HEALTH CONDITIONS AND CARE AT HOME

Parkinson's care at home: a guide for families

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IN BRIEF

Good Parkinson's care at home starts with medicines taken exactly on time, because late or missed doses can quickly make symptoms worse. Around that, a person can stay safer and more independent with help for movement and freezing, falls prevention, early swallowing checks, better nights and a team that includes a Parkinson's nurse, physiotherapist and speech and language therapist.



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How Parkinson's affects daily life

Parkinson's is a progressive condition of the brain. The best-known symptoms are tremor, slowness of movement and stiff muscles, but many people are more troubled by symptoms that others cannot see: tiredness, low mood or anxiety, poor sleep, constipation, pain, problems with balance and, for some, memory difficulties.

Symptoms often change through the day. Many people have "on" times, when medicines are working well, and "off" times, when movement becomes slow or stuck. The same person may walk to the kitchen easily at ten o'clock and struggle to stand up at two. Good care follows these changes rather than assuming a fixed level of need.

There is no cure yet, but treatment and the right support can keep people active and independent for many years.

Why Parkinson's medicines must be taken on time

Parkinson's medicines replace or mimic dopamine, the chemical messenger the brain is short of. Each dose works for a limited time, so when a dose is late, symptoms can return quickly: stiffness, freezing, tremor, difficulty swallowing and a much higher risk of falling. Parkinson's UK's long-running "Get It On Time" campaign exists because this happens so often in hospitals and care settings.

At home, the aim is simple: every dose at the prescribed time, every day. Practical ways to achieve this:

- Write out a medicines chart with the exact times, not just “three times a day”.
- Use phone, watch or pill-timer alarms, and keep the next doses where they are easy to reach.
- Ask the Parkinson’s nurse or specialist how doses should be timed around meals, as protein can affect how some medicines work for some people.
- Order repeat prescriptions early and never let supplies run low.
- If swallowing tablets becomes difficult, ask the specialist about alternatives, such as patches or liquids.
- Never stop or reduce Parkinson’s medicines suddenly without medical advice.

Family and carers should also watch for side effects the person may not notice in themselves, such as hallucinations, confusion or impulsive behaviour, and report them early.

Movement, slowness and freezing

Freezing is when the feet feel glued to the floor, often when starting to walk, turning, going through doorways or in busy places. It usually lasts seconds but can cause falls. Techniques suggested by Parkinson’s UK include:

- **Stop, think, plan, then go:** pause, take a breath and decide on the next step.
- **Weight shift:** gently rock from one foot to the other, then step.
- **Rhythm:** count out loud, hum a tune or march on the spot.
- **Visual cues:** strips of contrasting tape across doorways or turning spots give the feet a target.
- **Turn in a wide arc** rather than pivoting on the spot.

Carers should avoid pulling or rushing someone who is frozen; a calm word and a cue work better. A physiotherapist can teach techniques tailored to the person and advise on walking aids, as some aids can make freezing worse. An occupational therapist can suggest equipment for getting out of bed, chairs and the bath.

Preventing falls



Falls are a real risk in Parkinson's because of balance problems, freezing, low blood pressure on standing and night-time toilet trips. To reduce the risk:

- Stand up slowly, sitting on the edge of the bed for a moment first.
- Keep walkways clear, remove loose rugs and light the route to the toilet at night.
- Wear well-fitting shoes with low heels and good grip, not loose slippers.
- Avoid carrying things while walking, and avoid talking while walking if concentration is needed.
- Ask the GP or Parkinson's nurse to check lying and standing blood pressure if the person feels dizzy.

Our falls prevention guide covers home checks, exercise and alarms in more detail.

Swallowing and eating

Swallowing problems can develop gradually. Watch for coughing or choking when eating or drinking, a wet or gurgly voice, food sticking, drooling, taking much longer over meals, difficulty with tablets, weight loss or repeated chest infections. Parkinson's UK advises seeing a speech and language therapist early, even before problems start. The GP or Parkinson's nurse can refer, and some services accept self-referral.

At mealtimes, sit fully upright, take small mouthfuls, eat slowly, avoid distractions and plan meals for "on" times when possible. Constipation is common in Parkinson's, so fibre, fluids and regular activity help. Our nutrition and hydration guide explains texture-modified diets.

Sleep and night-time problems

Sleep problems are common at every stage. People may struggle to turn over in bed, wake with stiffness or tremor when medicines wear off, need the toilet often, have restless legs or act out vivid dreams, known as REM sleep behaviour disorder. Daytime sleepiness then follows.

