

Patient Information - Anticipatory Care Plan for Parkinson's Disease

Anticipatory Care Plan

Patient information leaflet

Parkinson's Disease

Darent Valley Hospital

Darenth Wood Road

Dartford

Kent

DA2 8DA

01322 428100

www.dgt.nhs.uk

Authors: Carol Hart

Reviewed: Penny Roberts and Grace Hogan

Title: Parkinson's Nurses

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What to do if your Parkinson's suddenly gets worse

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 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. FOR EXAMPLE EXTREMELY BREATHLESS, LOSING CONSCIOUSNESS OR IN CONSIDERABLE PAIN. SEEK MEDICAL HELP OR CALL AN AMBULANCE IMMEDIATELY.

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 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)

Sometimes the introduction of new drugs for another condition or an increase in its dose may worsen your symptoms.

If you suspect a change in medication has caused you to feel unwell contact your

Parkinson's Nurse, Neurologist, Consultant, GP, Pharmacist or the Parkinson's UK helpline to discuss the issue. Avoid abruptly stopping medication without first discussing it with a health care professional.

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

Is there anything else wrong with you?

Urine infection can cause a worsening of PD symptoms and can cause confusion in some people. Symptoms of urine infection 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

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 Infections 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 a urine infection is suspected, seek advice at your GP's surgery. 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 chest infections.

Please inform your PD Nurse or Neurologist/Consultant if you suspect this is the case.

Other Infections may also cause problems with your PD. Again, if infection is suspected seek advice at your surgery. You will need to rest and drink plenty of fluids. Regular paracetamol (max 4mg a 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. Constipation is not uncommon in PD and it could result in a worsening of your PD. 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 and anus). Once you have faecal impaction, it is very unlikely that you will be able to get rid of the stools naturally. Faecal impaction worsens constipation because it makes it harder for stools and waste products to pass out of your anus as the path is obstructed. If you experience faecal impaction, it can lead to a number of other complications.

These include:

- Swelling of the rectum
- Losing sensation in and around your anus
- Faecal incontinence, when you uncontrollably leak soft or liquid stools
- Bleeding from your anus
- Rectal prolapse, when part of your lower intestine protrudes from your anus

The leaking of liquid stools is sometimes mistaken for diarrhoea and any treatments for diarrhoea will only make the problem worse. If you suspect faecal impaction and laxatives have not helped, suppositories or enemas will be required. You may need to contact your surgery and ask for a nurse to help you administer these if you are unable to do so. You will also need to see your GP or district nurse if the impaction does not resolve or if you feel unwell.

Dehydration is common in the general population. Sometimes if severe, this can make your Parkinson's worse. You should aim to drink 6-8 glasses of fluid a day possibly more in hot weather Dartford and Gravesham NHS Trust Page 3 of 3 or if you are ill with diarrhoea etc.

Symptoms of mild dehydration 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) To avoid severe dehydration increase your 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 heartbeat
- Cool hands and feet
- Fits (seizures)
- Low level of consciousness
- Feeling tired (lethargic) or confused
- Blood in your stools (faeces) or vomit

Severe dehydration is a serious condition; you will need to seek medical help quickly as you may require admission to hospital for an intra-venous drip.

Once the underlying cause for the deterioration of your Parkinson's symptoms has been successfully treated, the Parkinson's should return to how it was in a few weeks. If after 4 weeks your Parkinson's is still causing concern please contact your PD nurse specialist or consultant asking for a review

Further information and support

Penny Roberts and Grace Hogan: Parkinson's nurses 01322 429100 ext 4759
tr.parkinsonsnurseservice@nhs.net

Parkinson's UK free helpline 0808 800 0303 Mon-Fri 9am-6pm and Sat 10am-2pm. Closed on Sundays and bank holidays.

<http://www.nhs.uk/Pages/HomePage.aspx>

NHS Direct: 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

This leaflet has been developed in partnership with the Patient Information Group and our DGT Patient Partners

Patient Information

Further patient leaflets are available from the Dartford and Gravesham NHS Trust website: <https://www.dgt.nhs.uk/patients-and-visitors/patient-information-leaflets>. Please ask a member of staff if you require information in another language or format.

Complaints, Comments, Concerns and Compliments

Please speak to the staff in the ward or department caring for you if you have any concerns or questions relating to your care or that of a loved one.

Compliments can be shared by visiting: <https://www.dgt.nhs.uk/contact-us/compliments>

Alternatively, please contact the Patient Advice and Liaison Service (PALS) on 01322 428382 Email: dgn-tr.PALS@nhs.net

Patient Property

Please do not bring large sums of money or valuable items into the hospital. Dartford and Gravesham NHS Trust accepts no responsibility for the loss or damage to personal property unless it is handed into Trust staff for safe-keeping.

Dartford and Gravesham NHS Trust operate smoke-free hospitals. This means that smoking is not permitted anywhere on hospital grounds. For help to quit smoking please visit www.kentcht.nhs.uk/service/one-you-smokefree/

Use of alcohol or illicit drugs is not permitted anywhere on the hospital site.
For drug and alcohol support please speak to your nurse or doctor or

Visit: www.changegrowlive.org/westkent/help

Call: 0330 128 1113

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