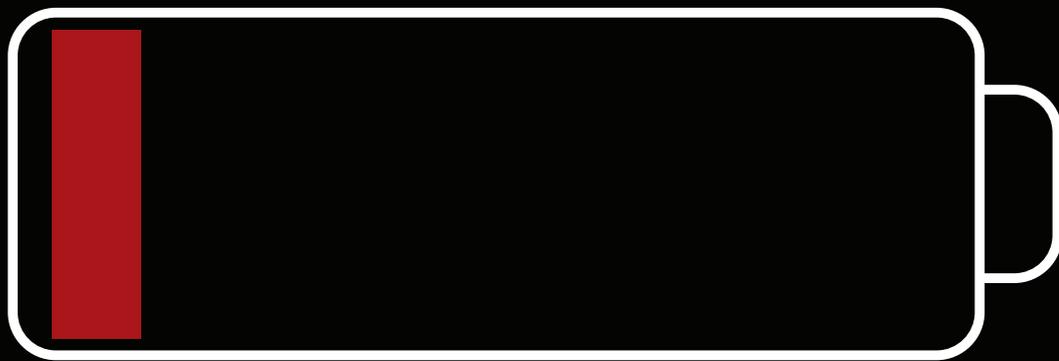


# Energy Impairment and Disability Inclusion

EASY READ VERSION

by Catherine Hale, Stef Benstead,  
Jenny Lyus, Evan Odell and Anna Ruddock





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Published by the **Centre for Welfare Reform**





**“Easy Read” information is designed for people with Learning Disabilities.**

It does **not** mean that everyone will be able to understand the information.

Please give people the **support** they need to understand this report.



## **Publishing Information**

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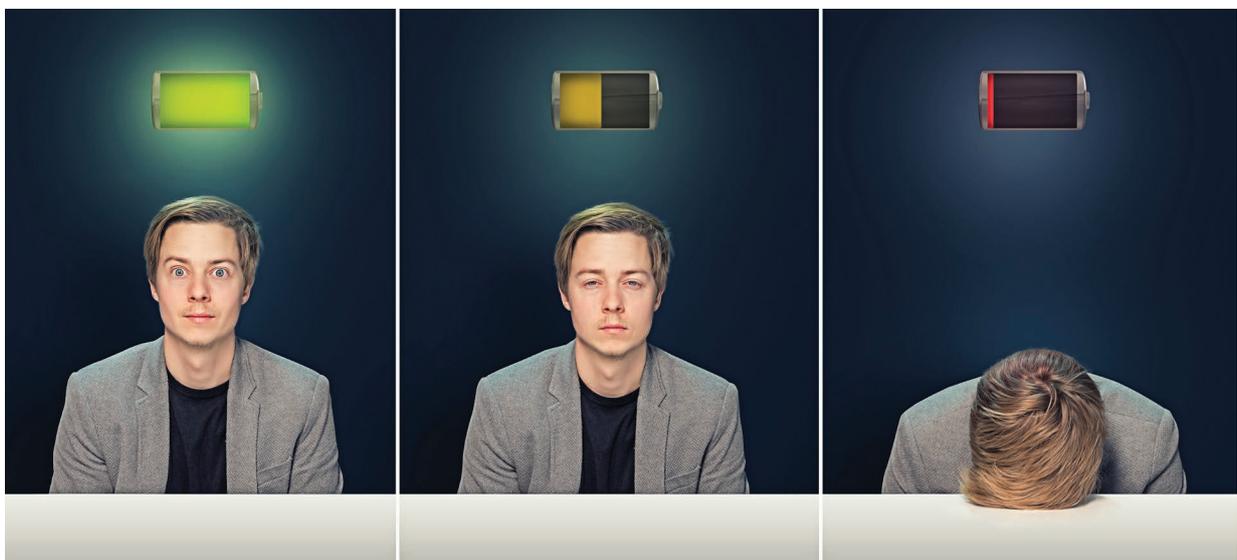
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# 1. Difficult words

There are important words in this report that might be new to you.



## Energy Impairment

The experience of having very low energy levels. This can be for a variety of reasons.

## Chronic

Lasts a long time, or permanent.



## Fatigue

Exhaustion. Extreme tiredness. Not the same as the tiredness after a busy day that most people would experience.



## Rights

People have rights in law.

For example, the right to family life, to not be treated unfairly, or the right to welfare benefits.

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## 2. Introduction

**We asked people who live with chronic illness to tell us about their lives.**

The people who did the research also have chronic illness. We want people with chronic illness to lead the lives they want to, and to be respected.

More than 2,000 people took part in the project, using focus groups and surveys:



- **Focus groups:** Small discussions, using the internet, for eight weeks.



