



Muscular Dystrophy Support Centre

inspiring independence

All Things Independence



An Update
from Taher



I can't

Look what happened
when I hot footed it off
to the NEC!

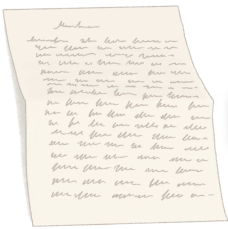
Inside this issue:

- Things get tricky with Ulrike!
- Ian shows us the sights of Coventry!
- And there are exciting times ahead for MDSC!



Real life Route
66 v Virtual
Route 66!





Letter from the Editor



Hiya Folks!

Emily here, wishing you a very warm welcome to the Spring Edition of our new look twice yearly magazine.

I can't begin to tell you how much fun and a pleasure it has been putting this magazine together for you all, any excuse to have a play about with design and I'm there! I am at my happiest when creating whether it be through words, music, art or humour, and now I've found a niche in creating and designing - something I never thought I'd see myself doing as I've been upper-limiting myself for a

very long time! No more!

We have an amazing journey to take during this edition which focuses on that all important topic - independence. There's such variation in all the differing ways we strive for independence in life, disabled person or not, I'm sure we could fill a book with all things relating to this matter. Speaking from a person with muscular dystrophy's perspective it's really important to get the balance right between remaining independent but also accepting help from others when necessary. It can be a tough pill to swallow at times admittedly, and we really are, to quote Dr Jon Rey-Hastie, more disabled by society and a lack of equipment/facilities than our actual condition, it's rather humbling don't you feel?

It is also a subject that I had first hand experience of recently whilst lying on the floor trapped between my wardrobe and equally heavy bed, phone out of reach and nobody close enough to hear my shouts for help. A day or 2 could of easily passed before anyone missed me (I got myself out in the end by hook and crook) but it's my choice to live alone and everyone should have a right to this decision - just make sure you have the fail safes in place so you don't endanger yourself. I now have an Echo Dot as well as my watch which I can usually send for help from, if I have it charged and connected that is...

So, in this issue we have some beautiful stories to share from our service users (my toilet humour aside), Ian takes us on a sight-seeing tour of Coventry with his 'City of Culture' volunteering, and there is a rather beautiful, heart-touching piece detailing a personal journey with disability, that will strongly resonate with a lot of us I'm sure.

We also have our regular updates from the team and I think you'll agree there are rather exciting times ahead with the upcoming move, coupled with the fact it is also MDSC's 10 Year Anniversary! More on this to follow. And so I've run out of room and therefore I'll leave it here, never forget how amazing you all are and enjoy the read!

Lots of love
Em x

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A Note from our Chief Executive

Welcome to our new look MDSC Magazine!

We are excited to share features and articles from our service user community – as well as information about what the team have been up to at the Centre recently and our exciting plans for the year ahead in this, the 10th anniversary year of the Charity!

Since our last publication in Summer 2021, there has been a huge amount going on at MDSC. We have really started to gain momentum on activities previously impacted by COVID. We were delighted to welcome new therapists Dan and Kelly to our therapy team (both of whom are introduced later in this edition) and to welcome Taher (previously one of our physiotherapists) into a new role of Clinical Services Manager. These important additions have enabled us to expand our service provision. We were able to open our latest Satellite Clinic to serve the Black Country region from Murray Hall in Tipton (the first of 3 planned new Satellite Clinics in our strategy), increase face-to-face availability at our Coventry and Birmingham locations, and add new group classes and one-to-one therapy sessions into our online therapy schedule. As I write, the team are working on how we can further expand our availability in Birmingham and Leicester to meet increasing demand for those clinic locations and we hope to have news on this shortly.

Of course, perhaps most thrilling of all, is that we are making progress on finding a new home for our Coventry Centre! We are negotiating on a space now and I hope to share more details (and a move date) soon – but we have listened carefully to the feedback of service users in recent years regarding our existing site – and while the move will be a big undertaking for us (and will have significant ongoing cost implications), it will be a fantastic development to secure the future of the Charity and provide a better experience and access for everyone. If you have time or resources to spare and can help us, please get in touch!

As I mentioned, this is MDSC's 10th anniversary year – and we are itching to invite our service users and stakeholders to see our new home and to celebrate our anniversary with us. We are planning a 2-day Open Day and New Home launch event in September, and from there will be scheduling a calendar of monthly events to bring our community together and to celebrate our 10th year. If you have a great idea and would like to run your own event to support please contact us. In the meantime, our brilliant supporters and volunteers have arranged some wonderful golf days (and of course our Route 66 challenge) for us to enjoy and look forward to – more about those later in this edition.

A huge thank you to you all for your continued support for the Centre throughout recent challenging times, and here's to a fabulous year ahead!

