

INFORMATION SHEET FOR PARTICIPANTS

Ethical Clearance Reference Number: HR/DP-22/23-34402



YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of project

How do parents attend to and support the needs of siblings of a child or adolescent who is affected by a rare neuroimmune condition and requires significant parental support and time?

Invitation Paragraph

I would like to invite you to participate in this research project which forms part of my MSc Family Therapy studies. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the project?

The purpose of the project is to explore how parents attend to and support the needs of the siblings of a child or adolescent who is affected by a rare neuroimmune condition and requires significant parental support and time. Being able to balance their attention on all their children was identified as a need by parents in a Facebook group for parents of children with rare neuroimmune conditions where I asked what topic would they like me to focus on for my research dissertation.

Rare neuroimmune conditions such as Transverse Myelitis (TM), Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica Spectrum Disorder (NMOSD), Acute Flaccid Myelitis (AFM), Myelin Oligodendrocyte Glycoprotein Antibody-associated Disease (MOGAD), Optic Neuritis (ON) and paediatric Multiple Sclerosis can have a life changing impact on a young person. It can result in life-long visible/invisible symptoms and/or disability and affects all areas of their life. It also affects their parents and siblings. Research on the impact of these disorders on families has not yet been identified.

The aims of the project include:

Develop an understanding of

- Siblings' experiences and ongoing needs according to the parents' perspectives.
- The issues parents face regarding the impact of the rare neuroimmune condition on family relationships and dynamics.
- How parents attempt to balance their attention and attend to the needs of all their children where one child requires significant parental attention and time. What have they tried? What has worked/not worked?
- What support, if any, parents seek to support them in this effort. What has worked/not worked?

To share the experiences and needs of parents in this position more widely among

- Parents to normalise their experiences and share what has and has not worked for other families.
- Medical and healthcare professionals and family therapists when they treat a young child with a rare neuro-inflammatory condition.

To contribute to

- Research on childhood neurological conditions and rare neuro-inflammatory conditions specifically and their impact on families.
- Family therapeutic research on the impact of rare neurological conditions on families and the support parents and families may require.

The management committee of the Transverse Myelitis Society (registered charity number: 1108179) has given its approval for this research to be conducted amongst its members. Non-members may also take part. Names of participants in this project will not be disclosed to the management committee of the Transverse Myelitis Society.

Why have I been invited to take part?

You are being invited to participate in this project because you responded to an advert about this research project in a Facebook group or email indicating your interest in taking part. Criteria for taking part are:

- You have a child aged 0-17 who has TM, ADEM, NMOSD, AFM, MOGAD, ON or MS.
- You have more than one child who live in the home.
- Is attending to and supporting the needs of siblings when the child who has TM, ADEM, NMOSD, AFM, MOGAD, ON or MS requires a lot of your time and attention something you think about?
- You live in the UK.
- You have a device and broadband which you can use for our interview, which will be online. We will use MS Teams (or Zoom as a backup) both which are free to download from the Internet.
- You are available for 60 minutes in Summer 2023 to attend an online interview.
- You may be married, in a committed partnership, separated, divorced, or a single parent. If both parents live in the same home, it would be ideal if both can participate.
- You consent to the interview being audio and video recorded and transcribed and the data included in a written dissertation. Aliases will be used in the dissertation to ensure confidentiality and that your family cannot be identified. More information on how data will be handled is given below.

What will happen if I take part?

If you choose to take part in the project you will be asked to take part in a semi-structured interview. During it, I will ask the following type of questions:

- About the neuro-immune condition your child has – Which neuro-immune condition does your child have? When was the onset? How is s/he affected now by it? What prognosis, if any, has been communicated to you? How much of your time, attention and support does this child's needs require from you?

- What is your experience of attending to and supporting the needs of the well siblings before the neuroimmune condition's onset, during the onset/acute phase and now?
- How do you try to balance your attention and time on the well siblings? What works and what does not?
- What support, if any, have you sought to support you in dealing with balancing your attention on all your children? What has worked/not worked?
- How do you determine what the well siblings' needs are? (observation, discussion with the well siblings, via discussions from others such as grandparents, aunts, uncles, cousins, siblings' friends, school teachers, etc.)
- What has been the impact on you as a parent, family relationships and family life?
- What advice would you give to parents who are new to this journey?

There are no right or wrong answers to these questions. The aim of these questions is to understand your experience as a parent. It is not to judge your parenting style.

Participation will take place online using MS Teams at a mutually convenient time. The interview will last 60 minutes. It will be audio and video recorded and transcribed only with your consent.