Helpful steps include a regular bedtime, short daytime naps, a cool bedroom, less caffeine later in the day, satin sheets or nightwear to make turning easier, and a commode or urinal by the bed. Mention night-time problems to the GP or specialist, because treatment can often help. If nights are disturbed for everyone, night care can give the family the rest they need.

Communication

Parkinson's can make the voice quieter and speech less clear, and it can reduce facial expression, so a person may look uninterested or unhappy when they are not. Speech and language therapists offer programmes such as Lee Silverman Voice Treatment (LSVT LOUD) to strengthen the voice.

Family members can help by facing the person, reducing background noise, allowing time, asking rather than guessing how they feel, and not finishing their sentences.

How live-in or night care can help

As Parkinson's progresses, many families find the hardest parts are medicines at exact times through the day and night, help during unpredictable "off" periods, and broken nights. A live-in carer is in the home all day, so medicine prompting or administration can follow the chart to the minute, and help is there whether the person is "on" or "off". A consistent carer also notices small changes, in swallowing, mood or mobility, that are easy to miss in short visits.

When to call the GP, 111 or 999

Call 999 if the person:

- Is choking and cannot breathe, cough or speak, and it does not clear.
- Has fallen and may have hurt their head, neck, back or hip, or cannot get up.
- Suddenly becomes very confused or drowsy, or shows signs of a stroke.

Contact the GP urgently or call NHS 111 (free, 24 hours) if:

- There are signs of a chest infection, such as fever, a new cough or breathlessness, especially if swallowing is difficult.
- Vomiting or illness means medicines cannot be taken or kept down.
- Doses have been missed and symptoms are much worse.

Contact the Parkinson's nurse or GP about new hallucinations, worsening falls or dizziness, low mood, constipation that does not settle, or changes in how well medicines are working.

How to get NHS help, step by step

Most people with Parkinson's are supported by a specialist (a neurologist or a doctor specialising in older people) and, in many areas, a Parkinson's nurse, who helps adjust medicines and refers to other services. To build the rest of the team:

1. **Parkinson's nurse:** ask the GP or specialist for a referral. Community Parkinson's nurses cover set areas, so ask the GP surgery whether one covers your practice. If not, the Parkinson's UK helpline can connect you with a local adviser.
2. **Physiotherapy:** ask the GP, specialist or Parkinson's nurse for a referral for movement, balance and freezing. Some areas also run Parkinson's exercise classes.
3. **Speech and language therapy:** ask the GP or Parkinson's nurse for a referral for speech or swallowing; some services accept self-referral.
4. **Occupational therapy and equipment:** ask the council's adult social care team for a care needs assessment, or ask the GP or hospital team.
5. **Falls service:** after any fall, ask the GP for a falls assessment; some areas let you refer yourself.
6. **Specialist review:** keep regular appointments with the specialist and take your diary of "on" and "off" times.

Checklist: a hospital bag for someone with Parkinson's

Tell staff on arrival that Parkinson's medicines are time-critical, and pack:

- All medicines in their original packaging.
- A written list of every medicine with the exact dose and time.

- The name and number of the Parkinson's nurse and specialist.
- A note of how the person is during "on" and "off" times.
- Glasses, hearing aids and phone charger.
- A family contact who can remind staff when doses are due.

Help with costs

- **Attendance Allowance** (over State Pension age) or **Personal Independence Payment** (under it), neither of which is means-tested.
- A free **care needs assessment** from the council, followed by a financial assessment.
- **Equipment and minor adaptations** costing £1,000 or less are free if the council assesses a need; larger changes may qualify for a means-tested Disabled Facilities Grant of up to £30,000 in England.
- **NHS Continuing Healthcare** may pay for all care if needs become complex in the later stages.
- **Carer's Allowance**, which a family member caring for at least 35 hours a week may be able to claim.

See our guides to Attendance Allowance and Personal Independence Payment.

Where to get support

- **Parkinson's UK Helpline:** 0808 800 0303 (free). Monday to Friday 9am to 6pm, Saturday 10am to 1pm. For people with Parkinson's, families and carers; the charity also runs local groups and exercise classes.
- **Age UK Advice Line:** 0800 678 1602 (free). 8am to 7pm, every day of the year.
- **Carers UK Helpline:** 0808 808 7777. Monday to Friday, 9am to 6pm.
- **Samaritans:** 116 123 (free), 24 hours a day.

