

Important Contacts

UHD Parkinson's service: Phone: **0300 019 8012**

8:30am to 4:30pm, open Monday to Friday

Email: **Parkinsons.service@uhd.nhs.uk**

For further information about Parkinson's contact:

Parkinson's UK: Phone: **020007318090**

Freephone helpline: **0808 800 0303**

Monday to Friday: 9am until 6pm Saturday 10am until 2pm

Email: **hello@parkinsons.org.uk**

www.parkinsons.org.uk

Produced by Parkinson's UK, first steps is an online programme for people recently diagnosed with Parkinson's and their family, friends and carers.

First Steps programme | Parkinson's UK
(**parkinsons.org.uk**)

The Cure Parkinson's Trust

Phone: **0207 487 3892** Email: **info@cureparkinsons.org.uk**

www.cureparkinsons.org.uk

Parkinson's local groups



For more information about groups or events local to you please ask the Parkinson's Nurse Specialist or look at the Parkinson's UK website and search for the full list of local groups.

The Royal Bournemouth Hospital,
Castle Lane East, Bournemouth, Dorset, BH7 7DW
Poole Hospital, Longfleet Road, Poole, Dorset, BH15 2JB

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w: **www.uhd.nhs.uk**

 **@UHD_NHS**  **@UHDTTrust**  **@uhd_nhs**

Planning for a Change in your Parkinson's Symptoms

Patient information

The information in this booklet is to support you living with Parkinson's. It will help you to anticipate possible future changes in your health and make plans should these changes occur.

t: **01202 303626** w: **www.uhd.nhs.uk**

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The rate of progression in Parkinson's is slow and predictable. If you develop a change in your symptoms or develop a new symptom within a few days or in a couple of weeks, this is unlikely due to Parkinson's - unless you have changed your medication. It is important that the cause of the deterioration is treated as, in most cases, this will prevent the worsening of your Parkinson's symptoms.

Guidance for self-care

GREEN SAFETY ZONE: keep watch

- Your Parkinson's symptoms have not changed
- You remain as active and mobile as you normally are

What should I do?

There is no need for a review by your Consultant, Parkinson Specialist Practitioner or General Practitioner apart from your regular reviews

AMBER WARNING ZONE: stay alert

- You experience a gradual worsening of your Parkinson's symptoms
- Your Parkinson's medication is no longer managing your symptoms effectively
- You have developed side effects from the Parkinson's medication

What should I do?

You should contact the Parkinson Specialist Practitioner:
Telephone: **0300 019 8012** - open 8:30am to 4:30pm, Monday to Friday
Email: **Parkinsons.service@uhd.nhs.uk**

Benefits

If you are unable to work or need help with your day-to-day needs, you may be entitled to some financial support. The benefits system supports people who are ill or disabled and those who care for someone who is. Some benefits are not normally affected by any other income you may have and are not based on your National Insurance contributions such as Attendance Allowance, Personal Independence Payments, and Carer's allowance.

The most up-to-date information is on the Parkinson's UK website at Parkinsons.org.uk/benefits or you can contact their helpline on **0808 800 0303**, which is open Monday to Friday, 9:00am to 4:30pm.

You can use the online benefits calculator at **www.turn2us.org.uk/get-support** to check what benefits you may be able to claim.

Support for Carers

Carers can register as a carer with their GP. This enables GPs to provide the correct support.

CRISP supports carers of people living in Bournemouth, Christchurch or Poole.

You can find out more information from:
www.crispweb.org or by contacting: Phone: **01202 128787**
Email: **carersupport@bcpcouncil.gov.uk**

If you live in the Dorset Council area, you can get in touch with Carer Support Dorset using the contact details below or by visiting their website:
www.carersupportdorset.co.uk Phone: **0800 368 8349**
Email: **admin@carersupportdorset.co.uk**

Hospital Admission

If you have a hospital admission planned for a procedure or surgery, please inform your health care team that you have Parkinson's, and that your medication should be given on time. They can then plan the time for procedure/surgery without missing your medications. They can also discuss you with the Parkinson's team if needed.

