

Welcome. This website is interactive. You can find more information by clicking on the for videos or to get more information."

Each signpost has a link to a video explaining what it is. On our website you will find answers to questions like these: Who is a 'carer'? What is a rare disease? And more information.

UNDERSTANDING THE RARE DISEASE CARER JOURNEY

Hello, this resource has been developed to support carers of loved ones with rare conditions.

Not sure if you are a carer? Watch these videos:



THE JOURNEY AHEAD - TIPS FROM CARERS

Carer tips from personal experience.

"We do virtual meetups, it's with parents like me." Carer



SELF CARE AND WELLBEING

Resources to help carers maximise their wellbeing.



IMPACT OF 'RARE CARE' ON THE FAMILY

The carer journey is often complex with many barriers.

Ways to enhance family wellbeing while living with a rare condition.



PRACTICAL INFORMATION TO HELP NAVIGATE FINANCES

Resources include carer's allowance, travel support, and equipment funding.



RESOURCES TO HELP NAVIGATE THE HEALTH AND SOCIAL CARE SYSTEM

Links to services and contacts and opportunities to be part of research.



CONNECTING WITH OTHERS

Learn about other carers' experiences or share your own.



GOING OUT - ACCESSIBLE PLACES AND EVENTS

Ideas and information about accessible spaces, facilities and events in NI.



This map was crafted and driven by carer voices sharing their experiences of caring for a loved one with a rare disease.

ACCESSING MORE INFORMATION

Visit our website by clicking on www.qub.ac.uk/sites/raredisease
Scan the QR code #RareDiseaseNI

UK Research and Innovation
 DoH
www.health-ni.gov.uk
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Public Health Agency
HSC R&D Division Northern Ireland
 ESRC
ECONOMIC & SOCIAL RESEARCH COUNCIL
 RAIN
A Rare Disease Research Network