



The Activity Issue!

Summer Edition 2023

Disability
Sports with
Jono!



On the Slopes
with Anna



Pumping Iron
with Maurice!



Climbing High
with Nick!

Also inside
this issue:

- Open Day highlights
- Fancy trying Boccia?
- Anthony's Story with MDSC



Letter from the Editor



Hello Folks!

Well, here it is! Our first Magazine of 2023 focusing on all things activity.

In this edition we explore a whole host of sports and activities undertaken by some of our service users, whether it's an adapted gym session or wheelchair sports.

Sometimes in life we find there is an easier path but the benefits from a more challenging path can give us a greater sense of achievement. Nick's article about walking up to a waterfall is a prime

example of this. Had he taken the easy route the end result would not have had the same impact or been as rewarding.

After talking to service users and Anna, one of our trustees regarding stories for this issue it has really made me feel like anything is possible.

I am reminded of a time when I rode around Silverstone on my Can Am Spyder with 'The Bike Experience', a charity set up by a motorcycle racer who had to adapt after he was paralysed (and yes, he still races!). On the same day as my visit there was an ex British Super Bike rider present, who again was paralysed after a nasty incident on track. This was his first time back on a bike and with the help of others and an adapted motorcycle he managed to ride a few metres in a straight line, an amazing feat. The emotion that he showed, well you just couldn't beat it. A very moving experience indeed, all made possible by a charitable act.

It reminds me very much of our Centre and the services we gratefully receive as service users. Living with muscular dystrophy can be very isolating so it is vital we have this community to fall back on. Also, it is encouraging to know that there are so many charities set up to make things possible for people with disabilities. Whether they are providing grants to help us travel or making sports accessible. Some are mentioned throughout this edition, and I am certainly feeling motivated to push against myself and my condition to try something new and become a lot more active on all levels. My only hope is that you too are inspired by what is out there. I just can't decide if I rather hit the surf or go sit skiing! Who's joining me?

Enjoy the read!

Lots of love

Em x

CONTENTS

- Page 4 - A Note from our Chair of Trustees Ruth
- Page 5 - Centre Roundup
- Page 6 - Open Day Roundup
- Page 8 - Therapy Update
- Page 10 - Upcoming Events
- Page 11 - Fundraising and Thank You's
- Page 13 - Climbing High
- Page 14 - Disability Sports
- Page 16 - Inclusive Gym
- Page 18 - Anthony's Story
- Page 19 - In the Trustee Spotlight
- Page 22 - Wellness Hub
- Page 24 - Travel Blog Series
- Page 25 - Keep in Touch



A Note from our Chair of Trustees Ruth

10 years! How time has flown from the Charity's formation in mid-2012 and our first physiotherapy session in January 2013!! Before its opening, the Centre was just a dream shared by MD UK's West Midlands Muscle Group members who were inspired by the Neuromuscular Centre (NMC) in Winsford.

An initial starter fund of £40,000 was raised over several years, and with the moral support and practical assistance of Matthew Lanham and his team at NMC as well as MD UK, the dream of opening a Midlands centre supporting people living with MD became a reality.

Who could have imagined that 10 years on our charity would have grown so much? We now have over 550 registered service users at 4 satellite locations (with a 5th in the works) and a new more accessible HQ in Coventry, supported by a dedicated core team of staff and volunteers like our guest editor, Emily, trustees, and external contractors including Lysa and Jen. And all of this operating under our revised banner of the Muscular Dystrophy Support Centre (MDSC).

MDSC's journey has been one of growth borne from challenges and adversity, of resilience and perseverance and of the continuous imagining and reimagining of what is possible and attainable. In some ways, I feel our journey reflects the journey of our service users as we all strive to adapt, thrive and reimagine ourselves and our lives in the face of change and challenges.

MDSC's mission is inspired by our service users and in turn, MDSC's support aims to inspire independence and better quality of life for our service users. We are stronger together and it is reflected in what we have achieved together thus far. It would not have been possible without the support of so many of you, thank you all so very much.

As we add more staff and expand services and locations to better meet the needs of people with MD in the Midlands, MDSC needs your support more than ever. Whether donating, volunteering or raising awareness with those you know, your involvement and support is essential to our charity's ability to continue providing therapies and support. Thank you to everyone who came to our 10th Anniversary Open Day in May to learn about and/or support our mission and celebrate this milestone with us. More events are in the works to commemorate our 10th year, and we hope you will join us for one of these events or help us celebrate with one of your own. Please join in so we can be stronger together!



Ruth

SINCE THE LAST EDITION...

SERVICE USER LED CHRISTMAS SOCIAL

»»» READ MORE

Service users Sheila Hawkins and Ros Seal initiated a Christmas social which was held at our new Coventry HQ back in December. We got together to decorate the office for Christmas, Ros is pictured with her husband Doug with our bespoke tree crafted by Sheila.



