacting the research team using the contact details at the end of this leaflet. You don't need to give a reason and your medical care and legal rights will not be affected. If you decide to withdraw, the anonymised information collected up to the point of withdrawal will still be used.

What will happen if I lose capacity during the Study?
In the unfortunate circumstance that you become more unwell and lose the ability to decide whether you should continue to participate in this research study we will approach a family member or friend who knows you well to ask their opinion. If they agree, we will appoint them as a consultee to advise on your behalf for the remainder of the study. Whatever decision is made about your continuing, we will use the information collected about you up to this point in the study and in keeping with your original consent we will look at your medical records.

What if something goes wrong?
It is very unlikely that you would be harmed by taking part in this type of research study.
However, if you have a concern about any aspect of this study, you should ask to speak to the researchers in the first instance who will do their best to answer your questions. If you remain unhappy and wish to address your concerns or complaints on a formal basis, you should contact the Patient Information and Liaison Service (PILS) Free phone line: 08081 788337 or alternatively write to: Patient Information and Liaison Service, The Firs, C/O Glenfield Hospital, Groby Road, Leicester, LE3 9QP. Email: pils@uhl-tr.nhs.uk

In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

What will happen to the results of the study?
The results of the study will be used to help health care professionals and services improve the care and support they provide to patients and families during serious illness. The researchers will prepare a report for the NHS who has funded the study. The results of the research will be made widely available through talks to the public and professionals, publications and conference presentations. We may include direct quotes from the interviews but these will not contain any personal details and you will not be able to be recognised from them. You will not be identified in any report of publication arising from the research.

With your permission we may use the anonymised data collected in this study to support other ethically approved research in the future. This may mean that the anonymised data may be shared with other researchers.

Who is organising and funding the research?
The research is being organised by the research team at LOROS Hospice and the University Hospitals of Leicester NHS Trust are the study Sponsor. The research is funded by the NHS National Institute of Health Research.

Who has reviewed the study?
This study has been reviewed by the Sponsor and the Health Research Authority which includes review by a Research Ethics Committee.

What should I do now?
If you are interested in taking part or receiving further information please contact the research team using the contact details below by phone, e-mail or post.

Please be aware that LOROS.co.uk is not a secure email address, and therefore any information that you send via email will not be encrypted. This means that it is not coded or password protected to stop hackers or other people reading it should they get hold of it.

A freepost envelope is provided for you to return the reply slip if your preference is to reply by post.

The research team will then contact you to discuss the study further and answer any questions you may have.

If required, an appropriately qualified interpreter can be provided to assist with your participation and translate on your behalf.

If you don't want to take part you do not need to do anything and we thank you for your time and consideration of this.

Further information and contact details
If you have any further questions or would like some more information, please feel free to contact **the LOROS research team on 0116 231 8498 or by email; research@loros.co.uk**
Our team will be happy to discuss any concerns and to answer your questions