

Fabry Education and Resilience Project 2025

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BACKGROUND

Fabry disease is a rare, progressive genetic condition with variable symptoms affecting multiple organ systems.

Individuals living with Fabry face challenges in understanding their condition, managing treatment and navigating social and healthcare systems.

Peer support and community education are key tools to enhance self-advocacy, resilience and well-being. Accessible, ongoing education helps empower people to live well with Fabry disease.



OBJECTIVES

To develop the *Fabry Education and Resilience Project*, a community-led, peer-supported education programme on:

- 1 Understanding of Fabry disease and its management
- 2 Confidence in self-advocacy and communication with healthcare professionals
- 3 Engagement with peer support networks and MPS Society initiatives



METHOD

We delivered monthly education in 2025 via the following channels:



Content was shared in peer support groups to encourage discussion, provide reliable resources and support understanding and self-management. Targeted webinars addressed topics relevant for our community.

Engagement was measured via peer group participation, webinar attendance, MPS Society membership and interaction with well-being content across social channels.

Topics included:

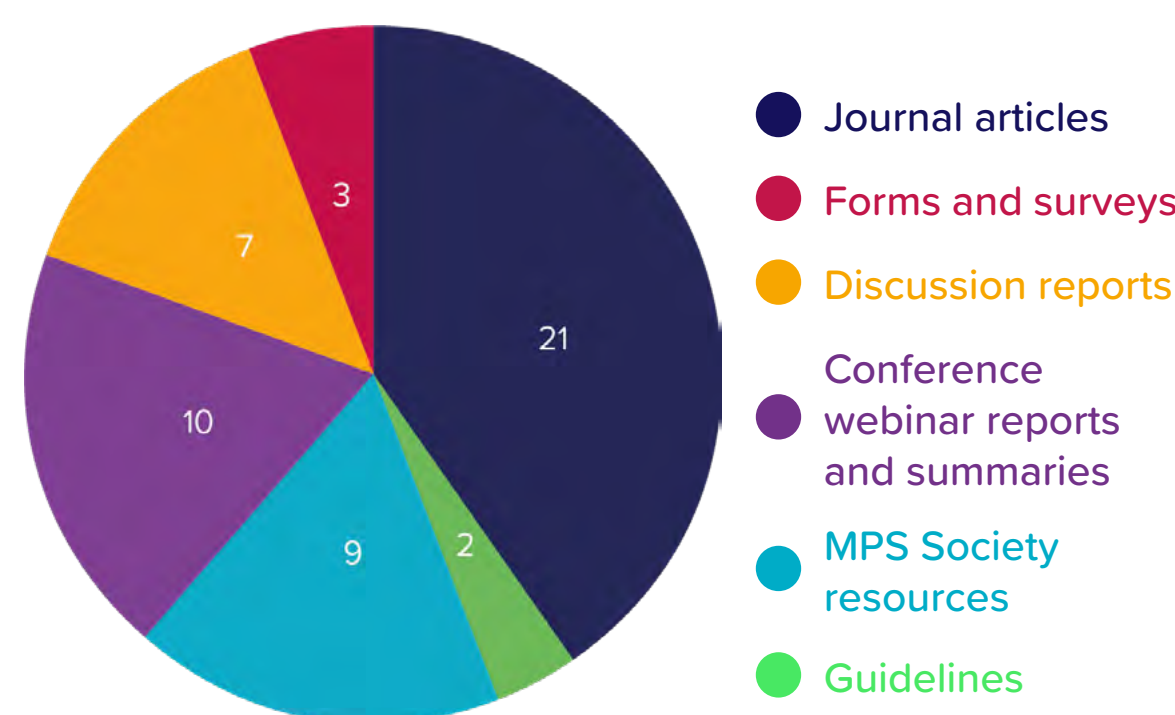
- Understanding Fabry
- Pain management
- Social and financial support
- Women's health
- Ageing
- Cardiac health
- GI and nutrition
- Scripting
- Self-advocacy
- Physical activity
- Asking big questions



RESULTS

1 Improve the understanding of Fabry disease and its management

- 52 resources shared, incl. medical papers, trial updates, research summaries and practical guides



