



**information
for
patients**



NHS

**East Suffolk and
North Essex
NHS Foundation Trust**

Parkinson's Anticipatory Care Plan: How to manage your Parkinson's symptoms

***Parkinson's Specialist Nurses
Ipswich Hospital***

(DPS: 04216-21)



What do I do if my Parkinson's symptoms suddenly get worse?

If it is an emergency, or if you are seriously unwell, call 999 immediately for an ambulance.

People with Parkinson's disease sometimes experience a worsening of their symptoms. It is unusual for a rapid deterioration to be caused by the Parkinson's disease (PD) alone. Often there are other reasons. In the event of a sudden worsening of symptoms the following steps may be helpful.



Has your anti-Parkinson's treatment recently been changed?

When treatments for Parkinson's disease are changed, most people notice an improvement in their symptoms. Occasionally, a change in medication can cause a worsening of symptoms. If the dose has recently been increased, or a new treatment started, the risk of side effects is higher.

Common side effects include:

- nausea and vomiting
- feeling dizzy or lightheaded (sometimes due to low blood pressure)
- feeling tired and sleeping excessively during the day
- involuntary writhing movement termed as 'dyskinesia'
- confusion
- hallucinations (seeing or hearing things that are not there)
- impulsive/compulsive behaviour (excessive shopping, binge eating, hyper sexuality).

Ensure all Parkinson's medications are taken at the time suggested by the Parkinson's team. These times are usually found on letters following appointments. If you are not sure, contact your GP for advice.

If you suspect that a change in medication has caused you to feel unwell, contact your GP. He or she will assess the situation and contact the Parkinson's team for advice and guidance. Avoid abruptly stopping Parkinson's medications without first discussing it with a healthcare professional.



Drug information can be found on the leaflet supplied with the medication. Further information about the treatment of Parkinson's is available in the 'Drug Treatment for Parkinson's' booklet from your Parkinson's team or Parkinson's UK.

Visit: <http://www.parkinsons.org.uk>

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What else can cause changes in Parkinson's symptoms?

A **urine infection** can cause a worsening of PD symptoms. Symptoms of a urinary tract infection (UTI) can include:

- confusion
- passing urine more often
- discoloured or cloudy urine (some drugs used to treat PD may discolour urine – Stanek, Sastravi and Stalevo)
- unusually unpleasant smelling urine
- pain on passing urine
- passing blood in your urine
- abdominal or back pain
- generally feeling unwell
- raised temperature or feeling feverish.

If you think you may have a urine infection, seek advice from your GP surgery. A sample of urine may be required for testing. Treatment will be essential if an infection is detected, to prevent further complications or decline in PD symptoms.



A **chest infection** may also worsen your Parkinson's.

Symptoms include:

- persistent chesty cough
- feeling breathless or wheezy
- coughing up yellow or green phlegm
- raised temperature
- chest pain
- generally feeling unwell.

If you think you may have a chest infection, seek advice from your GP. Swallowing problems can contribute to a chest infection. If you are unable to swallow Parkinson's medications, report this to your GP at the earliest opportunity who will contact the Parkinson's team for advice on alternative options. **Do not stop taking your PD medication.** There are dispersible or crushable forms of Parkinson's medications.

Your GP could consider referring you to the community Speech and Language team to prevent further chest infections and aspiration pneumonia.

Other infections or underlying conditions may also have an impact on Parkinson's symptoms. If you think you may have an infection, or worsening of any other existing problems such as heart failure or COPD, seek advice from your GP surgery. You will need to rest and drink plenty of fluids. Taking a simple pain relief medication, such as paracetamol, should help to treat a fever and relieve any aches and pains you may have, unless you have been told you should not take this sort of medication.



Constipation is common in the general population, particularly as we age. Mild constipation is not uncommon in PD and it could result in worsening of your Parkinson's symptoms. This can also affect the absorption of your medication. Constipation can usually be managed by a healthy diet with plenty of dietary fibre, fluids and exercise. Sometimes laxatives may be required. See the Parkinson's UK factsheet 'Looking after Your Bladder and Bowels' for further information.

Chronic constipation can increase the risk of faecal impaction (where dried, hard stools collect in your rectum). Once you have faecal impaction, it is very unlikely that you will be able to pass the stools naturally, and this can cause the leaking of liquid stools which is sometimes mistaken for diarrhoea. Any treatments to help diarrhoea will only make the problem worse.

A healthy diet, regular exercise, fluids and fibre will contribute to healthy bowel management. Take note of your regular bowel habits. Take any laxatives regularly, rather than as needed, as this will allow your bowel to get into a routine. You may find you need to take your laxatives twice a day, or it may be every three days; but you can work out what suits you best. If you change from your normal pattern, visit your GP or practice nurse for further treatment or advice. Leaving constipation untreated can cause worsening of PD symptoms, urinary retention and confusion, resulting in a hospital admission.



Dehydration is common in the general population. Sometimes, if severe, this can make your Parkinson's worse. You should aim to drink 1.5 litres of fluid a day, possibly more in hot weather or if you are ill with diarrhoea.

