PHYSICAL HEALTH & HEALTHY LIVING FACTSHEET

# Living With Long-Term Health Conditions

Practical support for health, daily life and what matters to you

**The short version**

Living with a long-term condition involves more than symptoms and appointments. It can affect energy, identity, family life, work, money, mobility, confidence and plans for the future. Good support combines appropriate clinical care with information, practical adjustments, self-management skills and attention to what matters to the individual. Self-management should never mean being left to cope alone.

## Long-term conditions are not all alike

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| **Stable** | Symptoms and treatment may remain relatively predictable for periods, although monitoring and preventive care can still matter. |
| **Fluctuating** | Ability and symptoms may vary by day, hour or season. A person may need flexible plans rather than one fixed level of activity. |
| **Progressive** | Needs may change over time, requiring review, equipment, treatment changes, future planning or additional care. |
| **Episodic** | Flares, attacks, relapses or acute episodes may occur between periods of relative stability and need a clear response plan. |
| **Invisible** | Pain, fatigue, breathlessness, cognitive changes and other limitations may not be obvious to others but can still be substantial. |
| **Multiple conditions** | Treatments and advice for different conditions may interact or conflict. Priorities should be coordinated around the whole person. |

# Supported self-management

Supported self-management means building the knowledge, skills and confidence to participate in health and care decisions, with suitable support. NHS England describes people as active and equal partners and recognises them as experts in their own lives.

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| **Understand** | Know the condition, likely symptoms, treatments, monitoring, warning signs and where to find reliable information in a form you can use. |
| **Participate** | Ask questions, express priorities, discuss benefits and risks and take part in shared decisions rather than being treated as a passive recipient. |
| **Plan** | Agree manageable actions for everyday care, symptom changes, appointments, medicines, flares and emergencies. |
| **Adapt** | Adjust tasks, routines, equipment and goals to current capacity instead of measuring success against life before illness or somebody else's body. |
| **Connect** | Use clinical, social-care, peer, family, community and workplace support where it adds value and is wanted. |
| **Review** | Notice what is working, what is becoming harder and what needs reassessment. A plan should change when the person or condition changes. |

**Self-management is not self-treatment**

Do not diagnose a new symptom, alter prescribed treatment or rely on lifestyle changes in place of necessary medical care. Self-management works alongside appropriate professional assessment and treatment.

# Choose goals that matter in real life

- attending a family occasion
- returning to a hobby or community role
- preparing for an appointment or treatment
- managing personal care with less strain
- reducing the impact of one difficult symptom
- building confidence using equipment or asking for help

## Understanding symptoms and changes

Symptoms may come from the condition, another condition, infection, treatment, medicines, sleep disruption, nutrition, stress or the environment. A new symptom should not automatically be attributed to an existing diagnosis.

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| **What changed?** | Record the symptom, when it started, location, quality, severity, frequency and whether it is new, worsening or different from usual. |
| **What surrounds it?** | Note activity, food, fluids, sleep, infection, stress, menstrual or hormonal factors, medicines, treatment and environmental conditions. |
| **What is the impact?** | Describe effects on breathing, mobility, eating, sleep, concentration, work, self-care and ability to do normal activities. |
| **What helped?** | Record treatments and practical measures tried, when they were used and whether benefit or side effects followed. |
| **What is the pattern?** | Look for repeated triggers or trends without assuming that timing proves cause. Share useful patterns with the care team. |

## Keep tracking proportionate

Tracking should answer a question or support a decision. It does not need to capture every sensation forever. Stop or simplify if monitoring creates anxiety, obsession or an unmanageable burden.

### Know the escalation plan

Ask the relevant care team which changes can be managed at home, which need a routine appointment, which require same-day advice and which are emergencies. Condition-specific instructions should take priority over general information.

## General emergency warning signs

- severe breathing difficulty or blue, grey or very pale skin or lips
- new chest pressure or severe chest pain
- signs of stroke, sudden weakness, facial droop or speech difficulty
- collapse, unresponsiveness, severe confusion or a prolonged seizure
- serious bleeding, a severe allergic reaction or major injury
- an immediate risk of harm to self or somebody else

Call 999 for a life-threatening emergency. Use NHS 111 when urgent help is needed but it is not a 999 emergency.

## Medicines, treatment and monitoring

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| **Keep one current list** | Include prescribed, pharmacy, herbal and supplement products, doses, timing, allergies and who prescribed them. Carry it to appointments. |
| **Understand purpose** | Know why each medicine is used, what benefit to expect, important side effects, monitoring and what to do after a missed dose. |
| **Use safely** | Follow storage, timing and administration instructions. Ask for help with packaging, swallowing, reminders, inhalers, injections or complicated schedules. |
| **Attend monitoring** | Blood tests, blood pressure, scans or other checks may be needed to assess effectiveness and safety. Know who reviews the results. |
| **Review regularly** | A structured medication review considers benefits, risks, interactions, alternatives, practical burden and what matters to the person. |
| **Report problems** | Discuss suspected side effects, difficulty taking treatment, affordability, confusion or lack of benefit. Do not quietly stop essential treatment. |

**Multiple medicines need coordination**

When several medicines are used, potential harm, interactions or an unmanageable routine can outweigh benefit. Ask the GP practice or pharmacist about a medication review, particularly after hospital care, a new diagnosis or a significant health change.