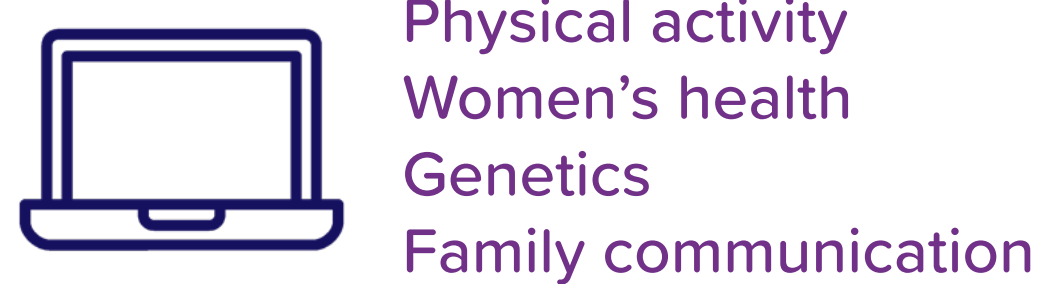
50 participants had strong participation in four themed webinars and Q&A sessions

- Participants reported improved understanding of Fabry disease and its management

It was great to have a focus on how to talk about Fabry. I feel like I can explain myself better now. I used to stumble over my words but now I have the words to say.

2 Increase confidence in self-advocacy and communication with healthcare professionals

- Webinars and Q&A sessions addressing topics relevant to clinical conversations, included:



- Resources supported awareness of treatment options, symptom management and lived experience, resources shared included:



- Participants reported improved confidence in self-advocacy

I've gained confidence, knowing more helps me to speak up.

- Participants reported improved ability to communicate effectively with healthcare professionals

Being able to advocate for myself in A&E has been a game changer. Having a script about Fabry has helped me to explain Fabry without getting stressed.

3 Increase engagement with peer support networks and MPS Society initiatives

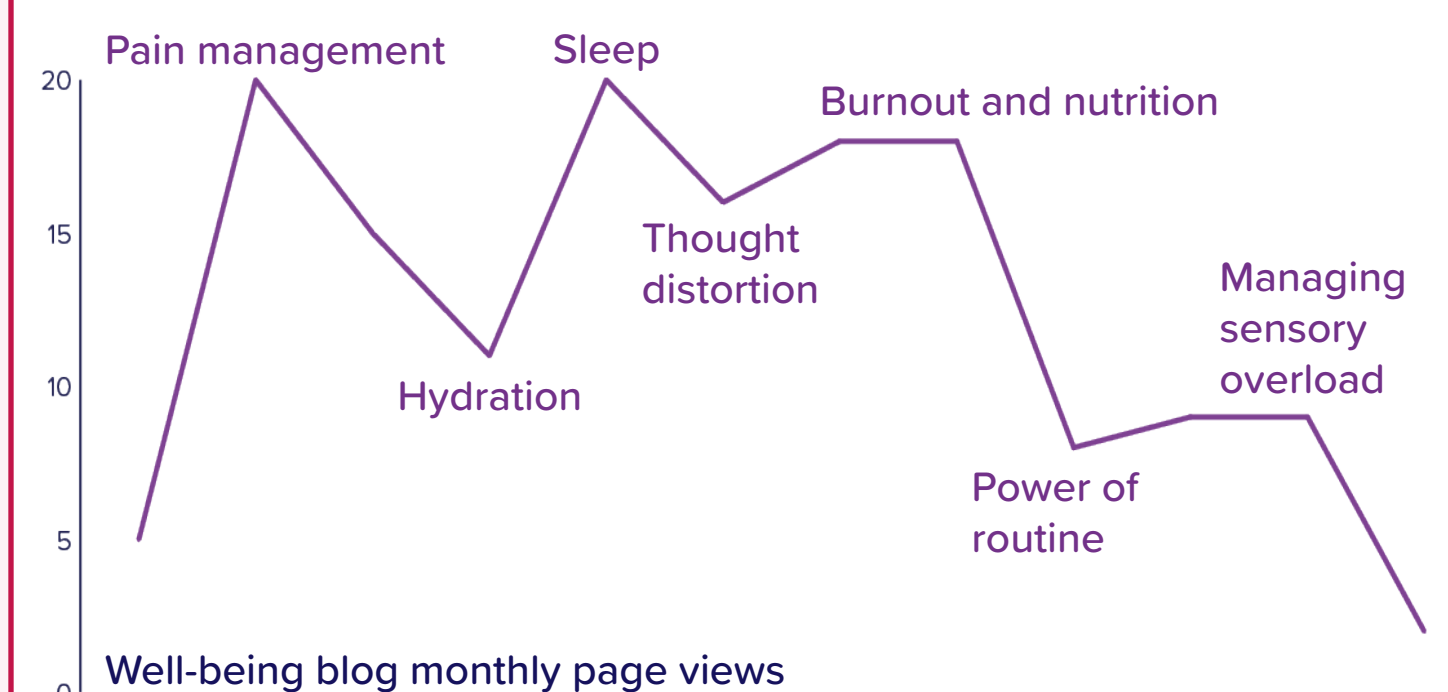
70 members took part, sharing experiences, advice and questions