- **Surveys:** People answered a list of questions.

## 3. Chronic Illness



“**Chronic illness**” is being unwell for a long time.

Most people with chronic illness have one or more **medical conditions**.

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The **most common** conditions include:

- ME, or chronic fatigue syndrome
- Fibromyalgia
- Hypermobility syndrome
- Lupus
- Respiratory diseases
- Rheumatoid arthritis

Lots of people with chronic illness experience:

- **Very low energy**, affecting day to day life
- **Pain and fatigue**
- Feeling that people **do not believe them**.



## 4. Social Model of Disability



“**The social model**” is a way of thinking about disability. It says that the difficulties that disabled people have are because of **society**, not because of the **disability**.



**For example:** A person in a **wheelchair** cannot get into a building because there is a **step**. The social model says that the problem is the **building**, not the **person**.



The social model has helped many people with disabilities to **get their rights** and to **make services more accessible**.



**We asked people what they think** of the social model. We wanted to find out whether the social model could help people with chronic illness.



## People agreed with some of the social model:

- **Harmful messages** stop us feeling accepted and getting help.
- The messages come from **other people**, not us.
- This affects **other people with chronic illness** too.
- **If we work together** we can say "no" to the harmful messages.

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## People disagreed with some of the model.



- Disability is definitely **about their body** and they wished it could be fixed.
- They want to be healthier.
- **Medicine and medical treatment** can help.



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## 5. What people told us



The worst things about my illness are **pain** and **fatigue**.

Fatigue is **not the same** as feeling tired.

Fatigue has **changed my whole life**.



I can't **walk far**, or I can't **walk at all**.

It affects my brain and **stops me thinking** and speaking. It makes my **whole body shut down** and stop working.



I'm **stuck at home**. My **energy runs out** too quickly if I go out and do anything.

## What other people think:



People **can't see** that I need support.

People think **I should just try harder.**

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People think **I'm lazy.**

People think **I'm pretending.**



## How this affects me:

These things **hurt me** and make me **feel bad** about myself.

They make me feel like **I don't deserve help** and **shouldn't ask for it**.

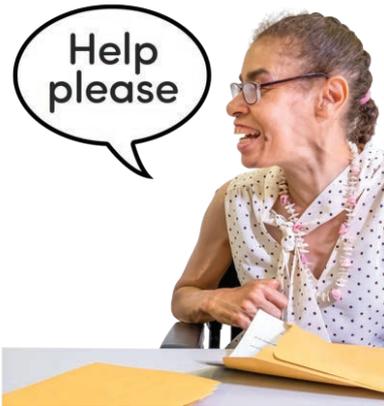
People not understanding **makes me feel lonely**.

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Being **stuck at home** instead of out working or meeting my friends makes me lonely.

It stops me doing things. I **worry** about **people judging me** and telling the government that I'm **not really disabled** and that I am a cheat.



I try to **be like everyone else** but this makes my illness **worse**.

It's **too difficult to ask for help** because often people don't believe that I'm disabled.



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When I **find the strength to challenge** these harmful messages, I feel better. When I find the **confidence** to say I need **help and support**, I can have a **better life**.



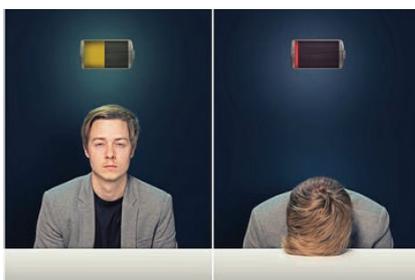
## 6. Ideas for the future

We could have **better lives** if people in power **listened to us**. Especially:

- **Doctors** and the **health system**
- The **benefit system**



Everyone should use the words “**energy impairment**” to describe our experience, and they need to understand what it means.



The **government needs to recognise energy impairment**, so we can get better support to live our lives. People’s experiences should be heard and understood when designing support.





Do more **medical research** to find out about the causes of our symptoms.

**Start a user-led organisation** (which could be virtual / online) to:



- Make sure our **voices are heard**
- Improve **services and knowledge**
- Make sure people's **rights are respected**
- Provide **information and training** about energy impairment

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"I feel **isolated** and **alone**, with **no support**."



"Everyone knows what it's like to be **tired**, so **they think they understand** the fatigue levels associated with chronic illness when **they really don't**."



"I feel like every day I am **battling** to **prove myself**: that I am really this sick, that I am working hard, how **exhausted** I feel, how **difficult** things are for me, in order to avoid their **judgements**."

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"It has taken me a **long** time to realise what help I can get... This was down to me not thinking of myself as disabled, so I just thought I'd **struggle through** it or **avoid** going to things. Using the term 'disabled' ...means that...

**I can have my life back... "**



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