

Self-advocacy in the community: Accessing public spaces with Fabry disease

Living with Fabry disease can mean that day-to-day activities in public spaces sometimes require extra planning or specific accommodations.

Whether it's navigating busy airports, attending events, visiting leisure centres, or going shopping; advocating for your needs can make these experiences more accessible, less stressful and more enjoyable.

This guide offers practical ideas to help you speak up for yourself and make the most of the rights and adjustments you are entitled to under UK equality and disability law.

Understanding your rights

In the UK, the Equality Act 2010 (Disability Discrimination Act 1995 in Northern Ireland) protects people with long-term health conditions from discrimination and requires service providers to make reasonable adjustments so disabled people can access their services.

You do not need to be receiving disability benefits to be protected under the law.

Examples of reasonable adjustments in public spaces include:

- Providing step-free or lift access instead of stairs
- Offering priority or early entry to reduce time spent in queues
- Allowing entry with mobility aids or service animals
- Providing accessible toilets close to activity areas
- Permitting you to carry water, snacks, medication or cooling aids even if this is against the usual venue rules
- Reserving accessible or quiet seating areas

If Fabry disease symptoms such as fatigue, reduced mobility, pain, heat intolerance, dizziness or gastrointestinal issues affect you in public settings, you can request adjustments in advance or on the day.

Practical tools and schemes to help

Sunflower lanyard scheme

- Widely recognised in UK airports, supermarkets and transport hubs, this signals that you have a hidden disability and may need extra assistance
- Lanyards are free from many participating venues or can be ordered online (search *Hidden disabilities sunflower scheme*)
- You can also request matching ID cards to explain your needs in brief



Venue and event accessibility passes

- Many venues offer special passes for disabled visitors. These may allow:
 - Use of an accessible entrance
 - Reduced queueing time
 - A carer ticket at no extra cost
- These usually need to be booked in advance and require proof of disability (GP letter, PIP award, Blue Badge)
- You may wish to request a basic confirmation of diagnosis letter from your Specialist Centre that you can keep with you when out and about, this will provide a means of providing proof of disability, without disclosing more about your personal health/ benefit entitlement than you are comfortable with

Quiet spaces and accessible seating

- Ask venues whether they have a designated quiet room or rest area
- For events, contact the accessibility team to arrange seating close to exits, toilets or in shaded/cooler areas if heat affects you
- If you use a wheelchair or mobility aid, check that seating arrangements provide enough space, clear access routes, lift or ramp access and an unobstructed view
- Ask whether accessible seating is located near carers (if you require a support person)



Queue-jumping and fast-track access

- Particularly useful in airports, museums, festivals and busy tourist attractions
- Policies vary, so check their accessibility policy online or contact customer service
- Carry supporting information, such as a letter from your GP or a relevant assistance card, to make these conversations quicker and easier

Mobility and transport support

Regional differences may apply depending on public transport providers. Contact your local transport provider and ask to speak to their disability access team for specific advice.

The Sunflower Lanyard Scheme is particularly helpful with regards to public transport.

Bus and coach travel

Ask about priority seating and boarding arrangements

Rail travel

Use the passenger assist (or equivalent) service to arrange help boarding, finding seats, or carrying luggage.

Airport

Book *special assistance* when you buy your ticket or at least 48 hours before travel. Can include wheelchair provision, help through security, or transport between gates.



Tips for speaking up

- Plan ahead, check venue websites for accessibility pages or contact them directly
- Be clear and specific, e.g. *Because of Fabry disease, I can't stand for long periods and need a seat close to the exit.*
- Carry documentation, GP letters, disability ID, PIP award notice or Blue Badge can help smooth the process
- Use visible cues, a sunflower lanyard or assistance card can make it easier for staff to approach and offer help
- Stay polite but firm, most staff want to help but you may need to explain your needs more than once, especially in busy settings

If you encounter barriers

If a venue refuses to make reasonable adjustments or you face poor treatment:

Ask to speak to a duty manager or accessibility coordinator

Explain your request and why it's needed, referring to the Equality Act 2010

Make a written follow-up if needed, email is best so you have a record

Contact the Equality Advisory and Support Service for advice

Organisations such as Disability Rights UK can offer further guidance

Useful contact and resources

[Hidden Disabilities Sunflower Scheme](#)
[Equality Advisory Support Service \(EASS\)](#)
[Disability Rights UK](#)

[Passenger Assist \(National Rail\)](#)
[Access Card](#)



Support from the MPS Society

We can:

- Help you prepare accessibility requests to venues or service providers
- Offer information on your rights under UK equality law
- Share tips and examples from others in the Fabry community

This guide is for general information only and should not be taken as direct advice.

For guidance specific to your circumstances, please contact the MPS Society Support and Advocacy Team or use the links within this document to find further help.



MPS Society Alison Wilson, Support & Advocacy Officer, August 2025