



Are you an adult  
living with mito?

# Fighting mito, finding hope.

## We're here for you

Being diagnosed with mitochondrial disease can be frightening and upsetting, but also very lonely. Because mito is so rare, it's hard to find people in the same situation, and that's why The Lily Foundation exists. Here are some of the ways we provide ongoing support.

## Lily Young Adult Weekend

Young people living with mito come together in the Lake District to socialise and enjoy outdoor activities in a safe, fully accessible environment.

## Patient Information Days

Come and meet us at these informal yet informative occasions hosted by the specialist mitochondrial clinics in Newcastle, Oxford and London.

## Private Facebook group

Our private Facebook group for adults is somewhere you can connect with others who understand your situation, share experiences and make friends.

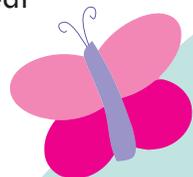
## Virtual coffee mornings

Patients from all over the country come together over Zoom for these informal weekly meetings, a great way to feel less isolated and better informed about mito.

## The latest news, support and registries

We're committed to funding research to learn more about mito and improve the lives of patients. Sign up to our newsletter via our website and we'll keep you up to date with the latest research and clinical trials, plus news about Lily events, campaigns, personal stories and more.

If you'd like to create an account with us and become part of our registry, please scan the QR code overleaf to start your Lily journey.



## Access to medical registries

Registries like our UK Mito Patient Registry are a great way for patients to share details of their condition to improve care, guide research and help develop new treatments.

## Lily Wish Fund

A grant scheme designed for patients to access something to improve their lives, such as specialist equipment, a home or garden adaptation or even a short break. Visit [thelilyfoundation.org.uk/lily-wish-fund](http://thelilyfoundation.org.uk/lily-wish-fund) to apply.

## Benefits advice

We'll take the stress out of understanding what benefits you might be entitled to and applying for those benefits.

## Just need someone to talk to?

Everyone's mito journey is different, and every person living with the condition faces their own challenges. But help *is* available – whether it's a specific question, a reassuring chat or some emotional support, we're here to listen.



I wanted to meet other people like myself who were going through a similar thing to what I was and who I felt I could relate to because it's such a lonely journey. Much of my life I've spent lonely and isolated and withdrawn from the world and The Lily Foundation have made me feel not withdrawn anymore... I'm just forever grateful to them.

-Amy



# You're not alone

## Join our Adult Facebook Support Group:

Search Facebook for “The Lily Adult Mito Support Group” and request to join.

## Find information online:

Visit [thelilyfoundation.org.uk](http://thelilyfoundation.org.uk) and [mitochondrialdisease.nhs.uk](http://mitochondrialdisease.nhs.uk).

## Join our database:

Scan the QR code to create an account on our website and begin your Lily journey.



## Talk confidentially:

Call Liz on 07947 257247 or email [liz@thelilyfoundation.org.uk](mailto:liz@thelilyfoundation.org.uk).

[thelilyfoundation.org.uk](http://thelilyfoundation.org.uk)

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