Patient information

East and North Hertfordshire Teaching NHS Trust

Anticipatory Care Plan

For people with Parkinson's disease, their family and carers

Exercise and physical activity

Remember the importance of exercise as part of your self-management. It is essential you keep active and rebuild activity after you have been unwell. Exercise is essential in all stages of your life and condition. Exercise will reduce the risk of ill health that can be a cause of hospital admission.

Planning for an expected change in your condition is called **'Anticipatory Care Planning'**. People with Parkinson's disease (PD) sometimes experience a worsening of their symptoms. It is unusual for a rapid deterioration to be caused by the Parkinson's disease alone, often there are other reasons. In the event of a sudden worsening of symptoms these following steps may be helpful.

If you are clearly very ill, i.e. extremely breathless, losing consciousness or in considerable pain, seek urgent medical help or call 111.

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, particularly if a dose has been reduced. If the dose has 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 movements (called dyskinesia)
- Confusion
- Hallucinations / misperceptions (seeing or hearing things that are not there)

Do not abruptly stop medication without first discussing it with a healthcare professional.

Sometimes the introduction or increase of new drugs for another condition may worsen your symptoms. If you suspect a change in medication has caused you to feel unwell, contact your Parkinson's disease nurse specialist (PDNS), geriatrician, neurologist or GP to discuss. You could also speak to a pharmacist or the Parkinson's UK Helpline (see page 4) to discuss the issue.

Drug information can be found on the leaflet supplied with your medication.

Further information regarding the drug treatment of Parkinson's is available from your PDNS or Parkinson's UK.

Is there anything else wrong with you?

Urine infection - This can cause a worsening of PD symptoms and even cause confusion in some people. Symptoms can include:

- Passing urine more often
- Discoloured or cloudy urine (some drugs used to treat PD may discolour urine)
- 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

Action: If a urine infection is suspected, seek advice at your GP's surgery. A sample of urine may be required for testing but antibiotics are usually effective.

Chest infection - If suspected, seek advice from your GP. Symptoms can include:

- Persistent chesty cough
- Feeling breathless or wheezy
- Coughing up yellow or green phlegm
- Raised temperature
- Chest pain
- Generally feeling unwell

Not all infections require antibiotics and mild infections usually resolve themselves in around 3 weeks. If you are having problems with swallowing, this might be a cause of the chest infection.

Action: If a chest infection is confirmed by your GP, please inform your PDNS or neurologist.

Other infections may also cause problems with PD. Again, if infection is suspected, seek advice at your GP surgery and let your PDNS or neurologist know if this is confirmed.

If you are unwell, you will need to rest and drink plenty of fluids. Regular paracetamol (max 4g a day = 8 x 500mg tablets per day) should help to treat fever and any aches and pains you may have.

Constipation is common in the general population particularly as we age. Mild constipation is not uncommon in PD and it could result in a worsening of PD. Constipation can usually be managed by a healthy diet with plenty of dietary fibre, fluids and exercise. Sometimes laxatives may be required.

Constipation is defined as no bowel activity for 3 days. Symptoms can include:

- Abdominal discomfort
- Feeling bloated
- Loss of appetite
- Reduced bowel opening
- Difficulty in passing stools / straining

Action: Contact your PDNS, neurologist or GP for advice.

Dehydration is common in the general population. Sometimes, if severe, this can make your Parkinson's worse. A person should aim to drink 6-8 glasses of fluid a day, possibly more in hot weather or if you are ill with diarrhoea etc.

Symptoms of mild dehydration can include:

- Thirst
- Dizziness or light-headedness
- Headache
- Tiredness
- Dry mouth, lips and eyes
- Concentrated urine (dark yellow)
- Passing only small amounts of urine infrequently (less than three or four times a day)

Action: Increase fluid intake and address any potential causes, such as diarrhoea or infections. It can also be helpful to measure the amount of fluids you drink each day.

Orthostatic hypotension is common among people who are 65 or older because the body's ability to react to drops in blood pressure can slow down as a person ages. Symptoms can include:

- Feeling lightheaded or dizzy after standing up
- Blurry vision
- Weakness
- Fainting (syncope)
- Confusion
- Nausea

Prevention and management

There are several ways of managing or preventing orthostatic hypotension, most of which do not involve the use of medication.

- Keep hydrated by drinking plenty of fluids. Fluids lost from diarrhoea or vomiting should be replaced immediately
- Avoid or limit alcohol intake because alcohol can worsen orthostatic hypotension
- Use more salt in meals. However, consult a doctor first as too much salt in the diet can increase blood pressure
- Avoid strenuous activity during hot weather
- When getting out of bed, sit on the edge of the bed for a minute before standing
- Sleep with the head of your bed slightly elevated
- Compression stockings can promote circulation and help prevent fluid from pooling in the legs

If you suspect you are experiencing drops in blood pressure, it is essential you have resting and standing blood pressure recordings. Please discuss with your PDNS, neurologist or GP.

Delirium - There are different kinds of delirium. Some people may be agitated and restless, or have delusions and hallucinations, others may just become unusually sleepy.

You are at risk of delirium if you are 65 or older, already have difficulties with memory or understanding (known as cognitive impairment), or have dementia, a broken hip, or are unwell. Symptoms can be:

- Changes in consciousness
- Confusion
- Personality changes
- Hallucinations
- Unusually sleepy

The risk of delirium can be reduced if you are well hydrated, constipation is avoided and you seek advice from a healthcare professional if you suspect you are developing an infection.

Some medications can contribute to delirium. If you suspect a new medication or a change of dose has caused you to feel unwell, contact your PDNS, geriatrician, neurologist or GP to discuss.

Once the underlying cause for the deterioration of your Parkinson's symptoms has been successfully treated, your Parkinson's should return to how it was after a few weeks. If after 4 weeks your Parkinson's is still causing concern, please contact your team to discuss.

Useful contact details

East and North Hertfordshire Teaching NHS Trust:

- Website www.enherts-tr.nhs.uk
- Telephone 01438 314333

Parkinson's Service Secretary:

- Telephone 01438 288355
- Email - sophie.robinson13@nhs.net

Neurology Service:

- Email - neurologysecretaries.enh-tr@nhs.net
- Email - neurologyqe2.enh-tr@nhs.net

Dedicated Parkinson's Nurse Telephone Advice Line:

for patients, carers and health and social care professionals.

- Telephone 01438 288652

(This is an answer machine, please leave a message and we will get back to you)

Parkinson's UK Local Advisor - East of England:

- Telephone 02079639256
- Email - jaldridge@parkinsons.org.uk

Parkinson's UK National Office:

- Telephone: 0207 931 8080
- Email: hello@parkinsons.org.uk
- www.parkinsons.org.uk

Parkinson's UK Freephone Helpline:

- Telephone: 0808 800 0303
  Monday to Friday, 9am - 6pm
  Saturday, 10am - 1pm

If you have any concerns that require immediate attention, please contact your GP

Out of Hours - You are advised to telephone **111**

NHS 111 can help if you need medical help or advice. It is available 24 hours a day, 7 days a week.

Leaflet information

You can request this information in a different format or another language; please speak to your doctor or nurse.

Date of publication: May 2018
Version number: 4
Author: Tracey Smith
Reference: Neurology
Review Date: November 2029

© East and North Hertfordshire Teaching NHS Trust
www.enherts-tr.nhs.uk