



East Cumbria

**Take time to
nurture your
inner garden**

Newsletter: Issue no. 18 – Autumn 2023

What's in the autumn newsletter



The year is rushing by. It's easy to get swept away in the daily turmoil, and can be hard to find the strength and presence of mind to step out of the race. In busy and anxious times, it can be difficult to stop and think about our own care. But just as we shouldn't wait to water our gardens until the plants droop and wilt, we shouldn't wait until we're totally stressed and burned out to consider our inner selves – be proactive! Don't get dragged under: take control of your wellbeing and find ways to flourish that work for you. This is as true for people with MS as it is for those who care for them.

In this newsletter, we reflect on the impact on partners and families of becoming a carer for somebody with MS; in light of the ongoing pressure of the cost of living, we share details of our small grants scheme; and we provide information on the

Patient Advice & Liaison Service to help empower you to resolve issues you may be having with your treatment by the NHS.

This edition puts the spotlight on Felix Young, Programme Manager for Bike the UK for MS, and we meet some of the Bike the UK riders who braved storm Betty on the first leg of this year's Sea to Sea adventure. Finally, we hear from Deb Cheshire about the realities of living with, and caring for, a person living with MS.

Remember, East Cumbria Group is here for you: you're not alone. If we can help or support you in any way, please reach out. If you've got comments, suggestions of new activities, or if you have news or a personal story you'd like to share, we'd love to hear from you – do drop us a line (all our contact details are on the back cover).

Caring for others & yourself

The journey from husband, wife, partner, son, daughter... to *carer* can be a tricky one – it's usually not something we expect, or want. Nevertheless, 3 in 5 of us will be a carer at some point in our lives.

Whether that journey is sudden or gradual, it may affect family and work relationships, and friendships; it's likely to involve healthcare and bureaucracy; and may leave you feeling frustrated and alone.

Fortunately, there are organisations that support carers. For example, *Carer support Carlisle & Eden* (www.carlisle-eden-carers.org.uk) offers free information, social activities and a listening ear (Penrith: 01768 890280; Carlisle: 01228 580214). You can find out more about some of their events at tinyurl.com/24bs47ym, and we've pinned more information about carer hubs on our Facebook page: www.facebook.com/groups/ECMSS/.

Supporting or caring for someone with MS can be emotionally and physically demanding. When you're immersed in that role, it's easy to neglect your own health and wellbeing. Nevertheless, it's important to find ways to help recharge your batteries and maintain your own physical and mental health.

One way is to take a break from caring. Breaks can take different forms, depending on what's right for you: *e.g.*, you might want to have a break at home, or have a supported holiday.

Social services offer practical and financial support to help with respite care or short breaks. If you're not eligible for this, you could still get help towards the costs from other organisations: find out more about this at tinyurl.com/y9d2kzrx; and there's information about arranging and paying for respite care from the Carers Trust at tinyurl.com/2kxzsrp. To explore your options further, email helpline@mssociety.org.uk.

NE & Cumbria hubs mobility advice & assessment services

North East Drive Mobility, based at Walkergate Park Hospital, Newcastle, has outreach centres based in Teesside and Cumbria. They carry out driving assessments, as well as passenger, powered wheelchair/mobility scooter, and soon also bicycle, assessments for people with medical conditions.

They aim to help people maintain or regain their driving independence; or, if driving is no longer possible, they offer other services that may be useful. If you'd like to learn more about them and how they may be able to help, please visit their website, where you'll find helpful videos that explain their services, as well as a service-user testimonial from a lady with MS: tinyurl.com/hvebcdb3. There's more info about the NE & Cumbria hubs mobility advice service at tinyurl.com/5n8r3fdt.

Or, for more details, feel free to contact Emma Stewart (Driving Adviser) either by phone or email: 0191 2875042, emma.stewart1@cntw.nhs.uk.

Do you have a grant enquiry?

Contact the Coordinating Team
Email: eastcumbria@mssociety.org.uk
Or Call: 07707 684 868

A Team member will confidentially discuss your eligibility with you: *e.g.*,

- *do you have MS?*
- *do you live in the UK?*
- *do you have savings under £6,000*

No

We'll signpost you to www.cac-e.org.uk or the helpline 0808 800 8000

Yes

We'll send you an application form & guidance notes

Fully complete the form & return it to the Team member

We'll explain what's needed so you can resubmit

No

We'll check that your form is complete & ready for assessment

Yes

The panel will check that you've

- *ticked the data-protection box*
- *signed the completed form*
- *included a letter of support*
- *noted any statutory funding*
- *provided two quotes; & will assess*
- *the value for money*
- *your financial position*
- *the impact of the award on you*