Sarah



Update from Clinical Services Manager - Taher Dhuliawala

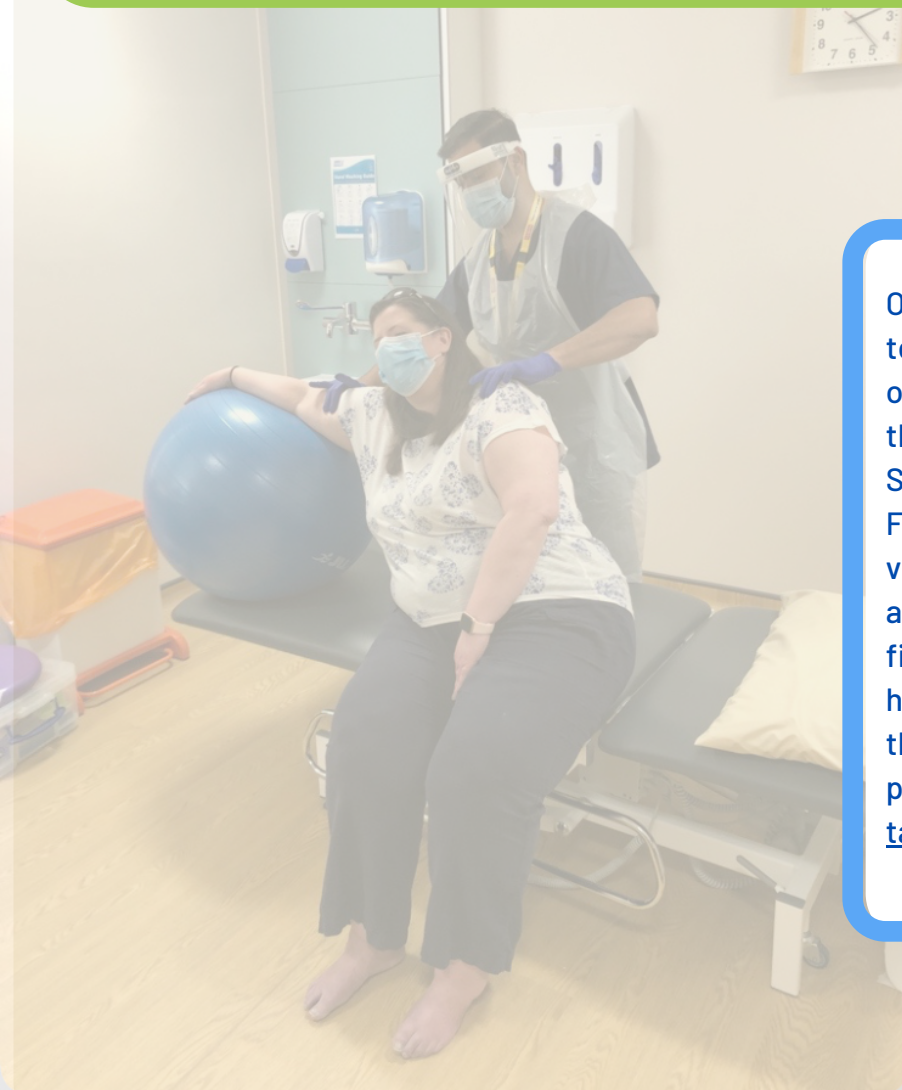


I am sure most of you know me by now, but to those who still haven't met me, I am a Neurological Physiotherapist who started working with MDSC in 2018. In 2019 I started running the clinic in Leicester at Rainbows Hospice. Since August 2021 I have been working as the Clinical Services Manager (CSM) at the Centre.

As a Physiotherapist, I have always been clinical and love doing hands-on therapy. Hence it was a tough decision to choose to become the CSM. I never thought I could become "hands off" - at least not until I was 99 years old! However there is a time in your life when you feel you want to do something more, something new. Working with this charity and the amazing team, I could not resist the role. I believe having a clinician working as a manager benefits the charity, and will help us to make the changes needed to progress.



Over the last 7 months I have worked towards some small and big goals to ensure our charity's sustainable future. Managing the clinical team and working alongside Sarah (CEO) and Natasha (Head of Fundraising) and other team members and volunteers has been very interesting. I have also been talking to our service users and finding out their stories and how the charity has supported them or can support them in the future. If you would like to talk to me, please contact me at:
taher.dhuliawala@mdsupportcentre.org



We have successfully...

❖ Increased our total number of therapy hours and are looking to specifically increase therapy hours at our satellite clinics going forward. From May 2022, we will be running six clinic days every month in Tipton and we are hopeful to increase our Leicester clinic days by adding a new physiotherapist soon. Our Droitwich Spa Osteo Clinic is also picking up in number of appointments. Please watch this space for further information.

❖ Completed our first planned block-booking of our successful online classes and the uptake has been good. We have added a drop-in class on a Thursday run by Lynn Ward and two online pre-booked classes run by Dan Foley and Siobhan Crowton.

❖ Started physiotherapy student placements from Coventry University. Our first student Mathew really enjoyed his placement and rated his experience with us as 9/10. He stated: *"The experience from this placement is very valuable because there are few placement settings that can provide such a lot of opportunity for using hand-on skills nowadays. The physios working here are all very experienced and friendly. It is also a very different experience working in a charity. The working environment is very friendly and less tense"*.

We are very fortunate to have more students joining us in coming weeks.

❖ Implemented our Service User DNA (Did not attend) Policy. From November 2021- January 2022 we had around 56 'no shows' for appointments. No reason was given for these no show cancellations. We also had 99 service users who cancelled their appointments late, giving us less than 48 hours notice. This meant we were unable to fill these appointments. We are still monitoring this as per our DNA policy because late cancellations and no shows for appointments cost the charity immensely.

❖ Added a new complementary therapy service at our Leicester satellite clinic location and welcomed Mani Kohli who is our new complementary therapist. We are looking to recruit more complementary therapist across all locations.

❖ Recruited and welcomed Grace Kabinga who is our Clinical Therapy Volunteer and has been working with us since the start of 2022. She works with us on a Wednesday. Linda Hill who is our long-term Clinical Therapy Volunteer works with us now on a Monday.

❖ Established relations with external stakeholders as well as other services including regional neuromuscular care advisors, community physiotherapy teams for adults and paediatric services.

❖ Lastly, started quarterly training days where all our clinicians discuss new therapy & equipment advances and share knowledge so we can constantly provide a quality service to all our service users.

We are exploring...

❖ The idea of completing initial assessments and annual reviews online for service users who are unable to attend the Centre or satellites. This is difficult as we need to assess all risks involved and weigh up the benefits of online reviews over clinic face to face ones. However, we are looking into this case by case and making decisions on how to establish safe reviews for all our service users.

❖ New therapy equipment that can benefit people with MD. We have already decided on a few new pieces of equipment that we would like for the new premises.

❖ How we can support our young adults. We are trying to integrate with regional therapy teams and care advisors to look into transition from childhood to adult services.



The Clinical Team and I thank you
all for your support during the last
few months

Thank You!

New Faces at the Centre

You might have seen a few new faces in the Centre since our last magazine was published. Granted, that was a while ago and these 'new' faces are now almost part of the furniture. Nevertheless, a huge welcome to our 'new' starters once again!



Kelly Garratt-Kirk

If you are a service user at our Black Country satellite Tipton, then you would have most likely received treatment from Kelly. She has been with us since July 2021.



Dan Foley

You might have seen our physio Dan at our Coventry hub or the Birmingham Satellite. He started with us last July and cheers up everyone in the office with his friendly banter.

Barbara Clarke

Barbara joined us in January of this year and is our newest office angel. She joined us as the Administration Officer and keeps everyone and the office organised and up to date.



Mani Kohli

Mani started with us in December of last year and is offering her expertise in complementary therapy at LOROS in Leicester.



Emily Bonner

Emily is a long standing service user and has joined us as a content and engagement volunteer at the beginning of this year. Whilst you might not see her around the office much, she is the one behind a lot of our content in our social media channels.

Faith Duggan

Faith is our newest volunteer all the way from the US. She will join us shortly when she will get stuck in with communication and fundraising for the summer.