What should I do?

- Find out if you can administer your own medications while in hospital. If not, discuss the alternatives, and how you will get your medications on time. For example, if you use a medication timer or alarm, continue to use it during your hospital stay so you can ask for your medication when you need it.
- Consider writing down your troublesome symptoms and the support that you may need: for example, speech difficulties or help to get dressed. Give the nursing staff a copy of this information.
- If you use mobility equipment, take this into hospital with you. Discuss your needs in advance. Make sure you clearly label your own equipment.
- Bring your latest prescription and your medications with you to avoid missing any of your Parkinson's medication. The hospital pharmacy may not have in stock all possible drugs.

In case of unexpected admission to hospital, keep all your Parkinson's medication in a box or bag where ambulance men can find them easily and bring them into hospital. **It will be helpful if you, your family members or carers can inform the staff at the hospital that you are on medications that should be given on time.**

RED ALERT ZONE: seek help as soon as possible

- You experience a sudden change in your Parkinson's symptoms
- You have symptoms of an infection and/or you feel suddenly unwell
- You have become confused about your medications
- Your carer becomes ill or admitted to hospital and is unable to care for you

What should I do?

**You should contact your GP or NHS 111.
If you feel very unwell call 999.**

+Confused about specific doses/why you take specific medications or uncertain whether you have taken today's medication correctly.

Change in Parkinson's Medication

Generally, when medications for Parkinson's are changed, you can expect to experience an improvement in your symptoms. However, a change in medication can sometimes lead to a worsening of your symptoms, particularly if the dose of your Parkinson's medication has been reduced. If the dose has recently been increased or a new medication has been started, the risk of side effects will be higher.

Common side effects that you may experience include:

- Nausea and vomiting
- Feeling dizzy or lightheaded
- Feeling tired and sleeping excessively during the day
- Involuntary movements (dyskinesia)

- Confusion
- Hallucinations / misperceptions (seeing or hearing things that are not there)

What should I do?

- Do **not** abruptly stop your Parkinson's medication
- Contact the Parkinson's Specialist Practitioners by telephone or email to discuss your symptoms following change in medication

If your Parkinson's symptoms have become noticeably worse and you have recently started any new medication, over the counter or prescribed, please inform your Parkinson's Specialist Practitioner.

Constipation

Constipation refers to how easily and how often your bowels are opened. You may be constipated if you have bowel movements less frequently than your normal routine or when you pass hard or pellet-like stools and have a frequent need to strain when attempting to open your bowels.

Constipation can cause crampy pains in your lower tummy. You may also feel bloated and feel sick if you have severe constipation.

Parkinson's affects the muscles in the bowel wall. Food is not moved as easily along the bowel leading to constipation. Some medications, such as codeine and iron tablets, can worsen constipation.

Your bowel can become loaded with hard stools leading to difficulty in passing stools naturally. This is called faecal impaction. Faecal impaction can lead to the leakage of lumps of stool or a brownish mucus like diarrhoea.

If you have low blood pressure then you should avoid:

- Standing up quickly especially after waking up in the or after you have rested
- Standing for long periods
- Hot environments such as hot baths or centrally heated rooms.
- Large carbohydrate or fat rich meals
- Strenuous exercise or lifting
- Constipation

What should I do if I have low blood pressure?

- Do not sit in the sun or a hot environment for too long
- Get up slowly from a chair to a standing position. Stand for a while until you feel steady
- Dangle your feet off the side of the bed before standing
- Increase your fluid intake - discuss suitability with your GP or Parkinson's team
- Increase your salt intake - discuss suitability with your GP or Parkinson's team
- Sleep with your head up thirty degrees
- Eat small frequent meals and rest after eating
- Support or compression stockings - discuss suitability with GP

If you feel dizzy or faint, sit with your legs raised or lie down, until the feeling passes.