We'll refer your application to our Grant Panel

Overview of East Cumbria Group's grant-application & grant-award process

The panel will inform you whether your application was approved or declined

Yes

We'll tell you

- *the grant amount*
- *how long it'll be held open*
- *any conditions that may apply*
- *how long before you can re-apply*
- *to get the supplier to invoice us*

No

You may be able to find help at www.cac-e.org.uk

East Cumbria Group's small grants

We offer small grants (up to £500) to help pay for things to maintain or improve the health and wellbeing of people affected by MS. When awarding grants, we try to be fair, objective and transparent. Within the limits of our annual budget, we aim to have a positive impact and target the greatest needs.

The application process

If you'd like to make an application, you'll need to contact us: email eastcumbria@mssociety.org.uk or call 07707 684 868. A member of the Coordinating Team will help, in confidence, to check your eligibility: *i.e.*, you must have MS, live in the UK and have under £6,000 in savings; you must **not** have had a grant from us in the last year, or have paid for/ordered the item already. If you're eligible, the Team member will send you an application form (and guidance notes), which you'll need to complete and return. The Team member will then check that the form is complete and ready for review; if it is, an anonymised version of your application will be sent to our Grants Panel.

The Grants Panel comprises three other members of the Coordinating Team, who haven't helped with submitting your application. The panel will check that you've

- completed and signed the form;
- consented to data processing;
- provided a support letter from a health-/social-care professional, confirming that the item is needed and suitable;

- provided two quotes;
- provided confirmation of your MS diagnosis;
- applied for any statutory funding.

We aren't allowed to replace local-authority or NHS statutory funding, but we can augment it if you've received only part funding. Statutory funds cover wheelchairs, respite care, home adaptations, *etc.* If you apply to us for such items, you must have applied for statutory funds and provide evidence to show the value of the award, or explain why it wasn't awarded.

When the Panel assesses your application, they'll consider whether:

- the item will make a significant, lasting impact on your health and wellbeing (improve your mental or physical health, increase your independence, strengthen your social inclusion);
- you could afford the item without a grant (reviewing your savings versus the cost of the item and the money you have to live on);
- the requested item is a good value option to meet your needs.

The decision

After the review, we'll tell you the outcome. If successful, we'll tell you the grant amount, how long it will be held open, any conditions (*e.g.*, raising the remaining balance) and how long before you can re-apply. You'll then need to arrange for a supplier invoice to be sent to us for payment. If the award is declined, we'll explain why and may signpost you to other organisations for help.

Spotlight on Felix Young

Hi, I'm an avid cyclist with wide experience in coaching and event organisation, and I'm now the new Programme Manager for Bike the UK for MS. I've been a part of the BTUK community since its inception in 2014, and have experienced it from all angles: as a rider, Route Leader and Board Trustee.

My BTUK story began as a rider on the first John o' Groats to Land's End trip in 2014. The trip had a huge impact, with memories, friendships and experiences to last a lifetime. Sharing the ride, and riding for those we met, brought meaning and drive to our adventure, and it was with pride that we turned the pedals as our part to play in their lives. That sense of excitement, adventure and camaraderie have become part of the DNA of the charity, and continues through all of the riders who've been part of the last 9 years.

I returned in 2016 as a Route Leader. It was amazing to be able to help others, and to see and feel the experience again through those I was supporting.

I've also been a member of the Board of Trustees, a valuable insight into the charity and how it delivers its core values on the road. It's a real honour to be part of a charity that's so keen to innovate, explore and push the boundaries of what's possible. I'm excited by my new role: working with the rest of the team, I'm keen to make this year's trips the best yet, and to do even more to support people with MS.

Dealing with fatigue?

Fatigue is one of the most common invisible MS symptoms; it's also one that people don't fully understand.

Two distinct types of fatigue are recognised. The first, called primary fatigue, is caused by MS damage in the brain and spinal cord; the other is secondary fatigue, which results from living with MS symptoms, like chronic pain or disturbed sleep.

For some people, fatigue is the symptom that affects them most. But there are ways to manage it and to minimise its effects on your life. The MS Society has made a short animation to explain what fatigue is and how to deal with it: see tinyurl.com/adbvhbap.

You can find out more about fatigue at tinyurl.com/yeysedd2



Patient Advice & Liaison Service



Neurology services in Cumbria were severely hampered both by the pandemic and by the retirement of key MS neurologist, David Footitt,

Yvonne Trace and Sheila Greenwood (our Stakeholder Engagement and Regional Development Officers) have continued to attend meetings with NCIC Trust staff, spearheading advocacy efforts to maintain neurology services in Cumbria. This work has been hindered by a Trust-staff restructure, putting a brake on discussions and relationships.