Nicholas Gibson

Nicholas joined us in March as a digital volunteer. Nicholas is an all rounder and helps us with everything digital and IT, including our website.

Welcome to all our new staff and volunteers. We are lucky to have you all on our team!



Grace Kabinga

Grace joined us in January as a clinical therapy volunteer and you'll see her in the Centre typically on a Wednesday helping out the clinical team and assisting service users.



Fundraising Update

Christmas Auction - calling Santa's helpers!



MDSC's Virtual Christmas Auction 2021 raised a grand total of £2,306 for physical therapies for MD! Huge thanks must go to all our generous prize donors, and of course, our wonderful bidders!

Special thanks to those who worked tirelessly behind the scenes to help secure prizes and get people bidding. This year, we are formalising this approach and offering out the opportunity to form a volunteer committee to organise the virtual auction.

What's involved? Well, committee members will need to be willing to approach people/companies for auction prizes, prepare the online auction catalogue (draft descriptions and obtaining photos of prizes), and promote bidding to as many people as possible. The MDSC Fundraising Team will be on hand to guide the process, assist with running the virtual auction website, and receive the payments.

If you are interested and would like to find out more, please contact Nina by email on nina.hanks@mdsupportcentre.org or call her on 07480 046467

Do You Know Any Local Businesses?



MDSC is keen to partner with businesses to raise funds to support us providing your physical therapies. Over recent months we have worked with ABP Club, M3 Networks, and Midland Expressway, operators of the M6 Toll. We help to publicise the businesses who support us and offer tangible impact in the community.

If you know of a business that might be interested in partnering with MDSC, please let us know! Contact our team on fundraising@mdsupportcentre.org or call the Centre on 02476 100770.



Here's what ABP Club's Operations Director, Paul Dowling, has to say about working with us:



"Supporting a small independent charity like MD Support Centre is a great way for your business to have a direct and substantial impact in the community.

Every penny helps to provide support and physical therapies for people living with and affected by muscular dystrophy".



NEW HOME APPEAL

Every donation will help MDSC set up this brilliant new Centre so we can help more people with MD. Support our New Home appeal today!



WE ARE MOVING!

We are excited to announce that after nearly 10 years at Hereward College, our Coventry HQ is moving. As the contracts are still being drawn up, we can't share all the details yet, but we can confirm that we will be moving to a larger space and that we are not moving far – less than 2 miles from our present location. There will be more accessible facilities, including level access from the car park and shorter distances for you to travel both outside and inside. The new Centre will have larger therapy spaces allowing us to offer more therapies and there will also be indoor and outdoor break areas for service users, carers and staff. With everything on one level and in one larger standalone space, our new home promises to provide a far better experience and easier access for you!

We NEED your help

MDSC is a small charity dependent on voluntary donations. We need additional physiotherapy equipment for the new therapy suite and equipment and furniture to create a welcoming and comfortable centre environment for service users and carers. And crucially we need to fund the ongoing running costs of our service, which are increasing substantially as we move to our new home and expand our capacity to support more people with MD.

You can help by supporting our New Home Appeal today! There are two options when it comes to making a financial contribution:

- A Monthly Donation will help MDSC meet the ongoing costs of providing therapies in our new home. Setting up your Direct Debit is quick and easy and makes a real difference to the long-term future of our services.
- A One Off Donation by credit or debit card will help MDSC to establish the Centre in its new home and continue providing therapies for people with muscle-wasting conditions.

Get behind the new Home Appeal! No matter what contribution you give, your support will help bring the new Centre to life and secure MDSC's services for the long-term.

PS. Want to run your own fundraiser for MDSC? Get in touch, or visit

<https://mdsupportcentre.org/get-involved/fundraise-for-us/>

DONATE

Support our appeal today here:

<https://mdsupportcentre.org/new-home-appeal/>



Our Ian

Sent to Coventry...



Ian “stoned” after making use of public transport to attend a show at the NEC

By Emily Bonner

Most of us know that service user Ian could probably talk a glass eye to sleep (by his own admission) so it wasn't a surprise when we heard that he was volunteering as a 'City of Culture Host', such a suitable and ideal role for our chatty man Ian that has ultimately led to many more exciting opportunities and experiences, with disability awareness and independence as a core focus coming up trumps.

Despite initially wondering whether it would be worth all the stress of getting out, Ian hasn't looked back, saying “you do your first shift, you meet people and then you see what a wonderful city this is...”

So, what urged Ian to volunteer as a City of Culture host?

“COVID definitely, we've come out of the crisis (hopefully) and we could have just sat at home and felt sorry for ourselves but what a wonderful opportunity”

It's not been all fun and games (although larking about features frequently), on a more serious and hugely important note through his voluntary City of Culture hosting, Ian and his partner Jayne were not only both awarded with 'Host of the Month' but also rather excitingly invited to become members of Coventry City Councils Disability Equality Access Partnership and working as joint signatories on Coventry's Transport Charter. The Charter's main focus is to improve and support public transport for the disabled community by implementing priority seating policies, improving accessibility in regards to train travel for wheelchair users, advertising the availability of permit provisions for mobility scooters on public transport plus much more.

The aim is to raise much needed awareness with transport operators of the difficulties that disabled people can face whilst using public transport, and to reinforce the message that commitment is needed to put measures into place to improve accessibility.

“Hopefully that is a start to put accessibility on the map and the wider implication is that West Midlands Combined Authority are onboard. We will work hard on this going forward”

Ian has also rubbed shoulders with local MP Taiwo Owatemi, shared a “stage” with journalist Trish Adudu and even met Lady Godiva herself on several occasions.

Thankfully fully clothed and without horse, Lady Godiva aka Pru Porretta MBE has spent 30 plus years engaging and working with communities within the city to bring people together and is highly praised and recognised for her dedication and work.



Ian with Lady Godiva - the perfect brolly girl!

Ian has loved the experience, saying of it:

“The main message to get across is that volunteering is good for you, great to engage with people and get involved with people post pandemic and by being a proactive City Host can get you noticed - to be involved with Lady Godiva is an example of that, such an inspirational person in this great City”.

There’s the lighter side to volunteering and hosting as well.

We all know Coventry is a city with many a sight to be seen and Ian has had his fair share of fun, meeting people from all walks of life and relishing in many a photo opportunity.

I think he’d agree though, that the best meeting to come out of all of this was the friendship he developed with fellow City Host and now partner, Jayne.