If you share information regarding how your child is affected by the rare neuroimmune disorder, this is considered sensitive health information as per UK data protection law (including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018). Information on how I will handle and protect data is below.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact me if you have any questions that will help you make a decision about participating. If you decide to participate, I will ask you to sign a consent form and you will be given a copy to keep. The signed consent form will need to be returned prior to the interview.

The data/information you provide will not be shared with other agencies unless you have disclosed you are at risk to yourself or others or you know of someone who may wish to harm you or others. I will discuss this with you prior to making a referral.

What are the possible risks of taking part?

Some people report feeling tired after such an interview. Some aspects of the topic may feel difficult to talk about and sometimes people feel emotional. This is entirely understandable. If this were to happen, you have the choice not to talk about it. If you wish to talk about it, we will talk about it at a pace that suits you. We can also stop the interview at any time and resume it on another day. Or if you decide you no longer wish to take part in the research project, you can withdraw from it by letting me know.

Although urgent mental health risks are unlikely due to the nature of this research, if you disclose during the interview that you have been experiencing significant distress, such as having suicide ideations or self-harming or intending to, and/or you are concerned you

might harm others, or someone may harm you or others, I will ask you some questions to understand how long this has been happening, what support you currently have in place (family and friends for example), can you use that support, and what additional support would be useful. I would also signpost you to relevant organisations who can support you such as the ones in the table below. The charities on pages 9-11 also provide a range of services that might also be relevant to your and your family's needs.

Organisation	Contact Details
<p>If you are experiencing an emergency now, you are thinking of attempting suicide or have seriously harmed yourself, you require urgent medical help.</p>	<p>Call 999 for an ambulance.</p> <p>Go to A&E if you can.</p> <p>If you live in England, your local NHS Trust will have an urgent helpline you can call. Click on this link to find it.</p> <p>For Wales, Scotland and Northern Ireland, please call 999.</p>
<p>Breathing Space</p>	<p>Call 0800 83 85 87 (open Monday to Thursday 6pm to 2am and Friday 6pm to Monday 6am at weekends)</p>
<p>C.A.L.L. Helpline Wales (Wales only)</p>	<p>Call 0800 132 737 (open 24/7)</p> <p>Or text 'help' followed by a question to 81066</p>
<p>Campaign Against Living Miserably (CALM)</p> <p>For men - Open 5pm to midnight every day</p>	<p>Call 0800 58 58 58</p>
<p>Childline (Under 19's)</p>	<p>Call 0800 1111</p> <p>One-to-one chat with a counsellor</p>
<p>Mind</p> <p>Information and signposting service for topics related to mental health problems, where to get help near you, treatment options, and advocacy services. It does not provide a listening service or a crisis service.</p>	<p>Infoline: 0300 123 3393</p> <p>Email: info@mind.org.uk</p> <p>Post: Mind Infoline, PO Box 75225, London, E15 9FS</p>
<p>National Suicide Prevention Helpline UK</p> <p>Listening service for anyone with thoughts of suicide</p>	<p>Call 0800 689 5652 (6pm–3:30am every day)</p>
<p>Papyrus HOPELINEUK</p>	<p>Call 0800 068 4141 (weekdays 10am-10pm, weekends 2pm-10pm and bank holidays 2pm–10pm)</p>

Organisation	Contact Details
For under 35's who are struggling with suicidal feelings, or concerned about a young person who might be struggling.	Email: pat@papyrus-uk.org Text 07786 209 697
Samaritans Supportive listening service	Call 116 123 Email: jo@samaritans.org for a reply within 24 hours Samaritans Welsh Language Line on 0808 164 0123 (7pm–11pm every day)
SANELine	If you're experiencing a mental health problem or supporting someone else, call 0300 304 7000 (4.30pm–10.30pm every day)
Shout Confidential texting service	Text "SHOUT" to 85258 to contact the Shout Crisis Text Line, or text "YM" if you're under 19
Switchboard If you identify as gay, lesbian, bisexual or transgender.	Call 0300 330 0630 (10am–10pm every day) Email: chris@switchboard.lgbt Phone operators all identify as LGBT+.
The Mix For under 25's	Call 0808 808 4994 Support by email using this form on The Mix website Use their crisis text messenger service

We may find that you or a member of your family could use an additional form of support. A list of UK registered charities which provide support across a range of areas parents often ask about is at the end of this document on pages 9-11.

What are the possible benefits of taking part?

People who have participated in such interviews have described benefits such as gaining new perspectives on their situation, not feeling as alone which was helpful and it feels good to contribute to research that can potentially help people in a similar situation.

