

**PARKINSON'S<sup>UK</sup>**  
**CHANGE ATTITUDES.**  
**FIND A CURE.**  
**JOIN US.**



## **WELCOME TO THE MAY 2023 NEWSLETTER.**

This is your Newsletter, and it is important that it contains information that you want to read and not just what I choose. If there is anything you would like to include that might benefit others, please send me an email and with any links that I can share.

**Carers** – as we are a voluntary group of Parkinson's UK, we are unable to assume any responsibility for the action or needs of any individual and therefore it is strongly recommended that anyone who needs support should have a carer with them at all times.

## **TWO MORE POEMS/LIMERICKS WHICH HAD BEEN SUBMITTED TO CELEBRATE WORLD PARKINSON'S DAY APRIL 2022**

1. My Dad, my Superhero

Some days are "on".

Some days are "off".

But live to the full he will.

Celebrating together all days "on"

Olivier, London, Family member of someone with Parkinson's

2. I wish I had a crystal ball

Then I could predict when we'd cure you all

But for now, until that day

Drink plenty and exercise,

is what I say?

Christine Parker, Parkinson's Nurse Specialist for Buckinghamshire NHS Trust

**NAME THE ICONIC BUILDING** Well did you manage to recognise Tower Bridge from the cropped picture in the last issue. (full picture below) It would seem that it was an easy one this time, but if you did get it right, well done!

See if you can recognise this month's iconic building with only part of the picture revealed. No prize just pride in getting it right! Answer in the June Newsletter.

Quite a few of you responded so I intend to continue the theme.



## EVENTS PROGRAMME FOR MAY AND JUNE.

The Stockport Branch of Parkinson's UK meets every Wednesday between 2pm and 4pm at Stockport Masonic Guildhall, 169/171 Wellington Road South, Stockport, SK1 3UA. All are welcome and free parking is available at the rear of the building. For more information, please email me at: [stephen.scott687@yahoo.co.uk](mailto:stephen.scott687@yahoo.co.uk).

May 3rd	Singing with Helen.
May 10th	Sitting exercise class.
May 17th	Magistrates in the Community.
May 24th	Sitting exercise class.
May 31st	Sitting exercise class.
June 7th	Singing with Helen.
June 14th	Sitting exercise class.
June 21st	No meeting. Room not available.
June 28th	Sitting Exercise.

## HEALTHWATCH STOCKPORT DEMENTIA AWARENESS DAY

**On Thursday 18<sup>th</sup> May**, Healthwatch Stockport are hosting a collaborative event to find out more about Dementia and what support is available throughout the borough. The event will include stalls from organisations, charities, community and voluntary sector across Stockport that support Dementia - where you can see what's available for you and your loved ones.

It is hoped to have a stall representing our own Branch of Parkinson's UK. Giving out leaflets and information about our Wednesday club. If you can help in manning the stall, please let me know. (There will be no collecting of money)

### **More information and to book on**

**Event details:** Thursday 18th May 2023 10:00am - 16:00pm  
Stockport Town Hall, Edward St, Stockport SK1 3XE

**CO-BENELDOPA (INCLUDING MADOPAR.** Important changes about (special container) status. You might be already aware of these changes, but I felt it was important to share. From 1 February 2023 all Co-beneldopa products, including Madopar, have been provided in pack sizes of 100 only.

This change means that people with Parkinson's should speak to the person who prescribes their medicines, usually their GP, to ensure their prescription for Co-beneldopa or Madopar tablets and capsules, of all strengths, is adequate.

When the quantity prescribed falls exactly between 2 containers, pharmacists have been told to round down, and supply the nearest complete container. When the quantity ordered is more than halfway into the second pack size, the second complete container should also be supplied.

This could mean that a person with Parkinson's might need to access their next repeat prescription either a few days earlier or later than they usually would have done.

For example, a person who receives a decrease in supply, compared to the usually prescribed quantity, may need to access their next repeat prescription a few days earlier. However, a person who receives an increase in supply compared to a prescribed quantity may need to access their next repeat prescription a few days later.

What you should do

If you take Co-beneldopa or Madopar, this change could mean you get more or less than you're used to.

If this is the case, speak to your prescriber to ensure you have enough medication and that this change is reflected on your records.

Pharmacists and their teams should explain what these changes mean to each person affected.

### **GOING INTO HOSPITAL?**

**Below is an extract from NICE (National Institute for Health and Care Excellence) Quality standard (QS164) Published: 09 February 2018 regarding the administration of Levodopa to persons with Parkinson's disease whilst in hospital or a care home.**

#### **Quality statement**

*Adults with Parkinson's disease who are in hospital or a care home take levodopa within 30 minutes of their individually prescribed administration time.*

#### **Rationale**

Serious complications can develop if levodopa is not taken on time. These include acute akinesia and, if delays are significant, neuroleptic malignant syndrome. These complications can lead to increased care needs and increased length of stay in hospital or a care home.

