

Nicola Turner  
Postgraduate Student  
School of Health Sciences  
B33, Medical School  
Queen's Medical Centre  
Nottingham  
NG7 2HA

### **Living with a parent who has a serious illness**

I would like to invite you to take part in a research study. Before you decide whether you would like to take part, I would like you to understand why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Ask me if there is anything that is not clear or if you would like more information. My contact details are on the back of this sheet.

#### **What is the purpose of the study?**

We know that families can offer reassurance, comfort and care for people when they have a serious illness. Researchers have looked at the roles, responsibilities and experiences of family members when someone is seriously ill, but so far, this research has concentrated on adults in the family. We want to find out how young people experience family life when a parent has a serious illness, and to understand more about their role within the family during this time. We would also like to explore how family life changes for young people when a parent has a serious illness, and how they see their future.

#### **Why have I been invited?**

You have been chosen because you have a parent with a serious illness who is not going to get better. I would also like to invite you to suggest up to two more people in your family who might be willing to take part in the study; for example, a parent, a sibling, a grandparent or someone else who is important to you. This will help me to understand more about your family, but if you do not want anyone else to take part, that is fine.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form at the start of the study. If you do decide to take part you are still free to withdraw at any time and without giving a reason. None of the services your family receives will be affected by whether or not you take part in the study. If you do decide to withdraw from the study then the information collected so far cannot be erased and this information may still be used in the study analysis.

**What will happen to me if I take part?**

You will be invited to an interview, either in your home, or at another location – whichever you prefer. I will ask you some questions and talk about your family with you. There will be time for you to say anything you think is important that you have not been asked. The interview will take approximately one hour. If you are in agreement, I would like to record the interview using a voice recorder.

**Expenses and payments**

You will not be paid to participate in the study.

**What are the possible disadvantages and risks of taking part?**

The experience of illness is often a cause of anxiety for families. There is a possibility that the interviews will touch on upsetting topics. However, you will not be under any pressure to answer questions or talk about topics that you prefer not to discuss. The interviews will focus on your experience of family life and what is important to you about your family.

**What are the possible benefits of taking part?**

Some people find it helpful to talk to somebody neutral during times of change. Sometimes research interviews help people to get their thoughts and ideas clear, which can help when they need to talk to people who provide services. We cannot promise the study will help you but the information we get from this study may help to improve the support provided to young people when a parent has a serious illness in the future.

**What if there is a problem?**

If you have a concern about any aspect of this study, please speak to me and I will do my best to answer your questions. Alternatively, you can contact my supervisor, Dr Kathryn Almack. Our contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting NHS Complaints. Details can be obtained from your health service provider.

**Will my taking part in this study be kept confidential?**

If you join the study, the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. It may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept strictly confidential, stored in a secure and locked office, and on a password protected database. Any information which leaves the research unit will have names and addresses removed so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for up to 1 year after the end of the study so that I can contact you about the findings of the study if you have requested this. All other research

## Participant Information Main Participant (Adult)

data will be kept securely for 7 years. After this time the data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain confidentiality. Only members of the research team will have access to personal data.

Anything you say during the interview will be treated as confidential unless you reveal something which indicates the likelihood of harm to yourself or others. In that case, I may need to raise the matter with the relevant people or agencies.

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

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

### **What will happen to the results of the research study?**

The findings of this study will be written up as part of a thesis for a higher degree at the University of Nottingham and may be made more widely available through journal publications and conference presentations. You and your family members will not be identified in any report or publication resulting from the research. We will send you a summary of the report at the end of the study if you would like.

### **Who is organising and funding the research?**

This study is being carried out by a researcher from the School of Nursing and the School of Sociology and Social Policy at the University of Nottingham and is being funded by the University of Nottingham.

### **Who has reviewed the study?**

This study has been reviewed and given favourable opinion by Derby Research Ethics Committee.

### **Further Information and contact details:**

Nicola Turner  
Postgraduate Student  
School of Health Sciences  
B33 Medical School  
Queen's Medical Centre  
Nottingham  
NG7 2HA

Tel: 0743 402 3847  
Email: [ntxnt4@nottingham.ac.uk](mailto:ntxnt4@nottingham.ac.uk)

Dr Kathryn Almack  
Senior Research Fellow  
School of Health Sciences  
B48a Medical School  
Queen's Medical Centre  
Nottingham  
NG7 2HA

Tel: 0115 82 31204  
Email: [k.almack@nottingham.ac.uk](mailto:k.almack@nottingham.ac.uk)