It is my hope that by sharing the results of this research project in written form, through presentations at conferences and online with relevant charities and associations will help other parents in a similar situation, support medical and healthcare professionals and family therapists who treat children and families like yours, contribute to research on childhood neurological conditions and family therapy research. Such charities and professional associations include: Transverse Myelitis Society, Backup Trust, SRNA (US-based charity), British Paediatric Neurology Association's UK-Childhood Neuro-Inflammatory Disorders Special Interest Group, British Paediatric Neurology Association annual conference, and British Academy of Childhood Disability.

Data handling and confidentiality

Your data will be processed under the terms of UK data protection law (including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018).

- Your family will be identified by a code to maintain anonymity so that your family cannot be identified.
- Regarding any sensitive health information about your child who has the rare neuroimmune disorder given in the interview, I will agree with you how to refer to that in the dissertation. For example, due to the disorder's impact, the child uses a wheelchair full-time, experiences urinary issues, chronic pain and fatigue.
- If you mention sensitive health issues relating to your own, spouse/partner's and/or other children's health, I will ask how you wish me to refer to this. For example, as chronic health issues, additional health stressors or just stressors.
- In addition to video and audio recording the interview as described above, I will use the transcription function in MS Teams to create a transcription of our interview. If however, this is not of a sufficient quality to analyse it, as a back-up option, I will use the Otter.ai app to transcribe the interview. Once the interview has been transcribed, I will download the transcription to my computer and delete the audio file from the Otter.ai app. Otter.ai's servers are based in the USA and it complies with the 'EU-U.S. Privacy Shield as set forth by the U.S. Department of Commerce regarding the collection, use, and retention of information transferred from the European Union and United Kingdom to the United States in reliance on Privacy Shield. Otter.ai has certified to the Department of Commerce that it adheres to the Privacy Shield Principles with respect to such information as per its [privacy policy](#).
- If we cannot use MS Teams to conduct the interview, we will use Zoom as a back-up and the Otter-ai app to transcribe the interview (as described above).
- Data will be stored electronically on my computer which is only used by me and is accessed via a password. Any written notes made will be transferred to electronic storage and then shredded. A back-up will be maintained in the cloud and is protected by a strong password which only I know.
- Printed materials will be kept in a locked safe.
- Data will be shared with research supervisors and tutors. Documents will be password protected to ensure secure electronic transfer.
- Emails to me regarding your participation in the research project will be deleted after either you have decided not to take part or, if you have decided to take part, after the interview has taken place. However, if you wish to receive a copy of any articles I write or attend a webinar about the research outcomes, then I will retain your email for that purpose.
- Audio/video recordings and handwritten notes will be deleted within one month after my dissertation has been marked, which is expected to be in Autumn 2023. If the dissertation is marked earlier, I will delete those items within a month of that date.
- Transcriptions and electronic notes will be deleted within 1 year following receipt of the MSc as per [King's College London guidance on data retention](#) when one expects to publish their research results. I expect this to be in Autumn 2024.

I would need to break confidentiality if you disclose that you or others are at significant risk of harm, or you or others are going to or have committed a crime/act of terror, or you require support after our interview.

Data Protection Statement

If you would like more information about how your data will be processed under the terms of UK data protection laws please visit the link below:

<https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

What if I change my mind about taking part?

You are free to withdraw from the project without having to give a reason and doing so will not affect you in any way. You can withdraw your data from the project up until 31st July 2023. If you choose to withdraw from the project, I will not retain the information you have given thus far. Files held on computer will be deleted, hardcopy notes will be shredded and emails between us to organise your participation deleted.

What will happen to the results of the project?

The results of the project will be used in my dissertation. I may also publish the results in relevant family therapy and neurology journals and present at a conference and/or online seminars. Anonymised data will be available in written/spoken form and aliases will be given so you and your family cannot be identified.

I would like to run an online seminar for families to share the results and you will be welcomed to attend that. If I publish an article, I can email you a copy.

Who should I contact for further information?

If you have any questions or require more information about this project, please contact me using the following contact details:

Barbara Babcock
Student/ Researcher
MSc Family Therapy
barbara.babcock@kcl.ac.uk

Dr. Grace Heaphy
Research Supervisor
grace.heaphy@kcl.ac.uk

Dr. Temitope Ademosu
Research Supervisor
temitope.ademosu@kcl.ac.uk

King's College London
Family Therapy Department
Addiction Sciences Building
4 Windsor Walk
London SE5 8AF
familytherapy-administration@kcl.ac.uk
020 7848 0693

What if I have further questions, or if something goes wrong?