- Peer support engagement increased, Fabry WhatsApp group membership nearly doubled:



11 coffee mornings provided informal peer support and specialist input

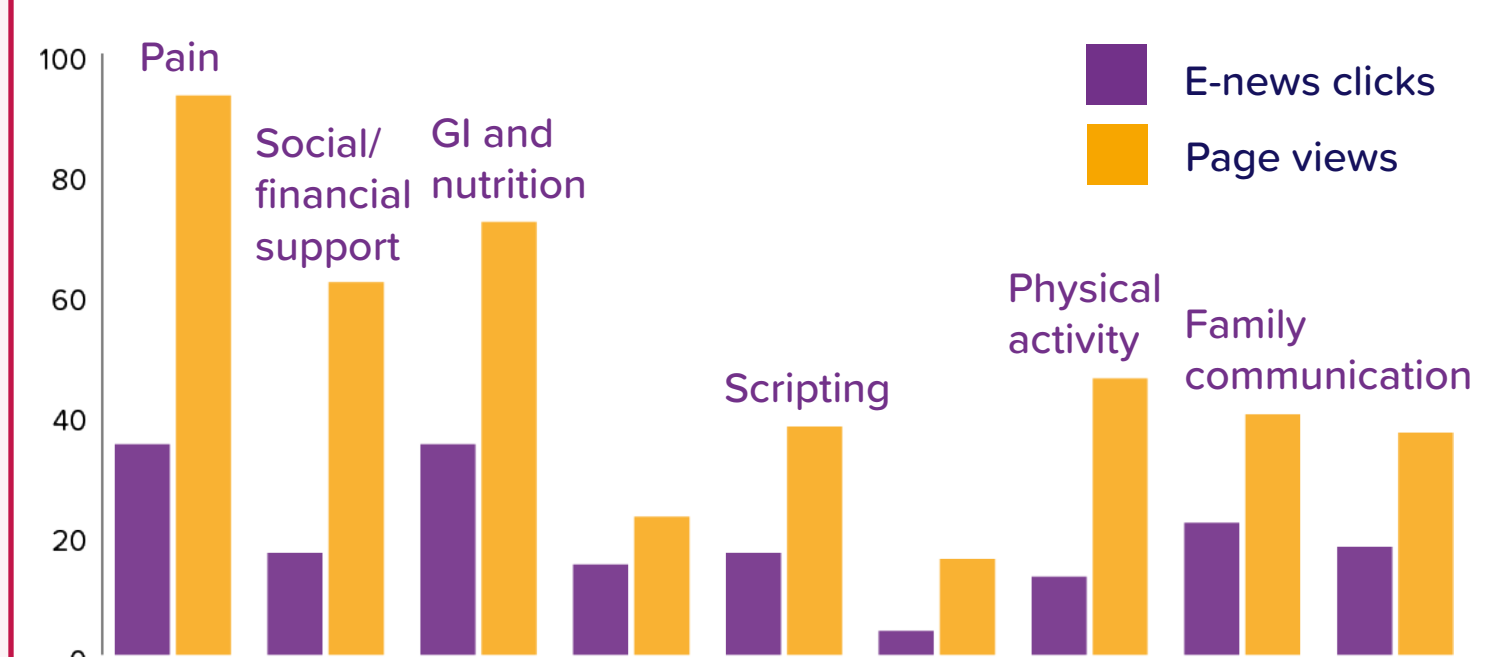
- 18 well-being blog topics generated 153 page views, driving ongoing social media engagement



- Membership among Fabry patients rose in 2025

25 new members and **20** non-members seeking Fabry specific advice

- Higher page views than clicks suggest deeper content exploration with Fabry focus topics



CONCLUSION

The *Fabry Education and Resilience Project* shows that community-led, peer-supported education effectively empowers individuals with Fabry disease. Delivering content via familiar networks promotes engagement, learning and resilience. Increased peer participation and membership suggest this model may be transferable to other rare disease communities, supporting advocacy, self-management and well-being.

