

How to stay well in the community when living with Parkinson's disease and Movement disorders

Information for patients and carers
to avoid hospital admission



The information provided in this leaflet is to address the most common reasons for hospital admission and ways to prevent them and who to contact or discuss with if and when such symptoms occur.

1. Neuropsychiatric Symptoms

Symptoms may include:

- Confusion
- Visual and / or auditory hallucinations
- Agitation
- Change in personality

How to help prevent admission to hospital

These symptoms can be caused by infection, changes to medications and memory problems. If symptoms occur then a prompt discussion with a health care professional is required.

Who to contact if symptoms occur:

- G.P.
- Parkinson's nurse **0113 392 6689**, pd.nurse@nhs.net
- Parkinson's UK **0808 800 0303**
- Memory Service (if already known to the service and changes to symptoms)
- Consultant outpatient review

2. Urinary Tract Infection

Symptoms may include:

- Frequent need to pass urine
- A constant, dull pain in the public region
- Pain when urinating (dysuria)
- Cloudy urine or blood in your urine
- Strong / unpleasant smelling urine
- Back pain
- General sense of feeling unwell
- Sudden onset of confusion and / or hallucinations

How to help prevent admission to hospital:

- Drink plenty of water to avoid dehydration and help flush bacteria from the urinary tract
- Go to the toilet as soon as you feel the need to urinate, rather than holding it in
- Female patients should wipe from front to back after going to the toilet
- Practise good hygiene by washing your genitals with soap and water every day or before and after sexual intercourse
- Empty your bladder after having sex

Who to contact if symptoms occur:

- G.P.
- Community matron (if under the care of a matron)
- District Nurse

Note: the community team will be able to carry out a urine infection screen and treat accordingly.

3.Falls

Parkinson's symptoms that cause poor mobility may include:

- Poor balance
- Freezing
- Small steps / shuffling
- Lack of arm swing
- Wearing 'off' of medication
- Involuntary movements (dyskinesia)
- Stiffness

How to help prevent admission to hospital:

- Adjusting Parkinson's medications may help poor mobility issues
- Ask your specialist team about being referred to physiotherapy and occupational therapy as this can be very beneficial for learning techniques and introducing equipment to help safeguard mobility and support carers.

Who to contact if symptoms occur:

- Parkinson's nurse **0113 392 6689**, pd.nurse@nhs.net
- G.P.
- Parkinson's UK **0808 800 0303**
- Consultant outpatient review

Environmental risk factors:

- Wet floors
- Cluttered environment
- Tripping hazards e.g. rugs, wires, pets
- Changes in the level and uneven floors
- Unstable chairs or tables
- Toilet seat too low
- Poor lighting
- Brakes not in use on beds, commodes or wheelchairs

Who to contact or discuss with:

- Parkinson's nurse **0113 392 6689**, pd.nurse@nhs.net
- G.P.
- Neighbourhood network team
- Occupational Therapy
- Physiotherapist

Physical risk factors:

Previous history of falls

- Impaired balance/restricted mobility
- Reduced muscle strength
- Bone density (osteoporosis and increased risk of fractures)
- Slower reaction times
- Mobility aids/inappropriate use
- Impaired vision
- Cognitive impairment
- Continence
- Postural hypotension
- Dizziness

Functional risk factors:

- Sleep disturbance
- Pain
- Alcohol /drug use / withdrawal
- Neurological (brain) conditions
- Dizziness
- Mobility
- Fear of falling

Clinical risk factors:

- Neurological (brain) conditions
- Dizziness
- Previous history of falls
- Heart conditions
- Medications - caused by almost any drug that acts on the brain, heart or circulation.

How to help prevent admission to hospital

Your symptoms, medications, general health and a bone health assessment should be discussed with your healthcare professionals involved in your care:

A fracture risk assessment can be performed quickly and assess your need for further interventions such as a DEXA bone density scan, vitamin D and calcium tablets or injections.

Vitamin D is extremely important for bone health and a healthy immune system. In the UK, sunlight doesn't contain enough UVB radiation in winter (October to early March) for our skin to be able to make vitamin D.

During these months, we rely on getting our vitamin D from food sources and supplements. Public Health England (PHE) advises us to take a vitamin D3 supplement daily during the winter months. Patients with Parkinson's disease are recommended to take 800units a day of Vitamin D3.

- GP
- Pharmacist
- Parkinson's nurse
- Community Matron

- District nurse
- Neighbourhood network team
- Physiotherapist
- Occupational Therapist
- Adult Social Care

Symptoms due to problems with blood pressure may include:

- Dizziness or light-headedness
- Unsteadiness
- Fainting
- Blurred vision
- Heartbeats that suddenly become more noticeable (palpitations)
- Confusion
- Feeling sick (nausea)
- General weakness

How to help prevent admission to hospital:

Immediate action if symptomatic:

- Stop what you're doing
- Sit or lie down
- Drink a glass of water

On-going management includes:

- Don't sit out in the sun, or any hot environment for too long
- Try not to sit or stand still for long periods

- Avoid large heavy meals, eat small meals more frequently
- Drink water with and after a meal and throughout the day
- Bend or reach for something slowly and hold onto things to support you
- Avoid caffeine at night
- Raising the head of the bed during sleep to prevent postural hypotension on rising
Increase salt intake
- Move lower limbs before attempting to stand if sat for a period of time
- Consider wearing flight socks (if possible, seek medical advice before purchasing)
- Review bone health and protection to prevent fractures (liaise with your GP or specialist team about this)
- Review suitability for medication such as midodrine or fludrocortisone and to review other medications for your heart and blood pressure which may be contributing to symptoms (GP or specialist team will advise on this)

