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The Marjorie Collins Wellbeing Centre

Working for and caring about You

NEWSLETTER APRIL 2023

Produced by Pauline
Connolly: Volunteer and
PWMS

*MS Awareness Week
2023 runs from 24-30
April. This year the
focus will be on mental
health and MS.*

Centre News:

- **Lunch update:** From Monday 6th March 2023.
- Charity Collection dates
- June's Afternoon Tea: **Monday 3rd July**
- **Don't Forget: The Centre will be closed Thursday 6th April and reopen Monday 24th April 2023**
- Centre Activities
- MS Society Awareness Week
- MS Research

CENTRE NEWS

LUNCH UPDATE: MONDAY 6th MARCH

As we all know, the cost of living has gone up dramatically and has affected all of us. Bearing this in mind, as from Monday 6th March, the price of lunch will go up to £7.00. It has become necessary to do this - for example - the price of fish and chips is £8.50.

If you require lunch - Please ring Lorna before 11 to place your order. Otherwise - please could you continue to bring in your own prepared ready to eat lunch (including disposable cutlery).

Personal Assistance:

If you require **ANY** assistance with walking, eating or your personal care - please note -

You **MUST** bring a carer with you as we are unable to provide assistance.

TRANSPORT:

As you know, Centre transport is extremely limited. Please could we ask you to arrange transport to and from the Centre.

Contactless payment:

Wherever possible please use our contactless service to pay for lunches, treatments etc.

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Centre Activities:

FUND RAISING

June's Afternoon Tea: Monday 3rd July 2023

Monday 6th March raised £232.00.

Please could I ask you, family and friends to continue to donate through our JustGiving page on:

www.msredbridge.online or in person at the Centre. Kind regards, Lorna Lawrence. *

More fund-raising events:

What type of events would you like to see at the Centre?

What do think would work well at the Centre?

Speak to Caroline at the Centre. Your opinion matters.

Charity Collection Dates at Morrisons

Friday *12th May 2023

Friday 4th August 2023

Wednesday 6th September 2023

*Volunteers needed for Friday 12th May - please speak to Lorna Lawrence.

Centre Closure dates:

Easter Break: Last day will be Thursday 6th April and will reopen on Monday 24th April 2023.

Summer Break: Last day will be Thursday 3rd August 2023 and will reopen on Monday 21st August 2023.

Winter Break: Last day will be Thursday 14th December and will reopen Monday 15 January 2024.

There will be three bank holidays in May:

Monday 1st

Monday 8th (for the King's Coronation)

And Monday 29th

MS Nurse News: We now have the services of a new Redbridge MS Nurse i.e., Nurse Bola. Nurse Bola will be at the centre on the last Thursday of every month.

MS NEWS:

MS Society Website: 17th March 2023:

This week the UK Government announced their biggest planned changes for disability benefits in a decade. We look at what these proposals mean for people with MS.

Some of these changes might be concerning, but they aren't coming in for years, so we have lots of time to campaign for them to work for people with MS.

The Good

1. Specialist benefit assessors

The UK Government will start testing the use of specialist assessors for specific health conditions. This means people with MS might no longer have to explain the basics of MS to their assessors.

We called for this in our PIP fails campaign. Over 20,000 of you signed our petition. It's great to know our campaigning can make a difference.

2. Automatically sharing assessment reports

The UK Government will test automatically sharing assessment reports with claimants before a decision has been made.

We're very pleased, as this is something we've been calling for, for years. It means people will see their assessment report without having to ask for a copy.

People with MS tell us their reports don't always reflect what happened in their assessment. Seeing the report before a decision means people can question it before the decision happens - and hopefully get the benefits they're owed sooner.

3. Energy Price Guarantee extended

The Energy Price Guarantee will be extended until June. That limits the unit cost on gas and electricity and the standing charges from energy providers.

This is a campaign win. We joined over 100 charities and Martin Lewis, the Money Saving Expert, to call for this.

The Bad

1. More people could face work-related requirements

The UK Government plans to scrap the Limited Capability for Work and Work-Related Activity (LCWRA) group. This means more people with MS could be made to carry out inappropriate work-related activity or face the threat of losing their financial support.