“I think the Grinch couldn’t resist a photo shoot with a couple of City Hosts”



Ian and Jayne - a prime example showcasing the lighter side of volunteering!

“THE MAIN MESSAGE TO GET ACROSS IS THAT VOLUNTEERING IS GOOD FOR YOU, GREAT TO ENGAGE WITH PEOPLE AND GET INVOLVED WITH PEOPLE POST PANDEMIC”



DOWN WITH A FLUSH!

By Emily Bonner

I can't miss an opportunity to make a song 'n' dance about my life-saver the humble Shewee!

I first came across a Shewee many moons ago when my not too distant neighbour Jezza (car enthusiast turned farmer) was presenting Top Gear. Not exactly the place is it, a motoring show, to expect such a thing to crop up but they were presenting their ideal Christmas gifts for the avid motorist and well, the said Shewee made an appearance, and if I remember correctly in case one would get caught short whilst stuck in traffic. I never thought back then that I'd come to rely on them and not only own one but I'm now up to four in my collection!

One for the car, one for the handbag (that you'll never see me with, a pocket is a great alternative and so much easier), one for home etc. you get me drift.

My first one is still tucked away in my old fishing box somewhere, (now that's a story within itself - a makeshift loo by a fishing lake, jeez I've never experienced anything like it and never wish to again. Now my fishing days are long over, I've moved on).

So here's the thing, public loos...



As my muscular dystrophy progressed and my legs weakened I soon started to realise that I could no longer use a public loo all that well. I started using accessible loos purely for the handrails so I could steady myself whilst squatting and then push myself back up to standing but after a time it became apparent that I needed to up my game as I was getting myself in all sorts of bother. Let's not go there. Cue the Shewee!

Initially brought for use at work as that was the only place I really went other than home, I soon started using it full time there too - if you saw how I got myself up off my loo you'd understand why. I used to throw myself forward basically into a nose dive place one arm on the radiator and swing the other up to the open door handle and somehow wiggle my feet inwards to standing. It was hit and miss at the best of times and well, knackered me. My heart is in me mouth as I write this now thinking about it. And in truth that was only but a year ago...

I got to the point where I developed a mental block, maybe as a safety mechanism and then I couldn't even get myself off my own loo. Instead I spent about 3 months purposefully getting down onto the floor and crawling over to my sofa where I knew I could get up - just. At least the tacks had long gone from my bathroom floor (yes I did have to avoid them for a few days when I first moved in) but the non-slip floor still hurt my chilblained toes as I dragged them over it, and yes there was blood as the skin got scraped off. The things we do! It was a feat I only had to complete once a day thanks to my Shewee.

Long story short, I eventually got a Vertica LiftSeat that's battery powered for my home loo so there's no more dancing with my radiator. Another life saver and highly recommended, Steve the chap who invented it works with a lot of MD patients and knows his stuff. I didn't even have to tell him I had limb girdle he just correctly assumed. It is also free standing, so if there's 2 folk able to lift it, I could also potentially take it away with me.

Back to the Shewee, honestly it was the best fiver ever spent! It made so much difference and it didn't take long for me to get used to it and perfect my aim! I've just cracked myself up writing that. Moving swiftly on...

If you are able to stand safely with one hand free I'd highly recommend one.

I assume people can use them seated too but I have no idea how without making a complete mess, I personally need gravity on my side! If you fancy an experiment then go for it and let me know how you get on!

MY PERSONAL JOURNEY WITH DISABILITY

By an MDSC Service User

I wanted to start by saying that hopefully by writing this article, it will help other people with what they are going through. Whether they have only been recently diagnosed, or have been diagnosed with a long term condition for most of their life.

The first part is about my own personal journey. The second part is about the Muscular Dystrophy Support Centre and how they have supported me.

Writing this piece has made me reflect about my life and thinking back, I have probably had this condition all my life. When I was a kid there were a few signs, which made me a bit different from the other school kids; struggling with sport for years, having a squint and walking a bit differently.

Retrospectively the condition has always been there, but never was identified properly, until things got to an untenable level. I always made the kids laugh as a deflection technique. Also I was a bit naughty so that the other kids did not single me out as being different, and I felt included by the other kids.

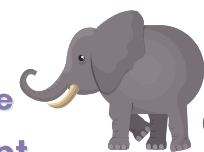
As my life has gone on my condition has got progressively worse. The condition began to affect many other areas of my body. I brushed it aside and put it down to other things, making excuses and found a different solution to make up for when I struggled to do something. I also made a joke of it as my defence mechanism, as I always have done.

All I ever wanted was to be accepted, and to not stand out from the crowd. This has followed me through life. Daily I felt like I was walking around in a lead diving suit; physically making my body move, as my muscles fatigued very quickly and this is still a daily battle for me now.

There is a quote from 'Elmer' by David McKee that explains how I felt when I was a kid at school, and sometimes how I feel now, when things get tough. "All the elephants of the jungle were grey except Elmer, who was a patchwork of brilliant colours until the day he got tired of being different and making the other elephants laugh".

“

All the elephants of the jungle were grey except Elmer, who was a patchwork of brilliant colours until the day he got tired of being different and making the other elephants laugh



”

I was medically diagnosed with a rare long-term health auto-immune condition in 2020 - Lambert Eaton Myasthenic Syndrome (LEMS). The immune system attacks the body itself and damages nerves and glands in different parts of the body, which leaves them poorly functioning or not functioning at all. If you can imagine how many parts of your body that may be affected, the possibilities are endless.

I was first referred to the neurology department, in 2018 and was diagnosed with (LEMS) in 2020. I have an excellent consultant, but it took a while to diagnose, which involved a lot of tests due to ruling out many other conditions before a definitive diagnosis was made.

I have had to come to terms both with my condition and losing my body's capability to move. This has been difficult, as I had to re-adjust my life my completely even though I didn't want to.

The first stage was denial, and I half thought I would get better. To start with I wouldn't entertain using a stick for support and I still wanted to drive my manual car which I found difficult, until I relented and thought that I perhaps couldn't do that because it wasn't safe. I had to get rid of the petrol car and buy an automatic, and have it adapted so that I could use hand controls, so I could still drive.

There are all sorts of barriers out there that you never even notice unless they affect you personally, and things you used to take for granted that your body could do. E.g. walking a short distance, climbing up and downstairs or stepping up and down curbs.

Mainly, because I am frightened of falling and hurting myself and not being able to get back up. Added to this is the feeling of being vulnerable, which mentally upsets me too.

