



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

Carer 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 if anything 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 support 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 have cared for a relative or close friend affected by a serious illness who has died in the last 3-12 months.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you decide to take part you are free to withdraw from the study at any time and without giving a reason.

What happens if I take part?

If after reading this information sheet 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, the interview will be audio recorded.

The interview will be an informal discussion usually lasting about 45 minutes and it can take place in your home, at LOROS Hospice or at a suitable place of your choice. The length of the interview is flexible, depending on your interest in the study and how you are feeling at the time. The interview will be arranged entirely at your convenience and 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 supporting and caring for a relative or friend living with a serious illness. We would like to find out:

- About your **experience of** caring for your relative or friend in the months before they died.
- How you and your relative or friend approached thinking about the future
- About the experiences for you and your relative or friend of talking with health care professionals about their illness and any discussions about their choices and their decisions about end of life care and treatments.
- What you found most and least helpful in the kind of support and information health care professionals have provided for you about supporting and caring for someone with a serious illness and if there are any ways in which this could be improved

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 we collect may help health professionals to understand the experiences of minority ethnic patients and their families. This should help to improve the care and support provided to patients in the future.

What are the possible disadvantages of taking part?

We understand that talking about issues relating to caring for someone with a serious 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 the 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 of up to £20.

Will my taking part 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 they have been transferred to the secure LOROS computers.

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.

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, without giving a reason, by contacting the research team using the contact details at the end of this leaflet. If you decide to withdraw, the anonymised information collected up to the point of withdrawal will still be used.



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.

If you would like to, you will be sent a summary of the findings and recommendations at the end of the study.

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. 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.

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.