If this project has harmed you in any way or if you wish to make a complaint about the conduct of the project you can contact King's College London using the details below for further advice and information:

Dr. Grace Heaphy
Course Director – MSc Family Therapy
King's College London
Family Therapy Department
Addiction Sciences Building
4 Windsor Walk
London SE5 8AF
familytherapy-administration@kcl.ac.uk
020 7848 0693

Thank you for reading this information sheet and for considering taking part in this research.

UK registered charities which provide support across a range of areas parents often ask about

The majority of the services offered by these charities are free. However, some may ask for a financial contribution. Where this is known, there is an asterisk * next to the service. If you are unable to make a financial contribution, it is not necessarily a barrier to receiving the service. Please discuss your circumstances with the charity.

Type of Support	UK Registered Charity or NHS organisation	Contact Details
Accessible Housing - Short-term housing whilst you source a permanent option	Aspire	https://www.aspire.org.uk housing@aspire.org.uk 020 8420 6720
Assistive Technology	Aspire	https://www.aspire.org.uk technology@aspire.org.uk 020 8420 6732
Benefits Advice	Aspire	https://www.aspire.org.uk welfarebenefits@aspire.org.uk 020 8420 6711
	Citizens Advice	https://www.citizensadvice.org.uk/
	Spinal Injuries Association	https://www.spinal.co.uk/ Support Line 0800 980 0501
Bowel Care	ERIC	https://eric.org.uk/ Helpline: 0808 169 9949
	Spinal Injuries Association	https://www.spinal.co.uk/ Support Line 0800 980 0501
Counselling	Spinal Injuries Association	https://www.spinal.co.uk/ Support Line 0800 980 0501
	NHS via referral from your GP	Please contact your GP
Equipment Grant Scheme *	Transverse Myelitis Society	https://www.myelitis.org.uk/ info@myelitis.org.uk

Type of Support	UK Registered Charity or NHS organisation	Contact Details
Housing advice	Aspire	https://www.aspire.org.uk housing@aspire.org.uk HousingAdvice@aspire.org.uk
Independent Living	Aspire	https://www.aspire.org.uk advice@aspire.org.uk 020 8420 6735
Medical issues	Your GP, neurologist, urologist, physiotherapist, occupational therapist as applicable	Contact the relevant medical professional or obtain a referral via your or your child's GP.
Mentoring from a family who has had similar experience	Backup Trust	https://www.backuptrust.org.uk/support-for-you/mentoring mentoring@backuptrust.org.uk
Multi-activity residential courses for under 13's and adolescents to build confidence and discover one's potential *	Backup Trust	https://www.backuptrust.org.uk/support-for-you/children-young-people/courses-for-young-people outreachandsupport@backuptrust.org.uk
Neurological related questions	Brain & Spine Foundation Information provided by the Helpline team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. The team does not give advice or opinions, either medical or personal.	https://www.brainandspine.org.uk/support-for-you/helpline/ helpline@brainandspine.org.uk Helpline: 0808 808 1000
NHS Specialist Multi-disciplinary Paediatric Treatment	Obtain referral to Stoke Mandeville Hospital	https://www.buckshealthcare.nhs.uk/our-services/spinal-injuries/ 01296 315872
Opportunities for parents and children to meet others like them	Backup Trust	https://www.backuptrust.org.uk/support-for-you/the-back-up-lounge outreachandsupport@backuptrust.org.uk
	Spinal Injuries Association	https://www.spinal.co.uk/

Type of Support	UK Registered Charity or NHS organisation	Contact Details
		Support Line 0800 980 0501
	The Encephalitis Society – For ADEM only	https://www.encephalitis.info/ support@encephalitis.info Support line: 01653 699599
	Transverse Myelitis Society	https://www.myelitis.org.uk/ info@myelitis.org.uk
Physiotherapy	Transverse Myelitis Society	https://www.myelitis.org.uk/ info@myelitis.org.uk
	Neurokinex	https://neurokinex.org/neurokinex-kids/ info@neurokinex.org 0300 77 77 188
	The Rooprai Trust	https://www.rstrust.com/ info@rstrust.com
School inclusion	Backup Trust	https://www.backuptrust.org.uk/support-for-you/children-young-people outreachandsupport@backuptrust.org.uk 020 8875 1805
Siblings – Support for	Sibs	https://www.sibs.org.uk/ Contact: https://sibs.beaconforms.com/form/75f0e136
Urinary Issues	ERIC	https://eric.org.uk/ Helpline: 0808 169 9949
Wheelchair skills	Backup Trust	https://www.backuptrust.org.uk/support-for-you/wheelchair-skills outreachandsupport@backuptrust.org.uk 020 8875 1805