It was hard to admit at the start that I couldn't cope, but there have been many improvements and adaptations made at home to make my life easier and future proof the property, so that I can manage for as long as I can in the future.

I have always been an independent person and I think this can help or hinder you. On a negative note it has meant carrying on regardless despite what is happening, because you don't want to admit defeat. Due to my condition I was unable to fulfil my job role that I had done for 8 years, which I had retrained and studied to do over many years, which hit me hard.

I felt I didn't have a purpose, didn't contribute and I felt useless for a long time, having always previously worked. I was also shunned by some people who just didn't know how to handle the issue or believed I wasn't any use to them anymore. My mental health was badly affected, as I was frightened of losing my job, of course for the income, but also my self-worth and purpose that were being taken from me.

This meant that I had to leave my job, but carried on a temporary contract in another department in a different role. On a positive note I managed to keep working in that other department, and eventually I managed to get a permanent part-time contract in October 2021. This role is very different to my old job, but I am so much happier, my boss is very sympathetic to my condition, and I feel very lucky. Also I am not treated any differently to anyone else in the respect of workload and I am not singled out due to my disability.

I have also come across many practical barriers that have hindered me too. Sometimes there is something that I would dearly love to do, that I used to be able to do, but can't. Or something that I would like to try that I cannot do, due to my condition, which still occasionally upsets me now.

I do find going out to do everyday activities a military operation and hard work, as I do have to plan a lot, to make it as easy as possible, so that I don't have an accident and leave myself open to problems.

On many occasions I have had to find solutions out

for myself, as I have found that if people do not tell you where to get help, you don't know. Therefore, it has been a huge learning experience and trial and error for me, but it does get easier and I have met some really lovely decent people along the way that have helped me.

On a positive note, being an independent person means that you won't give up either, and I haven't. In one respect my condition has done me a favour in a strange way, as I am now looking after myself properly, more than I have ever been. Since I have started on this health condition journey I have realised the people I have met or have seen in the media that people deem to be the weakest are inevitably the strongest and I have drawn great strength from that.

Retrospectively now that I have come to terms with my disability (up to a point), I still have a long way to go. Although it is not an easy road, I count myself very lucky to have a supportive husband, family, friends and work colleagues, which some people do not have.

We can always think about disabilities as limiting, but it's not the disability that limits the person, it's the world that we live in that limits people. Either by design of a home, street, property/business not being very disabled person friendly. Or the most hurtful society; people that don't want to know, don't understand, don't care, are oblivious to your situation, feel awkward because they can't cope with the situation, or are ignorant, because they haven't had the experience of being disabled.

In society there are a lot of misconceptions, myths and cruelty about disability, Disability is viewed by certain members of the public as something different from the norm and a weakness that people do not want to be associated with.

“It was hard to admit at the start that I couldn't cope, but there have been many improvements and adaptations made at home to make my life easier and future proof the property, so that I can manage for as long as I can in the future.”

Even though people have conditions that limit them, they still have so much to offer given the right support. Although we are in 2022 here are two sad indictments of the cruelty of society towards disability in the present.

A swimmer who represented Great Britain at the last Paralympic Games says he is "sick to death" of being laughed at because of his dwarfism. Will Perry, from Northamptonshire, said there was a "big party" after Tokyo 2020, but once the celebrations ended the abuse started again.

He has a common form of dwarfism called achondroplasia and said people like him were often filmed or laughed at in the street. The 21-year-old has called on people to challenge those doing it. He said: "With dwarfism, I face a lot of public abuse. I believe it happens because in so many films and on social media, we're depicted in a comical way, we're described as funny characters." Source BBC.

Comedian Lost Voice Guy Lee Ridley who won 'Britain's Got Talent' has Cerebral Palsy. One of the T-Shirt's he wears reads 'I am only in it for the parking'. As some people are quite vocal in saying that disabled people are just sponging off the benefit system when they don't need to and are work shy.

A personal experience I had was when my friend and I travelled to London, to see a show on the train. Although I had my friend to look after me, I had also booked assisted travel through the train company to help too. The journey down to London involved several changes. I was quite often put near the toilet because the train was full and there was nowhere else to put me and my chair even though I had first booked first class tickets and assisted travel.

Examples of misconception include; when we were in London, one particular taxi driver said to me when I was in my wheelchair 'do you really want the ramp, while looking at me and said that he thought I was able to manage'. Or on another occasion we were being met by a member of hotel staff, and they said that 'they were expecting someone a lot older due to my disability requirements issues I had told them about pre-visit'.

Plus people talking to my friend, who was pushing me in my wheel chair or talking loudly like I was stupid. Although my condition affects many parts of my body my brain still works, and I can still understand and articulate my thoughts quite well!

On the return train journey our train had been cancelled, so a supplementary replacement train was sent eventually. However, there were only two train carriages, we did manage to get on at a push, but that was really difficult. The problem expanded when we came to get off the other end, there was no assisted travel to help. The staff had lost control and there was a big crowd wanting to get off and on the train when we were trying getting off.

If it wasn't for my friend and two kind strangers, who helped by moving people out of the way, pushing the wheelchair, and physically lifting me off the train to put me on the platform, I wouldn't have been able to get off. I was quite shaken; people seemed oblivious or just didn't care. What happened to me was unnerving, but in the great scheme of things it was not too bad compared to what other people with disabilities have to go through.

During this journey through life, I have seen both sides of humanity and how they have reacted towards me and I do believe that certain people just don't care or are too wrapped up in themselves to take the time to understand, leading to prejudice in the world.

However, I also believe positively that other people do not view disability as inherent negative - it is simply another way of existing in the world. However, this cannot be achieved without support and understanding of people in society. With the proper support in place, people with disabilities can be free to work, play, love and experience fulfilling lives in their communities.



THE MUSCULAR DYSTROPHY SUPPORT CENTRE

I want to tell people about the help that I have received on my journey, and what I have found that is out there to help people who are in a similar position as myself.

There is no better place to start than with the Muscular Dystrophy Support Centre. It has been more than a tough couple of years, and I had been referred to physiotherapists before. However, because my condition is quite rare and long term too, it got to a point several times, when they would not treat me anymore, due to funding and lack of expertise.

Therefore, I was always back to square one, it made me feel awful and I turned to comfort eating. I would try to find something that would help, but because I did not have the benefit of someone's expertise who had experience of my condition or similar, I chose the wrong exercises, so I would get too tired, despondent and give up again – a vicious circle.