Symptoms of mild dehydration include:

- thirst
- dizziness or light-headedness
- headache
- tiredness
- dry mouth, lips and eyes
- concentrated urine (dark yellow – this colour can appear when you take Stanek, Sastravi or Stalevo)
- passing only small amounts of urine infrequently (less than three or four times a day)

To avoid severe dehydration, increase fluid intake and address any potential causes such as diarrhoea or infections.

Symptoms of severe dehydration include:

- dry, wrinkled skin that sags slowly into position when pinched up
- an inability to urinate or not passing urine for eight hours
- irritability
- sunken eyes
- low blood pressure (hypotension)
- weak pulse



- rapid heart rate
- cool hands and feet
- fits (seizures)
- low level of consciousness
- feeling tired (lethargic) or confused
- blood in stool (faeces) or vomit.

To avoid **severe dehydration** increase your fluid intake and address any potential causes such as diarrhoea or infections. Avoid this with adequate fluid intake. If you notice you are becoming dehydrated, report it to your GP so it can be treated/managed before the situation gets worse.

Severe dehydration is a serious condition; you will need to seek medical help quickly as you may need admission to hospital.

Other changes in your health will contribute to worsening of your PD symptoms. Even a common cold or uncontrolled pain has the potential to affect your Parkinson's.



Falls

Falls can happen in Parkinson's due to:

- poor balance
- involuntary movements (dyskinesia)
- freezing of gait
- posture
- general muscle weakness
- low blood pressure or drop in blood pressure on change in position (lying/sitting to standing)
- visual problems
- other hazards at home causing trips and falls.

How do I prevent falls?

- A safe environment and use of appropriate walking aids is essential.
- Improve your fluid intake to avoid low blood pressure or drop in blood pressure on change in position (lying/sitting to standing).
- Exercises safely, as you are able to.
- Wear appropriate footwear.
- Avoid rushing or turning quickly
- Your GP can refer you to a physiotherapist or occupational therapist for review and support.
- Your GP should check your lying and standing blood pressure.
- A self-referral to social services can be done using the contact number on page 11 for care support. Your Parkinson's local adviser also will be able to help with this (contact number on page 11).



Confusion, hallucinations and agitation/aggression can occur due to infections, constipation and dehydration or due to an increase in some of the Parkinson's medications. As soon as you notice changes, contact your GP to rule out the above conditions. Deterioration of Parkinson's disease or cognitive impairment/dementia can also cause a change in Parkinson's symptoms. However, these will occur gradually over time.

Once the underlying cause for the deterioration of your Parkinson's has been successfully treated, your Parkinson's should return to how it was within a few weeks. If, after four weeks, your Parkinson's is still causing a concern, please ask your GP to contact the Parkinson's Team for advice / review.

Preparation for hospital admission

If a hospital admission is planned for a procedure or surgery, please inform the admitting team that you have Parkinson's Disease and you are on timed medications, so that they can plan the time for procedure/surgery without missing your medications. They can also discuss with the Parkinson's team to plan if needed. Please make sure you bring your latest prescription and your own medications to avoid any missing you Parkinson's medications in hospital.

In case of unexpected admission, please keep all your Parkinson's medications together in a bag/box – or keep a list of your current medications – where ambulance staff can find them easily and bring them to hospital. It will be always helpful if you or your family members or carers can inform the staff at the hospital that you are on timed medications.



Useful contact numbers

- **Out-of-hours GP Service**
(via the number on your GP telephone service).
- **Suffolk Parkinson's helpline: 0808 164 2028**
Web: www.sueryder.org
Email: sryc.parkinsons.helpline@nhs.net
- **Parkinson's UK free helpline: 0808 800 0303**
(Local Adviser Suffolk: Carol Jacobs – 0344 225 3778).
- **NHS 111: Tel 111** – You should use the NHS 111 service if you urgently need medical help or advice but it's not a life-threatening situation.
- **Social Services: 0808 800 4005**
(for care support)
- **Suffolk Family Carers: 01473 835 477**
(for carer support and advice)
- **Dementia Together: 0808 168 8000**
(for general advice and support)
- **Medication Advice Line: 01473 704431**
(for availability issues/ interaction of Parkinson's medications with other regular medications)
- **Central Outpatients: 01473 703162**
(for appointment queries)
- **Older People's Services secretaries: 01473 704134**
(for general advice on your appointment or clinic letters)
- **Physiotherapy and Occupational Therapy team:**
0300 123 2425
(self-referral for assessment and support for balance issues/ falls)



Websites you may find useful

<https://www.gov.uk/power-of-attorney>

<https://www.carersuk.org/home>

<http://advancecareplan.org.uk/examples-document-templates/>

<https://www.parkinsons.org.uk/research/take-part-research>

This booklet is based, in part, on information from the Parkinson's UK website at www.parkinsons.org.uk

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Please ask if you need this leaflet in an alternative format.

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