If you are unsteady around your home, there is equipment that can help such as grab rails which you can hold and steady yourself with. An occupational therapist could help suggest ways in which home equipment could be beneficial. Discuss this with your doctor or Parkinson's team.

Medication

It is important to have your Parkinson's medication on time so that it can manage your symptoms and reduce your risk of falls. You can speak to your Parkinson's team if your medication is not working well to manage your symptoms. They may adjust your dosage or change the type of medication you are taking.

Low blood pressure (hypotension) can lead to dizziness and falling. This can be a symptom of Parkinson's or a side effect of your medication. It can also be associated with other health conditions such as high blood pressure, dehydration or a side effect of other medication such as drugs taken for prostate problems.

Normally, when you stand up, blood tends to move away from the head and chest down towards the legs. Your body stops blood pooling in your legs, due to gravity, by increasing your heart rate and squeezing your blood vessels to move your blood around the body. If blood does pool in your veins when you stand, less blood returns to the heart leading to less blood reaching the brain. This can lead to dizziness or light headedness, unsteadiness, and fainting.

Constipation can reduce the absorption of your Parkinson's medication which can lead to your Parkinson's symptoms getting worse.

How do I prevent constipation?

- Try to go to the toilet at a regular time or times every day.
- Have a good position on the toilet:
 - Place your feet on a footstool, about 20 to 30cm (8 to 10 inches) high
 - Lean forward and put your elbows on your knees
 - Keep your back straight and bulge your tummy out
- Eat regular meals
- Eat a diet with high fibre foods such as vegetables, fruit, cereals and wholegrain
 - Aim for a total of 20 to 30 grams of dietary fibre each day
- Drink at least two litres, about 8 to 10 cups, of fluid each day
- Exercise regularly if possible

What should I do if I am constipated?

- Drink plenty of water
- Slowly increase the amount of fibre you eat (such as cereals, wholegrain bread, vegetables and fruit)
- Exercise more. Begin by going for a brisk 30 minute walk every day, five days a week and increase this as you get fitter
- Set aside enough time to go to the toilet
- Go to the toilet when you feel the urge
- Use a laxative regularly
 - Discuss laxative options with your GP

- Softening laxatives are effective for long-term use in lower doses
- If you suspect faecal impaction you should contact your GP

Sudden or gradual change in bowel habit, occurring for no obvious reason should be reported to your GP - especially if you are bleeding from your bottom or have new tummy symptoms such as pain or bloating.

Urinary Tract Infection (UTI)

A UTI is a name given to a group of infections that occur anywhere in the urinary tract. The urinary tract includes the:

- kidneys (make urine)
- ureters (connect the bladder to the kidneys)
- bladder (stores urine)
- urethra (takes urine out of the body)

UTIs are usually caused by bacteria getting into your urethra or bladder.

Possible symptoms of a UTI:

- Passing urine more often than usual
- Burning pain or discomfort when passing urine
- Feeling the need to pass urine immediately
- Pain and tenderness in your lower tummy
- Blood in your urine
- Cloudy urine
- Feeling generally unwell, achy and tired
- New onset or worsening of pre-existing confusion

Co-ordination or balance (30 mins or more, 2 times a week)

A yoga or tai chi class can help with balance training. You can also introduce it into your daily routine, such as standing on one leg for short periods.

Strength (2-3 times week)

Strong muscles are needed to maintain and improve our ability to perform daily tasks. You should start slowly to avoid injury. You can use your body weight or a resistance band whilst seated at home.

Flexibility (10-20 minutes daily)

Regular stretching helps to ease muscle rigidity and helps to keep you flexible. Generally, flexibility can help to make everyday movements easier. Consider beginning your day by stretching and warming up your muscles.

How can I reduce my risk of falls around the home?