I am very pleased to say that since last September things started to change for the better. I was referred by my consultant to the Muscular Dystrophy Support Centre. It was decided that they could help. So since October 2021, I have been going to the Loros Hospice in Leicester, a satellite arm of the MD Support Centre, for physiotherapies.

Having this opportunity has meant the world to me, and I don't know what I would have done if I hadn't known about the Centre. The people at the charity have been amazing, so kind and supportive, and you get treated like a human being. You do not feel like you have been labelled as disabled and put in a societal box like on many other occasions. This has given me a wonderful boost in confidence, which makes me want to try more at life in general and has restored my faith a bit in human nature.

“

I am very pleased to say that since last September things started to change for the better. I was referred by my consultant to the Muscular Dystrophy Support Centre. It was decided that they could help. So since October 2021, I have been going to the Loros Hospice in Leicester for physiotherapy, this is a satellite arm of the MD Support Centre.”

I am classed as clinically vulnerable, so had to be very careful during the pandemic and will have to be beyond, so I don't catch any colds or viruses. The MD Support Centre, and its satellite clinics have provided a safe haven, because they have been very strict on having all the right safety measures in place to protect people.

I do have a long road ahead and my condition will never be cured, but it can be managed. The medication I take has helped me enormously, because otherwise I would not be able to move at all. However, by visiting the Loros satellite clinic, having a massage, and a physiotherapist session, plus doing the recommended exercises at home, has helped loosen and build up a little resilience in my muscles when my tablets become effective.

I am not saying it has been easy to exercise, even with the right support my condition makes it difficult, as my muscles get tired very quickly. Plus I do have set backs if I fall, or I get too over confident and damage something. I do think that there has been a small improvement, though, which for my condition is huge. So now it means I can get a little bit more out of life, which I couldn't do before. .

Sticky Situations

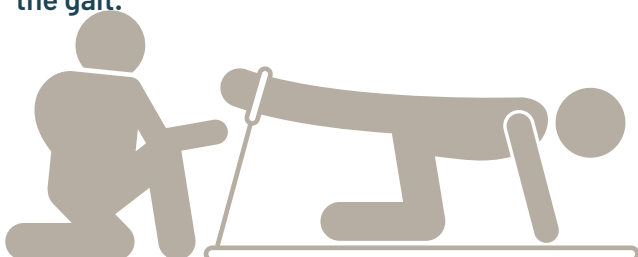
By Ulrike Uta

“Everyone should have the chance to live their lives to their full potential”

This is one of the most beautiful quotes describing my role as a Neuro Physiotherapist. As a physio this means working on optimising someone’s mobility, enabling them to participate in all the activities they wish to. What a great job I have!!!

When I was a newly qualified physio in Germany, however, I really didn’t like working in neurology and especially not with people with long term conditions.

In my early career, I dreaded advising on, or even discussing, lifestyle changes and other major decisions, such as changing walking aids or starting to use a wheelchair. Even though I was competent from a professional perspective and could see the necessity for such discussions, I felt very uncomfortable and inadequately equipped to support people in these decisions. I could sense that these were much bigger issues for my patients, way beyond the superficial rationale of improving the gait.



Fast forward 30 years (ouch) and I now love working with people with long term conditions, neurological and neuromuscular, and especially at MDSC. What has changed?

Basically, I have grown up (better: got older?). I now have a better understanding and greater empathy for how it feels when life is challenging. And about how it feels when our ideas about ourselves, our plans and goals go astray and we are confronted with not being as much in control of our lives and surroundings as we wish we were and pretend to be.

“ I now have a better understanding and greater empathy for how it feels when life is challenging ”

We all have ideas about who we are, how we appear to other people and society, how we see ourselves and what sort of goals we set ourselves. Being diagnosed with a condition which will ultimately lead to a deterioration of mobility, setting goals such as ‘not using a walking stick/ walking frame/wheelchair’ can be powerful motivators to stay focused on positive thinking and exercising.

But when mobility deteriorates, these ideas and goals can get massively challenged, potentially creating a sense of not being able to live up to them.

For many, it is not just about falls, weakness and the effort of keeping moving. It is more emotional. It is about having to come to terms with the fact that old goals, useful and good as they were, might no longer be appropriate. The difficulty of redefining yourself and accepting the progression of your condition. It is about both how we see ourselves and how we appear in the world, as society might see us differently. This process takes time and is hard work emotionally. It is okay to be upset and not want to face it. But ultimately, it won't just go away.

When my Mum, at the age of 80, finally started using a rollator when going shopping in her village, she noticed that people, despite knowing her, started talking more loudly to her. She complained that her hearing was good, just the legs not so much.



A friend of mine uses a wheelchair and she regularly notices that people are not looking at her, talking above or asking her if she is okay/lost when she is in the wheelchair by herself.

Situations like these will most likely happen and when starting to use a walking aid or wheelchair it's necessary to learn to deal with them. Everybody will respond differently but coming to terms with unhelpful comments from others requires a certain degree of resilience and security within oneself.

When we start mentioning using or changing mobility aids in a Physio session, these discussions can be tricky. However, we are happy to work through these difficulties, we want to be supportive and partners in the process of change. We are very lucky that at the MDSC, we have the time and space to explore issues gently and slowly, without the pressure of looming discharge deadlines. We have equipment which service users can try and think about in their own time and come to their conclusions about how to move forward.

Once people experience the relief of mobilising safely, conserving energy and being able to participate in activities again, very few feel that it was a step backwards. Some people wished they had started using a mobility aid earlier.

In the end, using a walking aid or wheelchair is all about being independent, safe and confident and being able to do the things which are important to each of us. Everyone should have the chance to live their lives to their full potential.

So, if you have any questions about the use of walking aids, wheelchairs or scooters, please do speak to myself or my colleagues. It's okay to feel hesitant about it and we won't push you into anything you are not prepared to do.



GET INVOLVED WITH OUR EVENTS

MONTHLY COFFEE MORNINGS AND WEEKLY COCKTAILS / MOCKTAILS

Every second Wednesday of the month we host an online coffee morning and chat. Join our social group on Facebook for regular invites and reminders or alternatively let Emily know you are interested by emailing her at: emily.bonner@mdsupportcentre.org

Our June coffee morning will be on Wednesday 8th at 11am. Everyone is welcome, come along to meet fellow service users and share stories.

Every Saturday evening we host our weekly Cocktails/Mocktails evening between 6.30-7.30pm. Again follow our social group or reach out for the link if you are interested. These evenings are also for catching up but often we additionally hold games nights for a bit more fun!

