

Participant Information Sheet

For both parents

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

Ethics number:

We would like to invite you and your child to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. 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 family, child or illness 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 families and across children as some children and families adjust very well to the challenges of MS and some not.

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

Your family has been invited to join our study because you have an adolescent child with a parent with MS. Sixty families will be studied in this phase of the project.

3. Do I have to take part?

It is up to you and your child. If you decide to take part, we will ask you to sign a consent form to show you have agreed you and your child to take part. Your child will be asked as well to sign an assent form if he/she agrees to take part. You are free to withdraw at any time, without giving any reason. This would not affect the standard of care you and/or your child receive.

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

The research project will involve filling in questionnaires (**mailed to you or online, depending on your preference**) regarding MS, psychosocial well-being and family communication, at two time points, **6** months apart. The completion of the questionnaires will take 30 to 45 minutes. You will also be asked to talk for 5 minutes

(phone communication) about your adolescent child and your relationship with him/her. Your adolescent child will be asked to fill in questionnaires about how he/she sees MS, his/her psychological well-being and about family environment. The researcher (Angeliki Bogosian) will arrange with you and your child a phone call before and after you complete the questionnaires to give you further clarifications and debrief you.

5. What will I and my child be asked to do?

The parent with MS will be asked to complete 6 questionnaires. The parent without MS will be asked to complete 5 questionnaires. Both parents will be asked to complete a “5 minutes speech sample” task. For the task we will ask you to speak about your child and your relationship with him/her for 5 minutes without interruptions. We will audiotape this short speech. The questionnaires will ask about your MS (only for parents with MS), your current mood, how MS currently affects your family communication and whether MS affect your child. The adolescent will be asked to complete 5 questionnaires. The questionnaires will be about how he/she views MS, how MS impact on his/her life, his/her current mood and how MS currently affects your family communication.

5. 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 you or your child gets upset you can take a break or decide not to continue. If you are very distressed we will offer 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. The study may help parents understand how to facilitate adjustment in their children.

7. Payments

A £5 voucher will be given as a “thank you” for your participation.

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.

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.

Participant 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 or I don't want to carry on with the study?

You can withdraw from the study at any point. Information collected may still be used. Any data that can still be identified as yours will be destroyed if you wish.

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 her best to answer your questions (Angeliki Bogosian on 02380 598721 or ab2406@soton.ac.uk). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedures. 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. 02380 525578, email bs1c06@soton.ac.uk)

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for legal action for compensation against University of Southampton and Southampton NHS trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

3. Will my and my child's taking part in this study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The procedures for handling, processing, storing and destroying data are compliant with the Data Protection Act 1998. Information about you and your child will be stored securely and will be available only to members of the research team. It will be used only for the purposes of the current study. Data from this study will be retained for 10 years and subsequently disposed of securely.

4. Involvement of the General Practitioner/Family doctor (GP)

Informing your GP about your participation is not necessary.

5. 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.

6. Who is organising the research?

The research is being organised and conducted by researchers from Southampton University.

7. Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a research Ethics Committee to protect your safety rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Southampton & South West Hampshire Research Ethics Committee and the University of Southampton Research Committee.

Contact details for further information

If you would like to discuss your potential involvement in this research further please contact:

Name: Angeliki Bogosian

Telephone number: **02380 598721**

Email address: **ab2406@soton.ac.uk**

Address: Department of Psychology, Shackleton Building, University of Southampton, Highfield Campus, Southampton, SO17 1BJ

ALTERNATIVELY: Fill in the attached contact details form, return it in a stamped addressed envelope and one of the researchers will contact you

Please retain this information sheet.

If, after discussing the research with us, you decide that you wish to participate we will ask you to complete and return a consent form. You will get a copy of the consent form to keep.