

Fabry and work: Employment guidance for people living with Fabry across the UK

This guide provides general guidance for people living with Fabry disease who are making decisions about employment, work-life balance, medical leave or retirement.

The MPS Society does not provide financial, legal or benefits advice. This guide is for information only. Always seek personalised advice from qualified professionals.

Understanding your rights at work

If you are living with Fabry disease, you may be protected under UK disability and equality law. These include:

- The Equality Act 2010 (England, Wales, Scotland)
- The Disability Discrimination Act 1995 (Northern Ireland)

These laws protect individuals with long-term health conditions from discrimination and unfair treatment at work.



You are entitled to:

- Reasonable adjustments to help you stay in or return to work
- Protection from disability discrimination
- Equal access to employment opportunities and promotion
- Time off for medical appointments, for treatment or to manage your health

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

For more:

- [ACAS](#)
- [Equality Advisory Support Service](#)

Reasonable adjustments: Making work sustainable

Living with Fabry disease can involve managing fatigue, pain, gastrointestinal symptoms, impact of stroke, cardiac disease and a range of other issues that impact your ability to work.

Reasonable adjustments may include:

- Hybrid or home working
- Flexible hours or reduced hours
- Adapted workload or modified tasks
- Longer or more frequent breaks
- Equipment or environment changes
- Adjustments for heat or temperature sensitivity



What works for one person may not be appropriate for another. You may be asked to provide medical evidence from your GP or consultant.

The MPS Society can support you to communicate your needs effectively to ensure that any adjustments required are based on the day-to-day impact of your condition.

Medical leave, sick leave and carer's leave

If you are managing symptoms or treatment

You may need to take short- or long-term medical leave.

Most people are entitled to:

- Statutory Sick Pay (SSP)
- Occupational sick pay (if part of your employer's scheme)
- Fit notes from your GP for time off or phased return plans

If you are a carer

You may be eligible for:

- Carer's leave or time off for dependants
- Flexible working requests to support your caring role

Speak to your HR department, occupational health or union (if applicable) for support. Seek the MPS Society's support in communicating your needs in the context of your Fabry disease.



Changing or leaving work

Changing jobs, reducing hours or stepping away from work are difficult decisions to navigate. Decisions should always be made following collaboration with your employer and the input of any support services that you require.

Options include:



If your symptoms make continuing in your current role difficult, it may be appropriate to explore medical retirement (depending on your pension scheme and medical evidence).

Support from Occupational Health can guide your employer in these discussions.

You may also wish to seek independent financial or career support.



Returning to work

If you've taken time away from work, you might consider returning in a capacity that suits your current health. You have the right to:

Learn more:
gov.uk

- A phased return to build up hours gradually
- Review or renew your reasonable adjustments (the MPS Society can support in ensuring all aspects of your Fabry-related symptoms have been taken into consideration)
- Apply for Access to Work support (transport, equipment or job coaching)

Jobcentre Plus

If you're not currently working, it may be helpful to remain connected with your local Jobcentre Plus (or similar services in devolved nations). The MPS Society can support in the provision of supplementary information in relation to health/disability components of benefits.

Why register?

to

protect your National Insurance (NI) record (important for your State Pension)
access work-related support or future benefit eligibility
stay informed of retraining or part-time opportunities when you're ready

[Register here](#)

Planning ahead: Guidance for those aged 60 and over

If you are over 60 and thinking about the next stage of your working life, here are some general points to consider:

State pension

[Check your forecast here](#)

- Most people can access their State Pension at age 66 or 67
- You usually need 35 qualifying years of NI contributions to receive the full amount



Private or workplace pension access

- Private pensions are usually accessible from age 55
- Only 25% is tax-free
- Early withdrawals can affect long-term income and benefits

[Use Pension Wise for free guidance](#)



Health-related benefits (general overview)

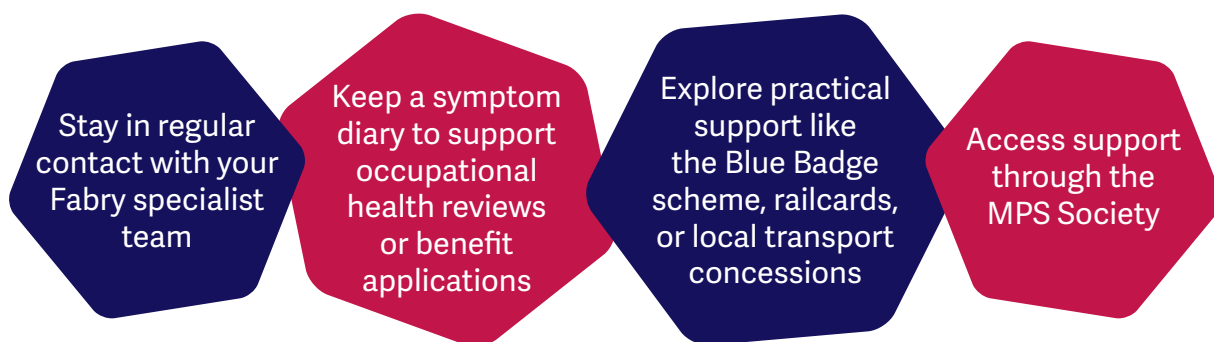
Living with Fabry disease may entitle you to certain benefits, depending on your circumstances.

You may be eligible for:



Some tips

There are sources of support out there to help you navigate working life and employment related decisions. Keeping track of your symptoms and accessing support that eases the burden will go a long way to supporting your goals.



Where to find help

Topic	Organisation / Contact
Workplace rights & adjustments	ACAS acas.org.uk
Equality law	Equality Advisory Support Services equalityadvisoryservice.com
Jobcentre / NI record	gov.uk/contact-jobcentre-plus
State pension / pensions	Pension Wise moneyhelper.org.uk
Benefit checks	Citizens Advice citizensadvice.org.uk
Financial advice	Find a regulated adviser unbiased.co.uk
Emotional & peer support	MPS Society mpsociety.org.uk

This information is intended to support those living with Fabry disease who are making employment-related decisions. It is not a substitute for personal, legal or financial advice. Always seek professional guidance before making decisions related to work, pensions, benefits or health. The MPS Society does not offer financial or benefits advice.

