MS Society

Lancaster, Morecambe & District

Summer Edition

Welcome to the Summer Edition of our Lancaster, Morecambe & District Local Support Newsletter.

It was MS Awareness Week (20 April – 26 April) which was a week of educating on and challenging the assumptions people may have about multiple sclerosis (MS), whilst also highlighting the great support that can be found when different communities come together in support of the long-term condition.

This was followed swiftly by Mental Health Awareness Week (11 May – 17 May), another key occasion closely tied to the MS community. The Week highlighted the importance of looking after your mind and wellbeing; especially when situations are challenging or tough.

In this edition, we take a closer look on the assumptions made on people with MS, an update on Fampridine, along with information on our upcoming social event.

See you soon &
with the warmest regards,

Claudia Mok

Chair & Group Coordinator Volunteer

MS Society
Lancaster, Morecambe & District Branch

What's inside...

Upcoming Bake Sale 04.07.26

Great news! We're holding a Bake Sale to raise money for our Charity. We'll be at **The Trimpell Sports & Social Club, Morecambe LA4 4UP, from 10am-4pm.** Please do come along and support. **Kindly note this will be a cash/coins only event.**

If you have any suggestions on Socials which you'd like us to host, please contact us via: **lancastermorecambe@mssociety.org.uk.**

MS Awareness Week: Challenging Assumptions - MS and symptoms

Volunteer MS Society Writer
Claudia Mok

In the lead up to MS Awareness Week, MS Society asked over 1,600 people living with MS what assumptions they face and the impact it has on them. They found that there was a general lack of understanding about MS symptoms, and people often felt judged because of their MS.

Lack of Understanding of MS

MS and symptoms can be invisible. Invisible disability is when a disability is not visually obvious. Of the survey, it was found that “half (50%) have been made to feel like their invisible symptoms aren’t real. And 81% of people report that they’ve been told that they ‘don’t look sick’, or received similar comments.”

What this shows is that, sadly, too often assumptions are made about people with disabilities that are not visible; especially when in relation to public spaces, like that of changing areas, toilets, or parking spaces to name a few. Some people may wish to disclose their disability by wearing a lanyard or carrying a badge, however others may prefer not to.

MS Awareness Week reminds us that not all disabilities or symptoms are visible, and for people with MS, sometimes symptoms can vary and change depending on the individual’s body and circumstance.

There still needs to be more education on MS and symptoms, but it is of course OK to not have a great understanding of what MS is to begin with. Information from MS Awareness Weeks and related events provides a way to learn more about MS; including how to self-manage or support others living with MS.

MS Awareness Week was closely followed by Mental Health Awareness Week (11 May – 17 May), which promoted the need to take care of our mental health and wellbeing. From holding events and speaking to people with MS, we as a local support group (MSS Lancaster, Morecambe & District) have heard of the many feelings and emotions MS can bring: stress, anxiety, worry, fatigue, feeling judged, feeling different, feeling embarrassed, to name a few. MS can understandably take its toll on a person's mental health and wellbeing. Information, signposting, and a general chat with someone can greatly help.

What MS Awareness Week & Mental Health Awareness Week has shown is that there is always support available and that people do not have to face their problems alone.

Please see below the webpages you can visit for more information, and do look out for our upcoming social events in this newsletter and online (Facebook and Instagram).

https://www.mssociety.org.uk/research/news/ms-awareness-week-survey-reveals-impact-assumptions

https://www.mssociety.org.uk/living-with-ms/physical-and-mental-health/mindfulness-and-ms

Our Partnership with CancerCare

As mentioned in our previous newsletter and on social media, we've launched our partnership with CancerCare .

MS Society Registered charity no.: 1139257 / SC041990

Great news! We'll be renewing our partnership with CancerCare, funding 6 free sessions of a service provided by CancerCare to people affected by MS.

The services available include (but are not limited to): counselling, hypnotherapy, EMDR, massage, aromatherapy and reflexology.

Depending on the type of service, these sessions can be in person or online at CancerCare's Morecambe or Lancaster centres.

If you're affected by MS and would like to be in receipt of this service, you'll need to self refer to CancerCare where an assessment will take place to see which service is the most suitable.

Please contact CancerCare to self refer: 01524 381820
Alternatively, if you have any questions, please email us direct at: lancastermorecambe@mssociety.org.uk
(Please note: to manage demand as a complementary service, spaces for the year will be limited; please contact CancerCare for more info.).

What other services would you like to see? Visit the link below and let us know: https://forms.office.com/Pages/ResponsePage.aspx?id=EZXw0P8H8kO2galYcKVmVtkUFi8tJxhLgRiiYpwKi85UQThKRUxBMzFUTEMyNE8xUzU4MkE4MjQyRi4u

Or alternatively, email us direct:
lancastermorecambe@mssociety.org.uk

MS Awareness Week: Challenging Assumptions - an insight

Volunteer MS Society Writer
Rose Stanley

MS Awareness Week 2026 ran from 20th to 26th April this year and the theme was challenging assumptions. MS charities across the UK shared stories from people living with MS to raise awareness about this condition, how varied it can be, the ways it can affect daily life and the harm that assumptions can cause.

Two people who have MS shared their experiences for this article.

What assumptions have people made about your MS?

