METABOLIC SUPPORT UK
Your rare condition. Our common fight.

beacon for rare diseases

LIVING WELL

THE LIVING WELL MOVEMENT

WHAT DOES IT MEAN TO "LIVE WELL" WITH A RARE DISEASE?

Should this be determined only by access to a specialist medical team, or by having one of the 5% of conditions where a life-changing treatment is in development or available?

Treatment access is vital but are the vast majority for whom this is not a current reality being empowered to live well today?

Our Living Well movement is designed to place greater focus on how we embed living well in our society, laws and policy, supporting the rare disease community to access the services they need to **“live well today”.**

GOALS

“Living Well” defined by the rare disease community and for these definitions to be reflected in rare disease policy.

Rare disease community to understand and advocate for their rights under the Equality Act 2010.

THIS WILL BE ACHIEVED THROUGH THREE DISTINCT PHASES.

Delivery of a Living Well Symposium in March 2025

Deliver a series of trainings through our delivery partners Beacon, focused on disability rights and self-advocacy.

Develop and deliver a campaign highlighting gaps within rare diseases policy and disability legislation that need to be addressed to support the rare diseases community to live well today.

LIVING WELL SYMPOSIUM: OBJECTIVES

Attendees will understand what it means to **“Live Well”** with a rare disease.

Attendees leaving the event will understand the importance of the Equality Act 2010 and how it can help people to **“Live Well”** with a rare disease.

Attendees will leave the event believing that with the right support and choice people living with a rare disease can “live well today”.

OBJECTIVES OF THE LIVING WELL TRAINING

Attendees will have access to bespoke training webinars covering the social model of disability, disability identity, activism and advocacy and the Equality Act.

Training will educate and positively influence patient advocates and Patient Advocacy Group leaders in understanding and being able to actively apply their rights under the current policy landscape and to better advocate for change.

People living with a rare disease will have a greater understanding of the legal and policy frameworks in which their health and social services are delivered and their individual rights.

THE LIVING WELL CAMPAIGN

This campaign will be informed by the **“Living Well”** symposium, enabling people living with rare disease a space to share what **“Living Well”** looks like.

Using this insight, we will set out the objectives of this campaign and will set out a roadmap to achieve them to ensure people living with rare diseases can **“Live Well”** today.

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