

Teenagers Information Sheet Part 1

Study Title: Teenagers' adjustment to their parent's Multiple Sclerosis (MS)

Researchers' names: Angeliki Bogosian, Prof. Rona Moss-Morris, Dr. Julie Hadwin

We are asking if you would take part in an anonymous research survey to find the answer to the question "How teenagers adjust to their parent's MS?" Before you decide if you want to join in it is important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk about it with your family and friends if you want to. **If both you and your parent are happy for you to take part in the study you will be asked to tick a box in the beginning of the online survey to confirm your consent.**

1. Why are we doing this research?

We are interested in finding out more which factors help teenagers to adjust to their parent's MS.

2. Why have I been invited to take part?

You have been invited to join our study because one of your parents has MS. 300 teenagers will be studied in this project.

3. Do I have to take part?

No, it is up to you. If you do, you'll be asked in the beginning of the online survey to check (tick) a box that both you and your mum/dad agree to take part in the project. You are free to leave the survey incomplete at any stage without giving any reason. Your survey will be anonymous. In other words, we do not need your name on any of the questionnaires.

4. What will happen to me if I take part?

The research project will involve filling in an online survey regarding MS, how you are currently feeling and family communication. The completion of the survey will take approximately 15 minutes.

5. Is there anything else to be worried about if I take part?

It is possible that some people might find it distressing answering questions about MS and their feelings. If you get upset you can take a break or decide not to continue. If you are very distressed, you can contact us and we will offer you some sources of support.

6. What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get might help young people with a parent with MS in the future.

Thank you for reading so far-if you are still interested, please go to Part 2

Teenagers Information Sheet Part 2

More detail- information you need to know if you still want to take part

1. What happens when the research project stops?

The information we will gain from this study will help us understand more about what it is like to have a parent of MS. Having this knowledge we can design and suggest support strategies to help young people who have a parent with MS if they need it.

2. What if there is a problem or something goes wrong?

In the unlikely event that you are unhappy with the way that the research is conducted the Southampton University complaint mechanisms are open to you. The person to contact in this regard is the chair of the Ethics Committee via Barbara Seiter, Academic Administrator (tel. +44 (0)2380 525578, email bs1c06@soton.ac.uk).

3. Will anyone else know I'm doing this?

No, no names are included in the online questionnaire.

4. What will happen to the results of the research study?

The study will be written up for publication in scientific journals and may be presented at scientific conferences. If you would like to know the results you can be provided with a summary sheet.

5. Who is organising and funding the research?

The research is being organised and conducted by researchers from Southampton University, UK and it is funded by the MS Society, UK.

6. Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Southampton Research Committee.

Thank you for reading this-please ask any questions if you need to.

Contact details for further information

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To fill in the survey please follow the link below:

www.isurvey.soton.ac.uk/619
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