The Impact of the Liverpool Care Pathway on Care at the End of Life
INFORMATION ABOUT THE RESEARCH FOR RELATIVES (2)

Introduction

We would like to invite you to consider taking part in our research study. In order for you to do this, it is important that we provide you with information to help you to understand why the research is being done and what it would involve for you. Please feel free to talk to anyone you feel comfortable with about the research before making your decision.

What is the purpose of the study?

The government's National End of Life Care Strategy (2008) emphasizes the importance of care at the end of life by promoting the use of the Liverpool Care Pathway for the Dying Patient (LCP) to support the delivery of quality care. The LCP is a 'good practice' template, underpinned by education and training, that staff caring for patients in the last hours or days of life can use to help them to deliver appropriate care. This study has been designed to understand whether the tool makes a difference to the quality of care provided. We have chosen to undertake this study in Intensive Care and Nursing Homes because these are two settings in which care should take into account the end of life.

The study involves collecting information from a variety of sources (policy documents, patient notes, by observing care as it is delivered to patients, interviewing staff and interviewing bereaved relatives) to help us to understand what care looks like in Intensive Care and Nursing Home settings that use the LCP to support care and those that do not. By comparing the care delivered with and without the support of the LCP we will be able to identify the impact of the LCP.

Why have I been approached?

You will probably remember that a researcher from the study observed the care that was provided for your relative/friend in the last days and hours of their lives. At that time you agreed to being approached to take part in an interview with the researcher to find out what you felt about the care that they received. We are approaching you now to find out if you remain happy to take part in the interview.

Do I have to take part?

No. We will describe the study and go through this information sheet with you. It is up to you to decide whether or not you wish to take part. If you agree to take part, we will then

ask you to sign a consent form. However, if at any time you change your mind about taking part, you can withdraw from the study without giving a reason or an explanation.

What will happen if I take part?

We would like to interview you to gain an understanding of your view of the care that was provided for your relative/friend in the last days and hours of their lives. This will be a semi-structured interview with the researcher that will last around an hour and will take place at a venue and time that is acceptable to you.

What will happen if I don't want the study to carry on?

If you change your mind about your taking part in the study you can withdraw your consent at any time without giving a reason.

Expenses and Payments
Any travel expenses that you may incur in order to attend the interview with the researcher will be repaid.

What are the possible disadvantages and risks of taking part?

We do not think that there are any major risks involved in being part of this study. However, it is possible that you may become upset during the interview with the researcher when asked to reflect on the last days or hours of your relative/friend's life. Please remember, you do not have to answer any questions that you find too upsetting and you can ask the researcher to stop the interview at any time, either for a short while or completely. If you have any concerns or feel a bit low after the interview we will leave you with the researcher's contact details so that you can be provided with appropriate support should you find it helpful.

What are the possible benefits of taking part?

There is unlikely to be any direct benefit, but your participation in this study will help us find out more about the impact that the LCP has on care at the very end of life.

Will my taking part in the research be kept confidential?

Yes. We will follow current ethical and legal practice and all information collected will be handled in confidence. However, we may need to breach confidentiality for any issues that may arise where we have a statutory duty to disclose. For example, if during the course of the interview issues of malpractice, sub-optimal care or abuse are identified, the researcher will report the 'incident' immediately in line with risk and governance arrangements operating within the organization. We would like to audio record the interview with the researcher, with your permission. You will not be identified by name on the recording and only the project team and the person transcribing the recording (who has signed a confidentiality agreement and has 10 years experience of undertaking such transcriptions without incident) will have access to the data. The recording will be stored in two ways: as an audio file and, as a transcript. The audio recording will be

stored on a password protected data stick which will be kept in a safe in the University of Liverpool for a period of 3 years after publication of the results of the study, after which, it will be securely destroyed. The transcripts of the interviews will be analysed by the researcher and other members of the project team. You will not be identified by name in the transcript – only a numeric identifier will be used. The transcript and the analysed materials will be kept in a locked filing cabinet in the University of Liverpool for 3 years after the publication of the results of the study, after which they will be securely destroyed.

What will happen to the results of this study?

All of the information that we collect from the various elements of the project will be brought together to help us to understand the impact of the LCP on care at the very end of life. The findings of this study will be useful in highlighting where services and the delivery of care can be improved in the future. The results will be written up as a final report for the funding body and will include recommendations for future practice. We also intend to publish the findings in peer reviewed journals and make presentations to national and international research conferences in order to make sure that the messages from this study are shared widely and appropriately.

Who is organising and funding the research?

The Principal Investigator for the study is Professor John Ellershaw, Director, Marie Curie Palliative Care Institute Liverpool, University of Liverpool. The study is sponsored by the University of Liverpool and funded by the National Institute for Health Research, Service Delivery and Organisation Programme.

Who has reviewed the study?

This proposal has been reviewed and approved by "North West Wales Research Ethics Committee", which is a committee whose task it is to make sure that research participants are protected from harm. You can find out more about the work of Research Ethics Committees by visiting the National Research Ethics Service website at http://www.nres.npsa.nhs.uk.

Please note

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (see contact information below). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure (or Private Institution). Details can be obtained from the hospital/nursing home.

Further Information

If you would like any further information about this study please contact:

Jacqueline Jones
PA to Professor John Ellershaw
Director, Marie Curie Palliative Care Institute, Liverpool
XXXX

Study number: REC Ref: Centre number:

Participant identification number for this study

CONSENT FORM

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Name of Researcher: Professor John Ellershaw Please initial box

I confirm that I have read and understand the information sheet dated August 2010 (Version 2) for the above study.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I agree to the interview being tape recorded and transcribed	
I understand that I am free to withdraw consent for my participation at any time without giving any reason, and without my care or legal rights being affected.	
I agree to take part in the above study	

Name of relative/friend:
Name of Participant : Date

Signature

Name of person taking consent: Date

Signature

When completed: 1 copy for participant; 1 copy for researcher