What to do next

1. Write an exact medicines timetable and set alarms for every dose.
2. Ask the GP or specialist for a referral to a Parkinson's nurse, physiotherapist and speech and language therapist if you do not have one.
3. Check the home for falls risks, especially the night-time route to the toilet.

4. Claim Attendance Allowance or PIP, and ask the council for a care needs assessment and a carer's assessment.
5. Keep a simple diary of "on" and "off" times, falls, sleep and side effects to share at appointments.

How we can help

Day and Nightcare supports people with Parkinson's through fully managed live-in care anywhere in England, from £1,550 a week, and home care visits, waking nights and sleep-ins across Oxfordshire, and 24-hour care with carers working in shifts anywhere in England. Medicines support is agreed in each person's care plan, so the times that matter are written down for every carer. Call 01865 715780 to arrange a free assessment and a written quote.

Common questions

Can Parkinson's medicines be stopped if they cause side effects?
Not without specialist advice. Parkinson's medicines should never be stopped or cut down suddenly, because this can cause a serious reaction. If side effects appear, such as sickness, dizziness, hallucinations, unusual sleepiness or new compulsive behaviour like gambling or excessive shopping, write down what you notice and contact the Parkinson's nurse, specialist or GP promptly. They can often adjust the dose, timing or type of medicine safely.

Can someone with Parkinson's keep driving?
Often, for a time. A diagnosis of Parkinson's must be reported to the DVLA and to the car insurer, but it does not automatically mean giving up driving. The DVLA asks about the condition and the doctors involved, then decides whether the person is safe to drive. Some medicines can cause sudden sleepiness, especially when doses are being increased, so check with the specialist before driving after any change.

Is exercise safe for someone with Parkinson's?

Yes, and it is one of the most helpful things they can do. The NHS says regular exercise can ease stiffness and improve mood. People with milder symptoms may enjoy more vigorous activity such as cycling or brisk walking, while those with more advanced symptoms can benefit from walking, gentle stretching and strengthening exercises. A physiotherapist can suggest what is safe, and the GP should be consulted before starting anything new.

Does Parkinson's affect mood and memory?

It can. Depression and anxiety are common in Parkinson's and are treatable, so mention low mood, worry or loss of interest to the GP or Parkinson's nurse. Some people develop problems with memory and thinking, and some go on to develop dementia. Hallucinations can be caused by the condition or by medicines, so report them promptly rather than assuming they are part of ageing.

Is Parkinson's care paid for by the NHS?

Medical treatment, the Parkinson's nurse and therapies are free on the NHS. Day-to-day care at home is social care, which is means-tested by the council. In the later stages, needs can become complex enough for NHS Continuing Healthcare, which pays the full cost of care. Attendance Allowance (over State Pension age) or Personal Independence Payment (under it) can help with costs whatever your savings.

Sources and further information

- NHS: Parkinson's disease
- NHS: Parkinson's disease treatment
- Parkinson's UK: Managing your medication in hospital
- Parkinson's UK: Freezing
- Parkinson's UK: Eating, swallowing and saliva control
- Parkinson's UK: Parkinson's nurses
- NICE: Parkinson's disease in adults (NG71)

Read next

HEALTH CONDITIONS AND CARE AT HOME

Falls prevention for older people: a practical guide

Why older people fall and how to reduce the risk at home: common causes, home hazards, footwear, eyesight, medication reviews, strength and balance exercise, what to do after a fall, personal alarms, and the free help available from the NHS and the council.

Read the guide →

LIVING SAFELY AND WELL AT HOME

Managing medication at home: a guide for families and carers

How medicines support works at home: prompting versus administering, blister packs and their limits, MAR charts, safe storage, medication reviews with the GP or pharmacist, the free New Medicine Service, what paid carers can and cannot do, and a medicines list template.

Read the guide →

PAYING FOR CARE AND REDUCING THE COST

Personal Independence Payment (PIP): a guide for families

PIP helps people aged 16 to State Pension age with the extra costs of a long-term condition or disability. The 2026/27 rates, how the points work, how to claim step by step, example wording for the form, end-of-life rules and PIP at State Pension age.

Read the guide →

All guides in the information centre Check what help you could get

Talk to our care team: 01865 715780

enquiries@dayandnightcare.co.uk · Out of hours: 07775 686272

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