Making things worse, another neurologist has left the region, and MS nurse, Heather Newlove, has retired. In consequence, the nurses are struggling. For patients, this means long waiting times to see a neurologist, slow response times to voicemails, interrupted supplies of DMTs, etc., leaving some people feeling exasperated and lost.

If you're unhappy with the service or treatment you've had from the NHS, you have a right to complain. It's best to raise your concerns as soon as possible, preferably with the people involved in your care. However, if you'd prefer not to do that, you can contact the Patient, Advice and Liaison Service (PALS): tinyurl.com/388yatrr.

PALS can help to resolve the issues you're having, and can give information about the NHS complaints procedure (tinyurl.com/4hyyb4nx), including getting independent help (e.g., via People First: tinyurl.com/4tjbpb52). The PALS team offers a phone, email and text service to patients, families and carers: email, pals@ncic.nhs.uk; freephone, 0800 633 5547; Cumberland Infirmary, 01228 814008; or you can write to the PALS team at the Infirmary. You don't have to sit there feeling alone and helpless!



Meeting BTUK for MS riders at Penrith & Carlisle Rugby Clubs

Meeting Bike the UK for MS riders

About Bike the UK

Bike the UK for MS (BTUK) is a registered charity that offers supported rides across the UK: riders can choose to tackle the Sea to Sea (C2C), Lôn Las Cymru, the North Coast 500 (NC500) and/or Land's End to John o' Groats (LEJoG). With every turn of the pedal, riders raise money both for MS research and, crucially, for local MS Society support groups: e.g., last year, after two members of East Cumbria Group's Coordinating Team rode the C2C and NC500, BTUK donated £1,900 of their sponsorship back to the Group to help sustain our activities.

Part of the ethos of BTUK is to minimise their costs in order to maximise their donations. Riders therefore camp at local Rugby Clubs, or hunker down in village or church halls. Each year, as so much of the money they raise is donated to Groups like ours, we try to meet and greet them at Carlisle and Penrith Rugby Clubs as they pass through on the LEJoG and C2C routes.

This year, to challenge the riders further, and make the ride as tough as possible, storm Betty barrelled into the UK on the eve of the C2C, and threw her weight around for the whole of the first day. Beginning at Whitehaven, the 150-mile C2C route runs through rugged Lakeland (with 11,969 ft of elevation), up Hartside Pass, over the wild Pennines and into Tynemouth. Setting off that morning, the cyclists braved the high winds and rain to start their adventure.

Meet some of the riders

After arriving in Penrith and preparing to set up camp, some of the exhausted, wind-blown riders chatted with us. *"Talking to people with MS, seeing how it affects their lives, helps me understand the condition and puts into perspective the suffering I went through on the ride,"* enthused Matthew Obeng. Rosie Pickering (who has MS) and husband Richard, added, *"BTUK is a great charity. It supports local MS groups, and provides funds for things we take for granted – it buys life back for so many people. Meeting people with MS has been awesome, and inspiring to us as riders. Bike the UK for MS, we love you!"*

Daniel Bell, riding with his friend, Jermaine Crombi, was diagnosed with MS two years ago and is learning to adjust. He said, *"Keeping fit helps – the more exercise I do, the less fatigued I am"*. Dan Derbyshire, back this year as a Route Leader, wanted to put something back and inspire his dad, who has MS: *"I want to motivate people to step out of their comfort zones, to get the best out of themselves, and have the best experiences."*

East Cumbria Group is indebted to BTUK riders for their fundraising, grit and determination, and for helping to raise the profile of MS in the UK. If you fancy a challenge, and would like to raise money for MS research, and for our Group, you can find out more at www.biketheukforms.org.

News from the Coordinating Team

As the year has marched on, we've been busy organising events and attending meetings. At the end of June, we organised a fundraiser at Penrith Morrisons, where we manned an info table for a full week; we also ran a fundraiser at ASDA Carlisle in September: we'd like to thank all those who gave their time to help. In July, we met BTUK for MS riders at Carlisle Rugby Club; in August, we greeted BTUK riders at Penrith Rugby Club. Also in August, we met with Sheila Greenwood, our Regional Development Officer, to discuss a range of issues, including the current lamentable state of neurology services in Cumbria, and plans to organise a recently-diagnosed info day next year. In addition, we met the Volunteer Communications Team to discuss strategies to make their communications more effective.