Save the Date!

MDSC Open Day & 10 year anniversary celebration - Friday 30th September and Saturday 1st October

UPCOMING EVENTS

- Coffee Morning - Jun 8th
- Naidex - Jul 6th & 7th (look out for our therapists who will be attending the event & happy to discuss any equipment with you)
- Gary Evans Golf Day - Jul 8th
- David Salt's Golf Day - Jul 8th
- Open Day - Sep 30th / Oct 1st

ROUTE 66 SPRING CHALLENGE



Our Spring Fundraising Challenge of virtually completing Route 66 is well on the way but we still have a way to go! Fancy joining us on the route? You can still join! Raise money for MDSC, get moving and it's accessible to all!

For more info contact Emily at: emily.bonner@mdsupportcentre.org

If you'd like to support us please follow this link <https://givi.ng/w580>

Thank you



COOKING WITH NEIL



Here's a vegetable soup recipe, tried and tested by our Neil! It is that good, the shop-bought version will no longer suffice, and he is sure to be in great demand!



You will need:

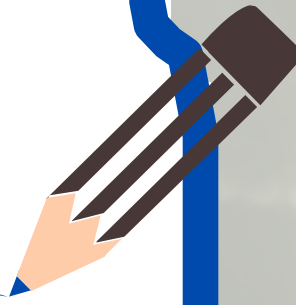
3 tbsp butter or olive oil
1 medium onion chopped
2 medium carrots chopped
2-3 stalks of celery chopped
3 cloves of garlic minced
1 tsp fresh or 1/4 tsp dried rosemary chopped
1/4 tsp red pepper flakes
3 tbsp plain flour
1l vegetable stock
1.5lb potatoes chopped
1 bay leaf
Salt and pepper
50ml double cream
2oz strong cheese such as Gruyère (optional)
Parsley for garnish (optional)

Directions

- In a large heavy-bottomed pot (like a Dutch oven), melt the butter or heat the oil over medium heat. When the butter is melted or oil heated, stir in the onions, carrots, and celery. Cook, stirring occasionally until they begin to soften; 5 to 6 minutes.
- Stir in the garlic, rosemary, red pepper flakes, 1/2 teaspoon of salt, and 1/4 teaspoon of black pepper, and then cook, stirring everything around the pot, for 30 seconds.
- Scatter the flour over the vegetables and cook, stirring, until it looks medium blonde in colour; about 1 minute. It will smell toasty, like browned butter.
- Slowly whisk in half of the stock, making sure there aren't any lumps of flour. It will be thick.
- Pour in the remaining stock and whisk until blended. Increase the heat and bring the soup to a boil then reduce to a simmer.
- Add the potatoes and bay leaf, and then cook, partially covered, until the potatoes are fork tender; about 20 minutes.
- Turn the heat to low, remove the bay leaf, and then stir in the cream and cheese.
- Taste for seasoning then adjust with more salt and pepper as needed. Serve with fresh herbs on top or for a thick and blended soup, use a potato masher to mash or an immersion blender to blend about half of the potatoes in the soup.



From the Route



How are we doing on our Spring Fundraiser?

Here's an update from the Route!

We're not in Kansas Anymore...

Welcome to 'Tornado Alley' - we're really eager to get through this part of the route for obvious reasons, it doesn't help that it's also tornado season! Hundreds of them will occur this month with more, typically double the number expected in May. Therefore we all can't wait to reach Texas - our 5th State, which also means when we do we'll be half-way through!

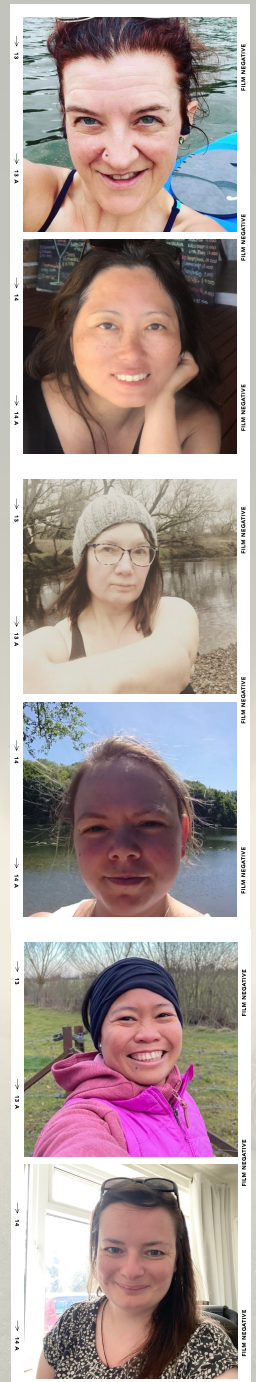
At the moment, after briefly entering Kansas, we are now in Oklahoma, heading towards Tulsa and then Oklahoma City as we make our way through land which used to be Cherokee. We made a quick detour to have a look at one of the largest totem poles ever!

As John Steinbeck would call it, we've been on 'The Mother Road' for over a month now and progress is going well. We are on target to finish by the end of June as expected if we keep up our current pace, although with these high winds we may need to take shelter every so often and fill up on pancakes! It's typically fast food or no food! Let's hope the wind is at our backs!

Fundraising is also getting off to an amazing start. We have raised well over £600 already for MDSC, and we'd love to reach our goal of £750 (and beyond). If you'd like to support us please follow the link at the bottom of this page, thank you.

The Route 66er's x

You can help us reach our target at <https://givi.ng/w580>





FUN SPRING STUFF WITH NINA!



MINI QUIZ!



Word Search

RUMFJKZAFFLOWERSSEQDW
 RTWDVMMXZIBAWNHTDGOI
 FALLSFDDHJVRIYYQGRQJ
 MSQXTXFQPOHJNSWZTZYD
 KNAPRILHDTKKDCMQUKWO
 PREUVJUQUGFVSAWUGJME
 FFIIOCIBSBJFWUDWMTRB
 SPQHXWNYHSMTBRRHYRAVB
 RIPTDIAFXQPKDBLXWFJB
 TVDAVSEDBKERHUUIOFMQ
 KTMTDQIEGMUSIDEUXNTJ
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 NPXWVKCVEIOPHXWVDEES
 AXSHOWERSUFAIKIHGCPW
 QPDNKFRCFMJGAUPXYGIB
 IBFFCBPUZABMEXLZBFFI

March
Winds

April
Showers

Spring
Falls

May
Flowers



1. Who was the Germanic Goddess responsible for bringing spring each year?
2. The weather in March is said to what?
3. What is said to happen to children during spring?
4. Vernal Equinox translates to what in English?
5. The Lent Lily is the UK's only native form of what?

