



## **Information leaflet for carers**

### **Project title**

Caring for someone with a rare disease: An insight into the life of a carer

### **About this project**

A rare disease is defined by the European Medicines Agency as a 'life-threatening or chronically debilitating' condition which affects no more than 5 per 10,000 people in the EU. Although individually rare, collectively rare diseases are much more common with 1 in 17 persons affected in their lifetime.

Many people with a rare disease are cared for by a family member. This can be a challenging role at times due to the nature of the disease and the unique, often complex, care required. From previous research conducted by the rare disease research group at QUB it has become apparent that carers often do not prioritise themselves. Because they are not the ones living with the disease they rarely take the time to consider their own needs. Neglecting to look after themselves can have devastating consequences on their own health which directly impacts the person they care for. It is therefore important that strategies are put in place to ensure that carers take the time they need to care for themselves and avail of any support offered to them from the health service, charities or support groups. From ongoing research within the team there have also been hints that there could be significant merit in networking with other carers experiencing circumstances as themselves.

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

This project is an exploratory study involving a survey with carers to gain an understanding of their experience of caring for someone with a rare disease. The survey will ask questions about the challenges they face, the services they access, their experience with the health service as well as aiming to form a picture of the type of support that would be useful for them going forward. Through this project it is hoped that general awareness will be raised of the issue of rare disease as well as improving situations for those who care for the individuals living with such conditions.

### **Invitation to take part in the study**

You have been invited to take part in this project because you currently care for someone with a rare disease.

This leaflet provides important information you will need to think about when deciding whether to take part in this project. The information contained in this leaflet may be made available in other formats – please just ask. If you want more detailed information about something, you can ask any at any time. Some important contact details are listed below:

Julie McMullan	Email: <a href="mailto:Julie.mcmullan@qub.ac.uk">Julie.mcmullan@qub.ac.uk</a>	Postdoctoral Research Fellow
	Phone: 028 90 638460	

Rare Disease Team	<a href="mailto:raredisease@qub.ac.uk">raredisease@qub.ac.uk</a>	General rare disease email address
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**Do I have to take part?**

You can take as much time as you need to think about participating in this project. Only you can choose if you want to take part. If you don't want to participate you don't have to say why.

You may wish to withdraw from this project and this is entirely your choice. There are two options for withdrawal:

1. No further contact, but continue to include my existing information in the project.
2. No further contact and no further use of the information I provided; all related details will be deleted.

**What do I have to do?**

At this time, we would like you to consider completing a survey to learn more about your experience of caring for someone with a rare disease. You will have to answer questions *via* an online survey. The survey is divided into two sections and will take approximately 15 minutes to complete. The completed surveys will be stored in a safe environment that complies with national data security standards and will only be available to the three researchers involved in the initial analysis. All future work will use summary data, which is anonymised.

**How will the results be used?**

The main purpose of the project is to explore the challenges carers face when looking after someone with a rare disease and identify how they could be better supported in this role. Through this project it is hoped that general awareness will be raised of the issue of rare disease as well as improving situations for those who care for the individuals living with such conditions. We appreciate and welcome your input to this project.

We aim:

- To perform a comprehensive literature review to gain awareness of the current research field.
- To explore carer's perceptions of looking after someone with a rare disease.
- To discover carer's experience of the health service and support services when caring for someone with a rare disease.
- To investigate the best way that support can be provided for those who care for someone with a rare disease.

**Are there any risks or disadvantages to taking part in the project?**

Some people worry about being identified as someone taking part in the project. The chance of this happening by anyone outside the immediate contact team is very small, and we will do everything we can to prevent this from happening. We can only look at your data for approved scientific and healthcare purposes.

**What are the advantages?**

By taking part in this study you will be helping the development of essential support services for those living and working with rare diseases. In the future we hope this project will help to better support rare disease patients and their carers.

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

We take information security very seriously. All electronic information from this project will be stored on an encrypted QUB computer in a secure data centre in Northern Ireland whose security level meets national data standards and no data will be stored in an unapproved location. Researchers cannot copy or take away any individual data from this storage area. Nobody outside this research project can access recorded or transcribed information; we will only share summative data that will go towards identifying priorities and improving rare disease resources. If anyone reveals your data on purpose in a way that identifies you, it is a legal breach (in other words, they have broken their contract or they have broken the law). Any person, institution or company that does this could face criminal charges or substantial fines.

**What do I do next?**

If after careful consideration you are keen to proceed with the survey, please contact the rare disease team ([raredisease@qub.ac.uk](mailto:raredisease@qub.ac.uk)) who will contact you with a web link for completion.

**THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION**