

Living with a Chronic Illness

Understanding, coping and supporting your wellbeing

Living with a long-term health condition can affect far more than the symptoms written in a medical record. It can influence energy, independence, identity, work, relationships, finances, confidence and plans for the future. Symptoms may be visible or invisible, predictable or fluctuating. Some days may feel manageable and others may require almost all of your available capacity.

Chronic illness is not one experience

The term chronic illness covers many long-term conditions. The impact differs between people and may also change over time. Pain, fatigue, breathlessness, digestive symptoms, cognitive difficulties, dizziness, mobility changes, sensory sensitivity, sleep disruption and treatment side effects can all influence daily life. Emotional responses can include grief, frustration, anxiety, anger, uncertainty, isolation or low mood.

There is no requirement to be positive all the time. Adapting to chronic illness can involve grieving what has changed while still finding meaningful ways to live within the life you have now.

Common areas of impact

Area	What you may notice	Helpful direction
Energy	Fatigue, crashes, reduced stamina, needing longer recovery.	Pace activity, plan rest before exhaustion, identify high-cost tasks.
Pain / symptoms	Flare-ups, disrupted sleep, difficulty concentrating.	Use your clinical plan, adapt tasks, track useful patterns without constant monitoring.
Mental wellbeing	Worry, sadness, irritability, grief, uncertainty.	Validate the emotional impact; seek psychological support when needed.
Social life	Cancelling plans, feeling misunderstood, isolation.	Use flexible plans, explain needs to trusted people, maintain low-demand connection.
Work / study	Reduced hours, concentration difficulties, access barriers.	Explore reasonable adjustments, occupational health and relevant benefits/support.
Identity	Feeling unlike your previous self or measuring yourself against old capacity.	Separate worth from productivity; notice what remains important and meaningful.

The aim is not to do everything you used to do in exactly the same way. Adaptation can mean finding different routes to the things that matter.

Managing Energy, Symptoms & Daily Demands

Pacing is often misunderstood as simply 'doing less'. A more useful idea is matching activity to available capacity and reducing the repeated boom-and-bust cycle in which a better day leads to doing everything, followed by a significant crash.

Think in energy costs

Activities have different physical, cognitive, emotional and sensory costs. A phone call may use little physical energy but a great deal of mental energy. A shower may involve standing, temperature change, sensory input and several steps. Socialising may be enjoyable while still requiring recovery afterwards.

Pacing questions

Before	During	After
What genuinely needs doing today?	Am I pushing through warning signs?	What recovery time will this need?
Can this be shortened, seated, delegated or divided?	Can I pause before I am completely depleted?	Did this cost more or less energy than expected?
What is my current capacity - not my ideal capacity?	Is pain, dizziness, breathlessness or cognition changing?	What would I adjust next time?

Practical adaptations

Reduce steps: keep frequently used items accessible, sit for tasks where possible, use aids that reduce effort and prepare essentials in advance.

Prioritise: decide what is necessary, what matters to you and what can wait.

Plan recovery: rest is more effective when it is part of the plan rather than something you are only 'allowed' after collapse.

Use support: practical help, mobility aids, delivery services, workplace adjustments and accessible technology can preserve energy for other parts of life.

Build flexibility: have a full-capacity plan and a low-capacity version.

A note about exercise and activity

There is no single activity prescription that is appropriate for every chronic condition. For some conditions, gradual physical activity is helpful; for others, particularly where post-exertional symptom exacerbation is present, pushing activity beyond individual limits can worsen symptoms. Follow condition-specific clinical advice rather than generic 'push through it' messages.

My energy budget

Today's essential tasks	Could wait / delegate	Something restorative

Protecting Mental & Emotional Wellbeing

Chronic illness can involve repeated losses: spontaneity, independence, certainty, employment, roles, hobbies or a previous picture of the future. These losses can create genuine grief. You may also experience relief when a condition is finally recognised, anger about delays in care, fear about symptoms, or guilt about needing help.

When your body feels unpredictable

Uncertainty can keep the nervous system scanning for what might happen next. It can help to distinguish between **useful monitoring** - noticing changes that guide treatment or safety - and **constant checking**, which may increase anxiety without giving you more control. Agreeing with clinicians what changes genuinely require action can reduce some of this uncertainty.

Supporting yourself emotionally

- Give difficult feelings language instead of immediately trying to remove them.
- Adjust expectations to current capacity rather than comparing every day with your best day.
- Keep some connection to identity beyond illness - interests, values, relationships, creativity, humour, learning or contribution.
- Use boundaries around advice from others, particularly simplistic cures or pressure to 'stay positive'.
- Consider counselling or psychological support if the emotional burden is persistent or difficult to carry alone.
- If treatment, pain or fatigue affects cognition, use written reminders and simplify decisions where possible.

Relationships and communication

People around you may care deeply and still misunderstand fluctuating illness. Specific communication is often easier than hoping someone will guess: "I want to come, but I may need to leave early"; "I need practical help rather than advice"; "I can talk for ten minutes today"; or "My symptoms have increased, so I need to change the plan."

Work, money and practical support

Long-term illness can affect income and employment as well as health. In the UK, support may include reasonable adjustments under the Equality Act 2010 where the legal definition of disability is met, Access to Work, occupational health input, and relevant benefits depending on circumstances. Citizens Advice and GOV.UK provide current information on benefits and employment support.

What is taking most of my capacity?

Physical	Emotional	Cognitive	Social / practical
_____	_____	_____	_____
_____	_____	_____	_____
One change that could reduce demand:			

Your Chronic Illness Wellbeing Plan

There is no right way to adapt to chronic illness. Use this page to identify what helps you, what drains you and what you want the people around you to understand.

My early signs that I am running low

Body	_____
Thinking / concentration	_____
Mood / emotions	_____
Sensory tolerance	_____
What others may notice	_____

My difficult-day plan

What can be cancelled or reduced? _____

Who can I contact? _____

Food/drink/medication or practical essentials I need accessible: _____

What makes the environment easier? _____

What do I need to remind myself? _____

When to seek additional help

Contact your usual healthcare team if symptoms are changing, treatment is difficult to manage, side effects are causing problems, or you are unsure what is expected for your condition. Seek urgent or emergency medical help for symptoms your clinical team has identified as red flags, or for new severe symptoms such as significant breathing difficulty, chest pain, loss of consciousness, stroke-like symptoms or another medical emergency. Mental-health support is also important: if distress becomes overwhelming or you feel unable to keep yourself safe, seek urgent support.

A message from Maggie

Living with chronic illness can ask you to make adjustments you never expected to make. It can be frustrating to have your plans determined by energy, symptoms or what your body can manage that day. I want this resource to remind you that adapting is not giving up. Rest is not a reward you have to earn, using support is not failure, and changing the way you do something does not make the outcome less meaningful. Be curious about what your body needs, protect the capacity you have, and build a life that works with you rather than constantly asking you to fight yourself.

Books & useful resources

Toni Bernhard: *How to Be Sick* - reflections and practical approaches to living with chronic illness.

Julie Rehmeyer: *Through the Shadowlands* - a personal account of navigating complex chronic illness.

NHS: condition-specific information and guidance on living with long-term conditions.

GOV.UK: Access to Work, reasonable-adjustment and benefits information.

Citizens Advice: benefits, work, money and practical rights guidance.

Mind: mental-health information and support when physical illness affects emotional wellbeing.

This guide provides general supportive information and is not a diagnosis or a substitute for condition-specific medical advice. Management should be tailored to the individual's diagnosis, symptoms and clinical guidance.