

**Teenagers' views about their parent's Multiple Sclerosis (MS)
Parents Information Sheet
Part 1**

Study Title: Psychosocial adjustment in adolescents with a parent with Multiple Sclerosis (MS)

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

We would like to invite your teenage child to take part in an anonymous research survey. Before you decide you need to understand why the research is being done and what it would involve for your child. Please take time to read the following information carefully. Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen to you and your child if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

We are interested in finding out more about how adolescents adjust to their parents' MS and which factors play a positive or a negative role in their adjustment. In this research project we would like to find out more about individual differences across children and families as some children adjust very well to the challenges of MS and some not.

2. Why has my child been invited to take part?

Your child has been invited to join our study because he/she has a parent with MS. 300 teenagers will be studied in this project.

3. Do I have to take part?

It is up to you and your child. If after reading this information sheets, you and your child agree to take part, your child will check (tick) a box on the online survey that you both agree for your child to take part. Your child is free to leave the survey incomplete at any stage, without giving any reason.

4. What will happen to me and my child if we take part?

The research project will involve filling in an online survey regarding MS, psychosocial well-being and family communication. The completion of the survey will take 15 minutes.

5. What will my child be asked to do?

Your child will be asked to fill in 5 questionnaires: the Teenager's Illness Perception Scale (TIPS), the Social Adjustment Scale, the Strength and Difficulties Questionnaire, the Parent-Adolescent Communication Scale

and a short demographic questionnaire. These are widely used published questionnaires.

6. What are the possible disadvantages and risks of taking part?

It is possible that some people might find it distressing to answer questionnaires about their experiences with MS. If your child gets upset he/she can take a break or decide not to continue. Researchers will be available to answer any questions.

7. 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.

8. What happens when the research study stops?

The information we will gain from this project will help us to identify factors that facilitate adolescents' adjustment to parental MS. This is important as a coherent understanding will allow us to develop possible support strategies to minimize the impact MS may have on children as well as making it easier for parents to manage their children in the face of their illness. Also, we are going to test the validity of a newly developed questionnaire (TIPS), which can help health professionals to identify teenager's views of MS and address these thoughts.

9. What if there is a problem?

Any complaint about the way you or your child has been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

10. Will our taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Parents Information Sheet Part 2

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

1. What will happen if my child doesn't want to carry on with the study?

You can withdraw from the study at any point. Information collected may still be used.

2. What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (Angeliki Bogosian on +44 (0)2380 598721 or ab2406@soton.ac.uk). Also, 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 my and my child's taking part in this study be kept confidential?

Yes. The online survey is anonymised. The procedures for handling, processing, storing and destroying data are compliant with the Data Protection Act 1998. Data from this study will be retained for 10 years and subsequently disposed of securely.

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

The results will be used to help the researchers develop a clear understanding of which factors influence adolescents' adjustment to parental MS. Further, this understanding will help us develop appropriate support strategies for adolescents and their parents to facilitate adjustment. The study will also 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 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.

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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