And whether people do lose that support (face 'sanctions') will depend on the individual work coach. We think this is unfair and subjective.

There's no evidence that sanctions get people into work. We want them to be scrapped for people with MS.

2. No increase to the rates of benefits

We're very disappointed the UK Government has made no commitment to increase benefits rates. People living with MS on benefits are at breaking point and making do with too little money.

We want them to increase the rate of benefits and increase them in line with inflation twice a year, rather than once.

The UK Government must also remove the benefit cap, two child limit, and debt deductions. We've been campaigning for these changes as part of our Breaking Point campaign.

And the Ugly

1. Support to get into work

The UK Government will change Universal Credit, so people can get back into work without the risk of losing their benefits. But we don't want people to be sanctioned for not giving work a go when it isn't appropriate.

If the UK Government is serious about increasing the number of people in work, people need to be supported to stay in work, and that work needs to be good. Read our proposals to make employment work for people with MS.

2. Removing the Work Capability Assessment

The UK Government is getting rid of the Work Capability Assessment (WCA). This means people on Universal Credit who get extra financial support for a health condition will be assessed by the Personal Independence Payment (PIP) assessment.

While many people with MS will welcome one fewer assessment, we know PIP does not work. Lots of people with MS are inaccurately assessed as part of PIP. So, people risk losing even more of their financial support.

If the UK Government wants to rely on PIP, it must make it work. This means making the assessment criteria fit for purpose, including scrapping the 20m rule. Read more about

our PIP and benefits campaigning.

What happens next?

These changes won't be brought in for years and there are lots of opportunities for us to campaign for better.

Benefits and the cost-of-living crisis are two of our key priorities for the rest of the year. Stay tuned for news on how you can get involved.

MS Awareness Week 2023

MS Awareness Week 2023 runs from 24-30 April. This year the focus will be on mental health and MS.

For the first time we've joined forces with other MS charities to deliver a united message for #MSAwarenessWeek.

We want to share a wide range of your stories about mental health for the media and on our social accounts.

If you'd like to know more and share your experiences, please email pressoffice@mssociety.org.uk.

The MS Society will share more in the coming months on [Facebook](#), [Twitter](#) and [Instagram](#).

MS SOCIETY RESEARCH: On-line Disease modifying tool, Octopus trial.

The MS Society recently launched a new tool to help people with MS explore treatment options and prepare for conversations with health professionals.

The tool asks a series of questions then suggests treatments that seem a good match based on what you tell it.

The tool's suggestions are not recommendations. You can use them as a starting point for a conversation with your neurologist or MS nurse who will be able to tell you which treatments are available for your MS.

****NB: You can only access this new tool via the MS Society website.**** If you are interested in using this online tool, then it will take about 15 mins to complete.

Why make a new DMT tool?

Evidence shows [treating MS early can slow progression](#). But deciding what therapy to take, or if you want to take one at all, can be one of the hardest, most personal choices someone with MS will make.

There are now around 20 approved branded therapies for MS. They're all different in terms of how you take them, what side-effects you might experience and how they impact your daily life.

Our [DMT information pages](#) can help people make this decision. And our [MS Helpline](#) is here for people to chat things through with. But

with a choice like this we wanted to go a step further to empower our community to explore their options and find the best DMT for them.

** (I have printed out just a few of the information pages contained in links from the MS Society website on these subjects. They are on the table where the signing-in pages are) - Pauline**

Octopus is a revolutionary trial that will transform the way we test treatments for progressive MS. A smarter way of testing potential treatments, it could deliver life-changing new treatments up to three times faster.

The trial team have now confirmed the first treatments they'll be testing. And right now, the trial team are working hard to get hospital sites around the UK ready for people with primary and secondary progressive MS to take part.

Register your interest in taking part in Octopus

We won't know if these drugs slow disability progression until 2028 at the earliest. This is because **Octopus** is combining what would normally be two separate trials into one. In the meantime, we'll be watching out for the results of other exciting trials for progressive MS, including MS-STAT2 and ChariotMS.

How does Octopus work?

Octopus uses what's called a multi-arm, multi-stage (MAMS) design - the first time this has even been done in MS.