## Preparing for treatment changes

- ask what is changing, why, when and how success will be measured
- clarify which side effects are expected and which need urgent advice
- ask whether existing medicines, supplements, diet or activities are affected
- know who to contact outside normal clinic hours
- request written or accessible information and a copy of the agreed plan

## Appointments and joined-up care

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| **Before** | Choose the main questions, update the medicine list, bring relevant records and decide whether another person, interpreter or communication support would help. |
| **During** | Describe changes and functional impact, ask for plain language, check options and write down decisions. It is reasonable to say when a plan is not manageable. |
| **After** | Check referrals, prescriptions, tests, follow-up dates and who owns each action. Contact the service if the written plan does not match the discussion. |
| **Between services** | Ask who coordinates care when several teams are involved. Share key letters and plans where systems do not communicate reliably. |
| **If dismissed** | Restate the change and its impact, ask what serious causes have been considered, request safety-netting and seek another appropriate review if concerns remain. |

## A useful personalised care plan may include

- what matters to you and agreed goals
- medicines, treatment and monitoring
- named contacts and care coordinator
- support for daily life, work and caring
- usual symptoms and your current baseline
- flare, urgent and emergency instructions
- access, communication and reasonable adjustments
- when and how the plan will be reviewed

**You should not have to retell everything every time**

NHS personalised care planning aims to create a coordinated, shareable plan built around the person's whole life. In practice, keeping a concise health summary can still help when records are fragmented.

## Daily life, pacing and adaptations

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| **Prioritise** | Identify what must happen, what matters most and what can wait, be simplified, delegated or stopped. |
| **Plan flexibly** | Use lower-capacity, usual and better-day plans. Protect recovery and avoid committing every good hour in advance. |
| **Pace** | Break tasks into stages, change position or type of demand and rest before complete exhaustion where possible. |
| **Adapt** | Use seating, mobility aids, grab rails, accessible storage, delivery, voice controls, reminder systems, adapted utensils or occupational-therapy advice. |
| **Ask for help** | Support may come from family, friends, carers, social care, community groups, charities, peer networks or paid services. Needing help is not a personal failure. |

## Flares and difficult days

- use the agreed condition-specific action plan
- keep medicines, food, fluids and key contacts accessible
- arrange help with children, pets, transport or household tasks
- review likely triggers without blaming yourself
- reduce non-essential demand without stopping necessary care
- monitor the features your care team has identified
- seek advice if the episode is new, severe, prolonged or different
- update the plan after recovery if it did not work

A flare plan should reduce decision-making when capacity is low. It can be kept on paper, on a phone and with a trusted person.

## Rights, support and the wider circumstances

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| **Work** | Disabled workers and workers with health conditions may be entitled to reasonable adjustments such as altered hours, duties, equipment, location, breaks or a phased return. |
| **Access to Work** | This may help with some additional workplace support or equipment costs. Eligibility and provision depend on current scheme rules and individual circumstances. |
| **Social care** | A needs assessment may lead to a care and support plan covering equipment, personal care, independence and practical support. Carers can request a carer's assessment. |
| **Social prescribing** | A link worker may connect people with community, practical, social and emotional support, particularly when non-medical circumstances affect health. |
| **Benefits and advice** | Independent welfare-rights or disability advice may help with benefits, housing, transport, grants and challenging decisions. |
| **Peer support** | Condition-specific communities can reduce isolation and share practical knowledge. Check medical claims and remember another person's treatment may not suit you. |

## Health is shaped by circumstances

Income, housing, transport, discrimination, caring, loneliness, accessible services and supportive relationships can make health management easier or harder. Difficulty following a plan does not automatically mean poor motivation; the plan or the surrounding conditions may need to change.

# You are more than a diagnosis

Good care protects health while making room for identity, relationships, pleasure, contribution and hope. The aim is not to perform illness perfectly—it is to build the best possible life with the support and choices available.

# Your long-term-condition checklist

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| **My baseline** | Usual symptoms, function, treatment and what a typical day looks like, including normal variation. |
| **My plan** | Everyday care, meaningful goals, monitoring, flare actions, urgent advice and emergency instructions. |
| **My medicines** | Current list, purpose, allergies, monitoring, side effects, practical difficulties and review date. |
| **My support** | Clinical contacts, care coordinator, family or carers, community support, workplace adjustments and social care. |
| **My access needs** | Mobility, fatigue, pain, sensory, cognitive, communication, transport, timing and information-format needs. |
| **My review** | What is helping, what is not manageable, what has changed and what decisions or referrals are needed next. |

**Important information**

This factsheet gives general education and cannot provide condition-specific diagnosis, treatment or emergency instructions. Follow advice from your own care team and seek assessment for new, severe, worsening or unusual symptoms. Call 999 for a life-threatening emergency and use NHS 111 for urgent advice when appropriate.

# Evidence and review

Prepared in line with Health Matters UK's Evidence & Editorial Standards. Information was checked against current NHS England, NHS, GOV.UK and Health and Safety Executive resources. External guidance remains the responsibility of the issuing organisation.


• NHS England. Personalised care and support planning. england.nhs.uk/personalisedcare/pcsp/

• NHS England. Supported self-management. england.nhs.uk/personalisedcare/supported-self-management/

• NHS England. Structured medication reviews and medicines optimisation. england.nhs.uk/primary-care/pharmacy/smr/

• NHS. Care and support plans. nhs.uk/social-care-and-support/help-from-social-services-and-charities/care-and-support-plans/

• NHS England. Social prescribing. england.nhs.uk/personalisedcare/social-prescribing/

• GOV.UK. Reasonable adjustments for workers with disabilities or health conditions. gov.uk/reasonable-adjustments-for-disabled-workers/

• HSE. Making reasonable adjustments. hse.gov.uk/disability/employers-duties/adjustments.htm



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