#### **What the quality statement means for different audiences**

**Service providers** (hospitals and care homes) ensure that adults with Parkinson's disease are identified on admission so that their requirements for levodopa can be accurately identified and monitored to reflect timings before admission. This should include an assessment of self-medication. Providers should ensure that staff are trained to understand the importance of taking levodopa at the appropriate times, and to report any medicines-related patient safety incidents.

**Health and social care practitioners** (such as doctors, nurses, pharmacists, and care home managers and staff) ensure that adults with Parkinson's disease have an accurate medicines chart that reflects timings for levodopa before admission. Practitioners should support adults with Parkinson's disease to take levodopa on time, which may include self-medication. Practitioners should report any medicines-related patient safety incidents for adults with Parkinson's disease.

**Adults with Parkinson's disease who are admitted to hospital or a care home** know that they need to take their levodopa medicine on time and are supported to do so. This will ensure that they do not develop complications that can happen when this medicine is not taken at the right time.

**MEMBERSHIP OF PARKINSON'S UK** Parkinson's UK depends on your membership and donations to fund research. If you are not a member yet, please ring the Help Line number below or go onto the Parkinson's UK website. [This applies to carers too!](#) Membership is free but, if you decide to donate on joining, membership subs do come to the branch eventually. Team Parkinson's brings together everyone who cares about Parkinson's. Join the movement to transform lives and find a cure. <https://www.parkinsons.org.uk/>

**COVID-19 TESTING APPROACH FROM APRIL 2023** Changes to COVID-19 testing came into effect on 1 April 2023, to ensure testing continues to focus on those at highest risk, enables appropriate clinical treatment and supports the management of outbreaks in high-risk settings including health and social care. For more information: <https://www.gov.uk/government/news/covid-19-testing-approach-from-april-2023>

**FUNDRAISING AT MORRISON'S STORE FRIDAY 14<sup>th</sup> APRIL** A big thank you to all who collected and helped to raise £673.92, and to the generous customers at Morrisons Cheadle many of whom stopped to chat and find out more about Parkinson's disease and our particular branch.

**A DATE FOR YOUR DIARIES** We are planning to have afternoon tea at The Unitarian Chapel, Dean Row, Wilmslow on Sunday 23<sup>rd</sup> July at 2.30pm. This was highly successful event when we had it last year so something to look forward to. More details to follow.

**ANOTHER DATE FOR YOUR DIARIES** The Trafford Branch of Parkinson's UK will be hosting a presentation by the Parkinson's UK Research Team. Date: 27<sup>th</sup> June 2023, 7.0pm for 7.30pm. Larkhill Centre, Thorley Lane, Timperley. WA15 7AZ. More details to follow in the June Newsletter.

### **NEW LAB TEST COULD HELP IMPROVE EARLIER DIAGNOSIS OF PARKINSON'S**

Those of you who visit the Parkinson.org website might have already seen this exciting news. Again, I felt it important enough to share.

Latest study results show a new test could help diagnose Parkinson's before cell damage occurs.

At the moment, there's no definitive test to confirm a Parkinson's diagnosis. This means that currently, it's estimated that 26% of people with Parkinson's are misdiagnosed at first. A simple diagnostic test for Parkinson's would help people have a smoother diagnosis, allowing them to get information, support and access to treatments and therapies more quickly.

What does the new test do?

The lab test involves taking a sample of cerebrospinal fluid (CSF), a clear liquid that surrounds the brain and spinal cord, via an injection into the spine called a lumbar puncture.

The research team then uses this to look for a protein called alpha-synuclein. In Parkinson's, clumps of a misfolded form of the alpha-synuclein protein can be found. This toxic form of the protein can damage dopamine-producing cells and may be responsible for the development and spread of the condition in the brain.

For more information, please follow the link: <https://www.parkinsons.org.uk/news/new-lab-test-could-help-improve-earlier-diagnosis-parkinsons>.

**FREE TO A GOOD HOME** One of our members has asked me to ask if anyone could make use of unopened, sealed night and day urine bags for catheters before they must be thrown away. If you can use these please let me know so that I can pass your details on.

**OUR RECORDS** - It is imperative that our list of contact numbers for next of kin etc is kept up to date. Please let Helen have any changes. Many thanks.

**LINKS** - To open any links in this newsletter – right click and select Open Hyperlink or in some cases you might need to copy and paste to a browser.

**USEFUL PHONE NUMBERS** - Karen Walsh (Local Adviser) – 0344-225-3738.

**PARKINSON'S UK HELPLINE** - 0808-800-0303

**PLEASE NOTE:** - All pictures and articles in the Newsletter are printed with kind permission of those portrayed or linked.

I appreciate that not everyone uses technology and therefore will not be able to follow the links on the Newsletter. If you want more information on any item, please contact me directly on 07941534670 and I will strive to get the information to you another way.

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