MAMS trials make it possible to test new treatments up to three times

faster by:

- Testing multiple drugs at once - and comparing them with a single control group.
- Using **MRI** to get an idea of whether a drug looks like it has potential, many months before we'd be able to see an effect of the drug on disability progression. Promising-looking drugs stay in the trial, with hundreds more people joining the existing participants. So, what would normally be two consecutive trials are delivered in one.
- Adding the flexibility to drop drugs that don't look promising, and slot in new drugs as they're discovered.

Merging separate trials may sound obvious. But launching a MAMS trial for MS needs so many things to line up perfectly. From hospitals around the country equipped to be trial sites, to the incredibly complicated statistics that underpin the design.

Memory Cafe:

The next cafe, which is sponsored by the Barking and Redbridge Rotary Club, is Wednesday 26th April 2023. Thereafter it will be on the third Wednesday of the month. As usual the cafe is free of charge.

Please ask friends and family if they could shout out for new volunteers to sign up:

We still urgently need new volunteers (including volunteer drivers,

passenger assistants). They will need to commit to a few hours on Tuesdays and Thursdays. If you know of anyone who would like to volunteer, please ask them to contact Lorna at the Centre.

Members and Centre Users contact details.

If any of your address details, phone number/email address etc have changed in the last year - Could you let us know so that we can have the latest details on file for you.

MS National Help Line

The MS National Help line has a world of information at their fingertips and is able to offer advice and support to anyone who needs it. Please, if something is worrying you or you don't know where to go for help or you just have a general enquiry then please give them a call on: 0808 800 8000 where a member of the dedicated team will help you.

Centre

Activities:

Fit for fun free classes:
led by Rama:
NB: contact her directly.
Number available from reception Mondays

Centre

Activities

Hairdressing:
Katy:
Every Tuesday
10.30-13.30

Chiropodist:

Thursday 9
March

Centre Activities

Card Craft: Tuesdays: 2pm-3pm
Bingo - Tues 11.30am -12pm and
Thurs 12pm-12.30pm
Boccia: Tuesdays and Thursdays
Foot Clinic - Thurs 1pm-3pm
(Appointments only)

Special Thanks to each and every one of you who Volunteer at and support the MCWC Marjorie Collins

11:00-12:00
Tuesdays
12:00-1:00

Nails,
Thursdays, by
appointment
only

Wellbeing Centre, not only with
your regular work but also for
committing to collection dates and
fundraisers. Truly amazing, well
done.

Daffodils

Yellow, yellow daffodils

You are dancing in the sun

Yellow, yellow daffodils

You tell me Spring has come

DIRECTORY

MS Society

MS National Centre
372 Edgware Road
London NW2 6ND
020 8438 0700

National MS Helpline

0808 800 8000

Membership

0300 500 8084

supportercare@mssociety.org.uk

Contact DWP

Barking Citizens Advice

Barking Learning Centre 2 Town
Square
BARKING Essex
IG11 7NB

<http://www.bdcab.org.uk/>

020 8594 6715/020 8507 5969

Redbridge Citizens Advice

Broadway Chambers 1 Cranbrook
Road
ILFORD

Essex IG1 4DU

<http://www.citizensadvice.org.uk/redbridge>

General information

DWP Online Helpdesk 0800 169 0154

Telephone: 0345 850 3322

Textphone: 0345 601 6677

Monday to Friday, 8am to 6pm

DWP - Personal Independence

Payment claims

PIP enquiry line

Telephone: 0800 121 4433

Textphone: 0800 121 4493

Monday to Friday, 8am to 6pm

Women Against MS:

confidential Cosupport and advice for women who have MS, their carers, families, friends, and employers. 020 8542

1712info@womenagaistms.org.uk

0208 514 1878 (for general enquiries only - not an advice line)

Newham (East End) Citizens Advice Bureau

300 Mare Street, London E8 1HE

0208 525 6350

<https://www.eastendcab.org.uk/newham>

SUPPORT GROUPS

Asian MS

A national support group for Asian people with MS, their carers, friends, and family.

asianms@mssociety.org.uk

Mutual Support (Armed Forces)

For serving and ex-serving members of the Armed Forces and Reserves affected by MS, their dependants, and carers.

support-team@mutual-support.org.uk