Answers on page 24!

NINA'S BAKES - APFELSTRUDEL!



Apfelstrudel (Apple Strudel)

For the Strudel dough:

- 200g/7oz plain flour
- 1 pinch salt
- 75ml lukewarm water
- 50g/2oz butter

For the filling:

- 1-1.5kg/2.25-3.75lb apples
- 2-3 drops rum essence
- 1-2 drops lemon essence
- 75g/ 2.5oz butter
- 50g/ 2oz breadcrumbs
- 50g/ 2oz raisins
- 100g/ 3.5oz sugar
- 3 drops vanilla essence in 1tbs sugar
- 50g/ 2oz chopped blanched almonds

Make the dough:

- Sift flour into bowl and add all other dough ingredients. Knead either by hand or with mixer until the dough is smooth. Transfer dough into a warm pan or bowl, cover with towel or lid and leave to stand for 30 minutes.

Make the filling:

- Peel and cut apples into small chunks. Stir in the rum and lemon essence. Melt the butter.
- Roll out the dough on a large floured tea towel and brush lightly with melted butter. Stretch dough by hand to make a rectangle (approx. 70x50cm)
- Brush the rectangle dough with two thirds of the butter and sprinkle with breadcrumbs, leaving a 3cm edge.
- Sprinkle the apple pieces, raisins, sugar, vanilla sugar and almonds over the top.
- Fold the edges of the short side that have been left uncovered over the filling.
- Using the cloth to help you, start rolling the dough from the longer side and press ends together tightly.
- Transfer strudel to a baking tray, brush with a little of butter and bake at:
 - Electric: 180C
 - Fan: 160C
 - Gas: 4

Bake for about 30 minutes, then brush again with the remainder of the butter. Bake for a further 20 minutes, remove from oven and leave to cool slightly before serving with custard or vanilla ice cream.



THANK YOU!

As always, MDSC has a long list of individuals and organisations to whom we owe a debt of gratitude for their support in recent months. We simply could not run the Centre without the generous help of our volunteers, supporters and cheerleaders. Thank you!

Fundraisers and organisations

29th May 1961 Charitable Trust
ABP Club
Acorns Children's Hospice
Amazon Smile
Amy & Freddy Monegro - NY, USA
Andy Collins
Birmingham District Nursing Charitable Trust
Birmingham Hospital Saturday Fund
Christadelphian Samaritan Fund
Cristian Mezei / Mezei Design
Dan Foley
David Salt
DMF Ellis Charitable Trust
Emily Bonner
Eveson Charitable Trust
Eric Stanton Northampton Trust
February Foundation
Forrester Family Trust
Garfield Weston Foundation
Gary Evans and family
Gayle Armson and family
Gilander Foundation
Grace Trust
Gordon Trust
Hasluck Charitable Trust
Heart of England Community Foundation
HEARTH Foundation
Hereward College
James Wise Charitable Trust
Joseph Hopkins & Henry James Sayer Charity
JT Matthews
Keith Coombs Charitable Trust
Leamington Spa Community Fund
Leicestershire County Council Community Grants
LogMeIn
Lord Barnby's Foundation
LOROS Hospice
M3 Networks
Marsh Charitable Trust

Michael And Anna Wix Charitable Trust
Microsoft
Midland Expressway Ltd (Operators of the M6toll)
Muntz Trust
Murray Hall Community Trust
Neil Corfield and family
Nick Randle and family
Paul Dowling
Postcode Community Trust
PF Charitable Trust
Provincial Grand Lodge of Warwickshire
QuestionPro
R S Brownless Charitable Trust
Richard Cadbury Charitable Trust
Sandra Charitable Trust
Smugmug.com
Start.me
Street Foundation
The National Lottery Community Fund
Tracey Pratt and family
Trelix Charitable Trust
Wilmcote Charitrust

Volunteers

Bill Roddie
Bryan Gould
Emily Bonner
Grace Kabinga
Linda Hill
Neil Corfield
Nicholas Gibson
Terry McDonagh
MDSC Steering Group participants
MDSC Project Board Members

And finally

All our generous individual donors
All our Christmas Auction prize donors
All those who have run a Facebook birthday fundraiser
And finally, all those who wish to remain anonymous.

READ IT

Keep In Touch!



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Find us on LinkedIn here:
<https://www.linkedin.com/company/muscular-dystrophy-support-centre>



Sign Up!

To hear about our fundraising, events and all things MDSC sign up to our e-newsletters here:

<https://mdsupportcentre.org/sign-up-for-our-supporter-e-newsletters/>

Join Our Social Group!

To connect with other service users, to share ideas and support and to keep up with our social events including the monthly coffee mornings and weekly Saturday night get togethers. Or just to share how amazing you are!

CLICK HERE



www.facebook.com/groups/mdscsocial



Fun Stuff Answers:

RUMFJKZAEFLOWERSSEQDW
RTWDVMMXZIBAWNHTDGOI
FALLSFDHJVRILYYQGRQJ
MSQXTXFQPOHJNSWZTZYD
KNAPRIHDTKKDCMQUKWO
PREUVJUUGFVSAWUGJME
FFIIOCIBSBJFWUDWMTRB
SPQHXYWYHSM TBRHYRAVB
RIPTDIAFXQPKDBLXWFJB
TVDAVSEDBKERHUUIOFMQ
KTMNDQIEGMUSNDEUXNTJ
SDMALURNZEUSNXMGPM
VCLFYXGUVKEYJGCYXNA
UVFTQUKXJQHRRUXHRWR
WYKLSKHIYCJEIWHESHDC
YHUQOKZTUHWKVIPDTBJH
NPXWVKCVEIOPHXWVDEES
AXSHOWERSSUFAIKIHGCPW
QPDNKFRFCFMJGAUPXYGIB
IBFFFCBPUZABMEXLZBFFI

1. Ostara or Eostre
2. Come in like lion, go out like a lamb or come in like a lamb and go out like a lion
3. They grow faster!
4. Spring Equal Night
5. Daffodil

Would you like to feature in our next magazine? We are looking out for all things creativity.

Do you have some creative hobbies to share? Could you contribute a poem or showcase a piece of art? Would you like to talk about your hobbies and passions?

Please reach out to Nina or Emily to register your interest.