



The impact of Huntington's Disease on family dyads: A grounded theory analysis Information Sheet

Why is the research being done?

You are being invited to take part in research on the experience of families with Huntington's Disease. I am a Trainee Clinical Psychologist and am researching Huntington's Disease as part of my Doctorate in Clinical Psychology course. Before you decide whether or not to take part, please read through the information provided here, which will tell you what the research is about and what taking part will involve.

What is the study about?

I want to find out about the experiences of families with Huntington's Disease and what impact Huntington's Disease has had on them. The information from this will help to improve the understanding that service-providers have about what families with Huntington's experience and may help to influence services that are offered to help support people with Huntington's when they need it. To do this, I will be interviewing parent/offspring pairs from families with Huntington's Disease to find out about their experiences.

Why you?

I am contacting people who have Huntington's Disease in their family. You do not need to have the disease yourself.

What would you be asked to do?

I would like to arrange to meet with you and the other chosen member of your family and ask you some questions about your families' experience of Huntington's Disease. If you decide you want to take part, I will contact you and your chosen family member by telephone to arrange a time and place to meet that is convenient for you, e.g. a local health or community centre. The meeting will be an informal interview, in which I will ask you both questions about your family and relationships in relation to Huntington's Disease. This will probably last for about an hour, and will be audio-recorded. I will also ask you to sign a consent form.

Will the interview be confidential?

All the information you give will remain confidential. This means that any identifying details from the interview will not be seen by anybody else. Research supervisors at Lancaster University may see the transcript or listen to the recording in order to help with the process of analysis but will not have access to any identifying information. The only exception would be if I felt that you, or someone else, was at significant risk of harm. If this was the case, I would discuss it with you first, and only talk to the appropriate people to help.

The interview will be recorded and transcribed, after which the audio recording will be deleted. The electronic version of the transcript will be kept in a password-protected electronic file. A hard copy of the information will be kept in a locked filing cabinet for five years after publication or graduation (whichever is later), after which it will be destroyed.

Your name will not appear anywhere on the transcript or in the written report. The final report will include parts of the content of your interview, and may include quotations, but we will not use any information that could identify you.

What will happen to the information you give?

I will type up the recordings, and look for themes in what has been said. The information will be written up in a research report, which will be seen by appropriate people in Lancaster University and the NHS, and may be published in a journal. All the information from the interview, as well as any information about you, will be kept confidential.

What if you change your mind about taking part?

You are free to decide that you no longer want to take part in the study at any point up to two weeks after your interview. This is your decision and no reason needs to be given – just contact me using one of the methods below to let me know, and the recording, all electronic data and any written transcripts will be destroyed. If you are unsure at any point, feel free to contact me to discuss it.

What happens after the interview?

If the interview raises any difficult issues that you feel you need to discuss further, you can contact me on the number below and I will direct you to further support. Some other sources of support are given at the end of this information sheet.

Researcher Contact Details

If you have any queries about this research, please do not hesitate to contact me and I will be happy to discuss it with you. My name is Caroline Maxted, Trainee Clinical Psychologist. The best way to contact me is by email at the address below. Alternatively, you can call me on the number below:

Tel: 07508 406276

Email: c.maxted@lancaster.ac.uk

Expenses and payments

I am not offering any payments to take part in this research but, if you choose to come to an interview, your travel expenses will be paid back up to a value of ten pounds (£10).

Who has reviewed this study?

This research has been looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been recommended for approval by Lancaster University School of Health and Medicine's Research Ethics Committee and approved by the University Research Ethics Committee.

Complaints/Concerns

If you have any concerns about the research or the way it is being conducted, please contact me using the number or email address above. Should you feel your concern has not been adequately addressed, further queries or complaints can be directed to the following address:

Professor Jennie Popay, Research Director, Division of Health Research, Faculty of Health and Medicine, Lancaster University, Lancaster, LA1 4YT

Sources of support

The Huntington's Disease Association	0151 298 3298	www.hda.org.uk
NHS Direct	0845 4647	www.nhsdirect.nhs.uk
The Samaritans	08457 909090	www.samaritans.org

What happens now?

If you would like to take part in the study, please email or telephone me, and I will contact you in the near future to arrange a time and place for the interview.

Thank you!