Living Well
North Tyneside
Supporting Health and Wellbeing

What is Rare Disease Day?

Rare Disease Day is an annual event dedicated to raising awareness and advocating for better research, support, and treatment for individuals living with rare diseases. First launched in **2008** by EURORDIS (The European Organisation for Rare Diseases), it is now marked in over 100 countries worldwide.

With over 7,000 identified rare diseases, many of which are life-threatening or significantly impact daily life, the need for greater understanding, early diagnosis, and improved care is more urgent than ever.

What Defines a Rare Disease?

A disease is classified as rare when it affects fewer than 1 in 2,000 people. However, because there are thousands of rare conditions, collectively they affect 1 in 17 people in the UK. Many of these diseases are genetic, while others appear later in life.

Examples of rare diseases include:

- **Cystic fibrosis** – A genetic condition affecting the lungs and digestive system.
- **Ehlers-Danlos syndrome** – A group of disorders affecting connective tissue.
- **Huntington’s disease** – A progressive brain disorder impacting movement and cognitive function.
- **Duchenne muscular dystrophy** – A severe genetic disorder causing muscle degeneration.
- **Batten disease** – A rare neurological disorder that affects children.

Despite their rarity, these conditions share common challenges: delayed diagnosis, limited treatment options, and a lack of public awareness.

Why Rare Disease Day Matters

1. **Early Diagnosis Saves Lives** – Many rare diseases are misdiagnosed or go undiagnosed for years, leading to unnecessary suffering. Awareness helps healthcare professionals identify symptoms sooner.
2. **More Research is Needed** – Only 5% of rare diseases have an approved treatment. Increased awareness drives funding for research and drug development.
3. **Stronger Support for Families and Carers** – Living with a rare disease can be isolating. Raising awareness encourages better healthcare policies, workplace support, and educational resources for affected families.
4. **Inclusivity in Healthcare** – Rare disease patients often struggle to access the specialist care and medications they need. Advocacy helps push for fairer healthcare systems.

How to Get Involved in Rare Disease Day 2025

1. Wear Zebra Stripes

The zebra is a symbol for rare diseases because no two zebras have the same stripes, just as no two rare disease patients experience the same challenges. Wearing zebra stripes is a simple but powerful way to show support.

2. Share a Story

Many people living with rare diseases feel invisible. Sharing personal stories—whether your own or someone else’s—helps raise awareness and fosters understanding and compassion.

3. Support Rare Disease Charities

There are several UK-based organisations providing vital support, including:

- **Genetic Alliance UK** – Supports families affected by genetic disorders.
- **EURORDIS – Rare Diseases Europe** – An international alliance of rare disease patient organisations.

- **Metabolic Support UK** – Helps individuals with inherited metabolic disorders.

4. Attend an Event
Check for local events, online webinars, and charity fundraisers organised for Rare Disease Day 2025. Schools, hospitals, and advocacy groups often host awareness campaigns—get involved!

5. Advocate for Policy Change
Many rare diseases lack funding, research, and healthcare policies. Write to your local MP, sign petitions, and support initiatives that push for rare disease recognition and funding.

Rare Disease Support in North Tyneside

If you or a loved one is affected by a rare disease, there are local resources that can help:

Newcastle Health Research Partnership – A collaborative organisation working on cutting-edge health research, including rare disease studies.
Newcastle Hospitals Rare Disease Service – Offers specialist care for rare diseases in the North East.

Final Thoughts: A Call for Change

Rare Disease Day 2025 is a reminder that millions of people worldwide are affected by conditions that many have never heard of. By raising awareness, advocating for research, and supporting affected families, we can help improve diagnosis, treatment, and quality of life for those living with rare diseases.

Remember: A disease may be rare, but care, support, and hope should never be.

Related Links

- Newcastle Hospitals Rare Disease Service
- Newcastle Health Research Partnership
- Genetic Alliance UK
- EURORDIS – Rare Diseases Europe
- Metabolic Support UK

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