‘People can be too quick to try and help, and it can be more than you need. Like if my balance starts to go, people will grab hold of me when all I need is a little nudge. Their hearts are in the right place but they think it’s one rule for everyone.’

What would you want others to know about MS?

‘People assume that if you’ve got MS, there’s only one way it can be. But it’s different for everyone.’

“Have a rest.” This is such a difficult statement for someone living with MS. Having MS and struggling with movement means your brain is working incredibly hard to move your legs. Signals don’t naturally flow, so every step is a complete thought process: ‘Will my foot lift off the ground? Make sure you don’t catch that slight unevenness on the ground. Is there a slope? Make sure you swing your leg through. Is your foot going to land flat? Keep your balance. Make sure you transfer your weight onto the other leg…’ The list is endless. Within no time, you’re exhausted. Your brain has been focused 100% for what feels like forever. “Have a rest, then we’ll carry on.” Nope! My immune system does not work in that way. Once I hit the point of complete exhaustion,

no 10-minute rest will do. I lose my ability to think, form words, function in any way and the only thing to do is sleep.

“It’s a lovely day, you have your scooter, let’s go out.” If only it was that simple. I have to structure and plan everything I do now. I have to know where I’m going and then think: Is the path flat? Are there any hills? Will the battery last? How far is it? Will I need to stop for a toilet break? Are there toilets where we’re going? Will they be accessible? Once I loved jumping in the car and going somewhere new, now I need to plan it to every detail. Life has changed, but as long as I plan, I don’t miss out. Plans just need to change a little these days.’

If you have any stories you would like to share, please get in touch with us @ lancastermorecambe@mssociety.org.uk

Directory

Did you know there’s a directory for people in Lancaster?

This online resource has been developed to make it easier for people with MS to spot accessible places and venues.

It's also a great tool for people looking for services in general for a fun social outing.

Head over to the website and take a look: https://lancastercvs.org.uk/directory/

MS Update: Fampridine

Volunteer MS Society Writer
Natasha

You may have heard the name 'fampridine' or brand name Fampyra in the news recently. Fampridine is currently the only drug with a licence to improve walking speed in MS. It is taken as two tablets a day, 12 hours apart. These tablets are slow release and so taking them in this way ensures the levels remain stable in the body. Although it is not known for certain how fampridine works, it is believed its efficacy is linked to how it keeps potassium stored in nerves. The movement of potassium in and out of cells helps signals move along nerves, which stimulates muscles to work. By keeping potassium in nerves, fampridine makes them work better, with the result that you can walk faster. Some people find the drug also helps with their thinking and memory, how easy it is to use their hands, or with a tremor (uncontrollable shaking of an arm or leg).

While fampridine isn't suitable for everyone, those who do have success with the treatment can see their walking speed up by an average of 25%. People who have taken this have also found a positive effect on other MS symptoms like foot drop, dizziness, balance or fatigue. Despite these other noted benefits, fampridine is only available if it is noted that it helps improve walking speed.

Although this treatment is available on the NHS in Wales, Scotland and Northern Ireland, it has not been made available in England. Back in 2022, the National Institute for Health and Care Excellence (NICE) decided not to recommend fampridine for use in England, as they believed it not to be cost effective. Although this has been reviewed since this date, and it was agreed that NHS England would review

fampridine alongside other treatments, this process has been delayed several times, most recently in May 2026.

Currently, the only way patients in the UK can access this treatment is privately, which can cost between £200-£600 a month. However, the patent for Fampyra is due to expire in July 2026. This will open the doors for other companies to begin manufacturing and selling cheaper versions of fampridine. NHS England is likely to take this into consideration when they eventually hold their review.

We will of course be monitoring this closely and will provide an update as things change.

Donations

As a local charity, we depend on local volunteers and funds to provide support to our communities and continue running.

You may have noticed some collection tins dotted about in local shops around Lancaster, Morecambe and District area.

Please help encourage people to pop some change in there - it could make a real difference to our group and the communities we support.

Donations can also be made via our Enthuse page. All proceeds go directly to our group account.

Click here to find out more: https://msgroups.enthuse.com/lancastergroup/profile

Useful contacts

MS Society Helpline Number: 0808 800 8000

CancerCare (Lancaster): 01524 381820

Citizens Advice North Lancashire: 01524 481508

Disability Equality North West: 01772 558863

Lancashire Carers Service: 0345 688 7113 (option 2)

Lancashire County Council: 0300 123 6701

Lancaster City Council: 01524 582000

Lancashire County Council Adult Social Care: 0300 123 6720

Church By The Bay: 01524 406070

Lancaster District CVS: 01524 555900

Lancashire Age UK: 0300 303 1234

Follow us on Social Media:

Facebook page: Lancaster and Morecambe MSS
Instagram: mssocietylmb

Updating your contact details:

If you change any of your contact details then please let us know so that we can update our records and ensure that we're able to keep in contact with you.

Please email lancastermorecambe@mssociety.org.uk with your change in: Address - Telephone number - Email address

We'll contact you as soon as possible.

With thanks from The MS Society Lancaster, Morecambe & District Volunteers Team:

Claudia - Chair & Group Coordinator
Rose - Group Administrator
Natasha - Digital and Communications
Helen - Finance - Accounts
Vicky - Activities & Events - Organiser
Paul - Activities & Events - Social

Multiple Sclerosis Society. Registered charity no 1139257 / SC041990

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