- Wear good fitting and supportive footwear, not slippers with no back
- Reduce clutter around the home
- Remove any loose rugs
- Remove any trailing wires or leads
- Remove any unstable furniture
- Be careful when reaching above your head or below your knees as this is when you can become unsteady

It is also important to have regular eyesight and hearing tests.

How can I reduce my risk of falls?

Walking

When you are walking, try not to turn too quickly or pivot on the spot. Marching your feet around in the direction you need to turn can help.

Getting into a rhythm when you walk can help you take bigger, more focused strides. You could count each step or walk to a particular tune in your head, for example.

You may experience freezing, where your feet feel stuck to the floor. If you notice issues with balance and freezing, ask your General Practitioner to refer you to a physiotherapist for an assessment so they can advise you on improving your mobility.

Physical Activity

Regular, moderate to vigorous physical activity can improve overall mental and physical health. Activity helps you to maintain and improve your flexibility, balance and posture reducing your risk of falls as well as reducing both anxiety and depression.

Being active for 2.5 hours a week can help you to manage your Parkinson's symptoms. Doing something little and often whilst building up stamina gradually and doing something you enjoy is key. Physical activity can include everyday things such as walking or gardening. There are different types of activities that you can try and include in your everyday routine:

Aerobic (30 minutes, 5 times a week)

Aerobic activity raises your heart rate and improves your muscle tone. This should be moderate to high intensity and can include walking, cycling, dancing, or swimming.

How do I prevent a UTI?

- Drink enough fluids to make sure you pass urine regularly throughout the day
- Try to empty your bladder fully every time
- Wear loose fitting cotton underwear
- Change incontinent pads frequently
- Reduce the amount of caffeinated coffee, tea or alcohol you drink
- Women should wipe from front to back after going to the toilet
- Avoid lots of sugary foods, eat lots of fruit, vegetables and high fibre foods such as whole grain bread and pasta
- Pass urine as soon as you feel the urge
- Pass urine after sexual intercourse

What should I do if I have a UTI?

- Drink enough fluids to stop you feeling thirsty
 - Aim to drink 6 to 8 glasses of water, decaffeinated and sugar-free drinks
- Take paracetamol or ibuprofen at regular intervals for pain relief, if you've had no previous side effects
- Contact your GP for an urgent (same day) appointment or dial NHS 111

Any infection, such as a chest or skin infection, can lead to a deterioration in Parkinson's symptoms. Once successfully treated, you should return to your normal level of functioning, but this can take several weeks to occur. Your Parkinson's medication will NOT need to be changed during this time.

Dehydration

Dehydration occurs when your body loses too much fluid. The most common reasons for becoming dehydrated are vomiting, diarrhoea, high temperature or fever and not being able to drink normally.

Possible symptoms of dehydration include:

- Thirst
- Dizziness or light-headedness
- Headache
- Tiredness
- Dry mouth, lips and eyes
- Passing small amounts of urine less often
- Dark yellow and strong-smelling urine

The symptoms and signs vary depending on how severe the dehydration is.

What should I do if I am dehydrated?

- Increase fluid intake. If it's difficult to drink or you keep being sick, then keep taking small sips of fluid and gradually drink more if you can
- Drink enough during the day so your urine is a pale clear colour
- Eat food with a high-water content such as soups, jellies or fruits like melon
- If you're being sick or have diarrhoea and are losing too much fluid, you need to put back the sugar, salts and minerals that your body has lost. Your pharmacist can recommend oral rehydration powder sachets

- 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

Call 999 or go to the Emergency Department if you have any of the following symptoms:

- Feeling very weak and tired
- Feeling confused or disorientated
- Dizziness
- Not having passed urine for eight hours
- Cool hands and feet
- Rapid heartbeat
- Low level of consciousness

Falls

The risk of falling in Parkinson's can be associated with muscle stiffness, reduced mobility, and balance issues. Dizziness and falling can be a particular issue in Parkinson's. This can happen because of a drop in blood pressure that is linked to Parkinson's medication or the condition itself.