Throughout the summer, our men's socials continued, but have now

moved to The Near Boot, Carlisle; we also took two more groups of weather-hardy riders to Watchtree for spins around the nature reserve.

The whisper of winter is upon us, as the mornings get cooler, the nights get darker, and Christmas lurks around the corner. This year, we've organised festive lunches at Greenhill Hotel, Wigton, on 10 December, and Roundthorn Country House, Penrith, on 14 January. Save the dates!

We're still working to establish a physio-led exercise class in Carlisle, and a subsidised referral scheme for people who need maintenance therapy. We'll keep you posted.

If there are therapies or activities you'd like us to put on, or stories you'd like to share, do get in touch. And remember, if you need support, just call us (see back cover for contact details) – we're here to help!

Thanks to our generous donors

This quarter, we extend special thanks to Kath Bell for her donations (£265), and we're grateful to patrons of ABW Hardware (£34.34), Cochranes Nurseries (£28.96), Brampton PO (£22.75), Kirkup Butcher (£22.06), The Lunchbox (£7.28) and Mr Browns (£1.17) for their contributions to our collection boxes. Our week-long fundraiser at Morrisons collected £349.83, while our ASDA collection brought £96.21. Payments from the Charities Trust brought a further £114.02. Huge thanks to all of those whose generous donations continue to help our Group to support East Cumbria's MS community.

East Cumbria Group is still offering grants

The National Grants Programme remains suspended, including support for local group applications. However, we're still processing applications, but will continue to review the situation, to keep track of our funds. Although we won't have national support, we'll do our best to award grants on a case-by-case basis.

My Story – Deb Cheshire

You may recall that my husband, Ross, told his story in the last edition of the newsletter. When it was suggested I tell my story as his carer, my initial reaction was, *“but I’m not a carer!”*. However, I chatted to the children, who, with characteristic bluntness, said, *“Of course you are Mum! Could Dad live on his own now without help?”* So here I am: a carer.

I suppose becoming a carer can happen in a number of ways: a catastrophic event, the natural progression as parents age, or, as it has for me, gradually as a loved one’s condition progresses. For many years, Ross’ MS diagnosis had a relatively small impact on our family life, but in recent years it has really made its presence felt! We’ve had to adapt as things have changed, and, in some ways, the progressive nature of Ross’ MS has made that easier, as we just deal with each change as it comes along and get on with it. I’m sure we’ll continue to do so as new challenges arise.

We moved to the Lake District in 2021, as part of our longer-term plan; but MS focuses the mind! We thought, *“If not now, when?”* and decided to make the big move while we could. It’s been a busy time while we refurbish our new home, but the builders have finally left, and we hopefully have a home now that’s future-proofed for whatever the future brings.

I discovered the MS Society’s East Cumbria Group while looking on the

Internet for ways to become part of our new community. When I saw that the group needed a Finance Volunteer, it seemed an ideal fit, as I’m a Chartered Accountant; so I plucked up my courage, reached out and joined the Coordinating Team.

As Ross acknowledged in his piece for the last newsletter, he needed some persuading to get involved with the group, but we can honestly say that it has been one of the best things we have done since moving to the area. We have met lovely people, been on lots of activities, made some firm friends and really feel part of the community. I feel supported as a carer – after all, we are all living with MS and this breaks down any barriers. It feels really good to know that I now have a network of people who understand, and accept me, on good days and bad!



Accessing advice

To speak to our MS nurses, Sue Raynerd (Carlisle) or Stef Nixon (Allerdale, Copeland, Penrith, Upper Eden), or to speak to Rebecca Baker or Joanne Harrison about Tysabri infusions, or Nicola Hyslop about advanced MS, call 01228 602 190.

If you're considering claiming benefits or want to know what's available, these organisations give confidential, independent, free advice:

Citizens Advice Carlisle & Eden
03444 111 444

Welfare benefits, People First
01228 317 010

Benefits Advice Civic Centre Carlisle
01228 817 200

Age UK Carlisle (for over 50s)
01228 536 673

Age UK Penrith
01768 863 618



Our volunteer team

Terri Attwood
Group Coordinator

Sue Beattie
Admin Volunteer

Deborah Cheshire
Finance Volunteer

Linda Bussey
Support Volunteer & PR Volunteer

Sarah & Sheraton McGlinn-Shaw
Support Volunteers

Dawn Taylor
Fund-raising and H&S Volunteer

Vanessa Wade
Activities Volunteer

Contact details

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Email: eastcumbria@mssociety.org.uk

Phone: 07707 684 868

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