Who to contact if symptoms occur:

- Parkinson's Nurse **0113 3926689**, pd.nurse@nhs.net
- GP (Your GP can monitor your blood pressure in the community and help identify any underlying causes)
- Consultant outpatient review
- Community matron (if under the care of one)
- Parkinson's UK **0808 800 0303**

4.Chest infection / Pneumonia

Symptoms may include:

- Coughing and feeling unwell
- Coughing when taking oral diet and fluid
- Problems breathing such as a change in breathing pattern either shallow or
- Laboured, wet sound at the back of the throat
- Congestion in the head, nose and throat
- Feeling lethargic, exhausted tired
- Raised temperature

How to help prevent admission to hospital:

- Contact your GP, you may need antibiotics
- Continue to take oral diet and fluids. If having swallowing problems take small quantities with each mouthful
- Be alert, sit upright
- Chew your food
- Ensure the food and drink is completely cleared before taking additional food, this may take a couple of swallows
- Ensure you rest when needed

5. Constipation

Symptoms may include:

- Fewer bowel movements (less than 3 motions per week)
- Trouble having a bowel movement (straining)
- Hard or small faeces
- Lack or reduced appetite
- A sense that all the faeces didn't come out, incomplete emptying
- Swollen abdomen or abdominal pain
- Vomiting or nausea

How to help prevent admission to hospital:

- Eat a balanced diet, including plenty of fruit, vegetables and fibre
- Drink plenty of fluids, avoid alcohol, avoid fizzy drinks, a warm drink with breakfast can encourage the bowel into a more regular pattern of emptying
- Exercise, keeping active and mobile may help people whose bowel is sluggish
- Seek GP or Parkinson's Nurse Specialist advice for medication which may be helpful in alleviating constipation, if symptoms are long standing and problematic you may be referred onwards to a specialist team for further support and investigation

Who to contact if symptoms occur:

- G.P.
- Parkinson's Nurse **0113 392 6689**, pd.nurse@nhs.net
- Community matron (if known to one)
- Parkinson's UK **0808 800 0303**
- Community Continence Team

6.Swallowing difficulties

Symptoms may include:

- Food sticking in the throat
- Choking on food, liquid or saliva
- Coughing when eating or drinking
- Inability to clear food from the mouth
- Pain when swallowing
- Drooling
- Weight loss
- Gurgling voice
- Discomfort in the chest or throat
- Heartburn or reflux
- Repeated chest infections
- Loss or reduced appetite

How to help prevent admission to hospital:

- Referral to Speech Language therapist by Parkinson's Nurse Specialist or GP
- Changing your diet consistency to make foods and fluids easier and safer to swallow. Advised by the Speech and Language Therapist
- Liaise with your Parkinson's nurse, community matron or GP to see whether any problematic medication can be changed to a different form if you are struggling to swallow your daily medication

Who to contact if symptoms occur:

- Parkinson's Nurse **0113 392 6689**, pd.nurse@nhs.net
- G.P.
- Community matron (if known to one)
- Parkinson's UK **0808 800 0303**
- Speech and Language Therapist (if already under their care and symptoms are persistent or worsening)

7. Depression

Symptoms may include:

- Lowered mood
- Indecision
- Reduced appetite
- Low self-value (esteem)
- Feeling of guilt
- Decreased concentration
- Suicidal ideas (very rare in Parkinson's disease)
- Tiredness / exhaustion (replace with Fatigue)
- Loss of interest / drive
- Inability to experience pleasure
- Difficulty getting or staying asleep (replace with Insomnia)
- Mood swings / low in the morning
- Loss of libido

How to help prevent admission to hospital

DON'T ignore the signs, Seek advice from a health care professional

Who to contact if symptoms occur:

- G.P.
- Parkinson's Nurse **0113 392 6689**, pd.nurse@nhs.net
- Leeds and York Partnership Mental Health Team (If already known to them and symptoms persistent or getting worse)
- Community matron (if known to one)

8. Anxiety

Symptoms may include:

- Irrational fears
- Excessive worrying
- Sleep problems
- Muscle tension
- Sweating
- Panic attacks / increased anxiety
- Pounding or racing heart (palpitations)
- Flashbacks
- Feeling breathless
- Dizziness
- Trembling
- Chronic indigestion
- Nausea
- Stomach cramps
- Dry mouth
- Restlessness
- Self-consciousness and / or self-doubt
- Frequent trips to the toilet

How to help prevent admission to hospital

DON'T ignore the signs, Seek advice from a health care professional

Who to contact if symptoms occur:

- G.P.
- Parkinson's Nurse **0113 392 6689**, pd.nurse@nhs.net
- Leeds and York Partnership Mental Health Team (If already known to them and symptoms persistent or getting worse)
- Community matron (if known to one)

There are also a number of National and Local charities who can support you with symptoms of Anxiety, they include:

- Mindwell, (A Leeds based Mental Health Charity), they will take self-referrals via telephone or online: <https://www.mindwell-leeds.org.uk>, **0800 183 0558**
- Samaritans **116 123**
- Mind **0300 123 3393**
- Parkinson's UK **0808 800 0303**

NHS 111 is open **24/7** if you, or someone you know, needs urgent care but it's not life threatening. This includes advice for both your physical and mental health.

Adapted for use in Leeds from the Rotherham NHS Trust: Keeping well in the community. A guide to help prevent hospital admission for people with Parkinson's disease by Joanna Rose, Parkinson's Nurse Specialist.



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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