READ MORE



FIRST WELLNESS HUB EVENT ON RESPIRATORY HEALTH

This year has seen us implement a new online "Wellness Hub" and we held our first meetings in February and April.

Starting out with a popular session focusing on respiratory health, therapists gave presentations to service users and answered their questions. Service users also shared individual experiences. With such an informative session the recording will be made available to view on our website soon. A second meeting focused on nutrition featuring star guest 'Mr Cookfulness'. Check out page 22 for more information.

TEN YEAR ANNIVERSARY DINNER IN LEICESTER

»»» READ MORE

In March we hosted our first 10th anniversary celebration dinner for our Leicester satellite and raised £350 in the process! We have more dinners in the pipeline for each of our locations to continue to celebrate our 10th Anniversary Year!





OPEN DAY ROUNDUP



In May we held our first in person Open Day since 2019 and our biggest event to date! Here are some key highlights from the day. We wish to express our heart felt thanks and gratitude to all involved. That includes all staff, volunteers, sponsors, exhibitors, stallholders, service users and invited guests. We couldn't have done it without you all!

WE WELCOMED THE LORD MAYOR OF COVENTRY AND ARE PLEASED TO ANNOUNCE WE ARE ONE OF HIS CHOSEN CHARITIES FOR 23/24!



Lord Mayor of Coventry, Cllr Jaswant Singh-Birdi with his wife Lady Mayoress Krishna and our Clinical Services Manager, Taher.



Ruth Hereford leads an emotional speech focusing on our last 10 years as a charity and how we've grown.



Our first ever physiotherapist Lynn Ward joins Chair of Trustees Ruth Hereford and Chief Executive Sarah-Ann Moore on stage.



RUTH, OUR CHAIR OF TRUSTEES GAVE A MOVING SPEECH AND WELCOMED LYNN, OUR FIRST PHYSIOTHERAPIST ON STAGE FOR A SPECIAL THANK YOU

ALONG WITH SESSIONS ON BREATHING, MINDFULNESS AND SEATED EXERCISE FROM OUR THERAPY TEAM, A HIGHLIGHT OF OUR OPEN DAY WAS A POWERFUL AND INFORMATIVE INTERACTIVE SESSION LED BY OUR CO-LEAD PHYSIOS, LYNN AND ULRIKE, WITH A PANEL OF SERVICE USERS (TONY CORBETT, JOHN GOODMAN, LEANNE HERBERT AND RUTH HERFORD).

THE SESSION FOCUSED ON EXPERIENCES AND REFLECTIONS OF EACH PANEL PARTICIPANT AT DIFFERENT STAGES OF TRANSITION WITH INPUT FROM FELLOW SERVICE USERS IN THE AUDIENCE.

KAREN WONG FROM JOHN WALTON CENTRE IN NEWCASTLE ALSO SHARED RESULTS OF A RECENTLY COMPLETED SURVEY ON QUALITY OF LIFE FOR PEOPLE WITH MD WHICH REVEALED THAT QUALITY OF LIFE SCORES WERE HIGHER AFTER PEOPLE WITH MD BEGAN USING MOBILITY AIDS.

WE THANK THE PANEL FOR SHARING THEIR PERSONAL STORIES AND THE AUDIENCE FOR ENGAGING WITH AND PARTICIPATING IN THE DISCUSSION. AS THIS PRESENTATION STRONGLY RESONATED WITH SO MANY, WE WILL LOOK TO DEVELOP THIS FURTHER AND EXPLORE HOW WE CAN OFFER MORE ON NAVIGATING TRANSITION AS PART OF OUR EVERYDAY THERAPIES.



On the panel - Tony Corbett, John Goodman, Leanne Herbert and Ruth Hereford.



France Quirin guides everyone through some mindfulness techniques pictured with physiotherapists Lynn Ward, Siobhan Crowton and Chandni Patel.



Angus Drummond CEO and Co-Founder of Limitless Travel.



Paralympic Gold Medalist Robin Surgeoner MBE.

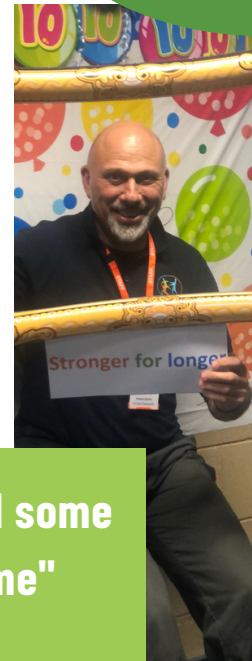


WE WELCOMED TWO VERY SPECIAL GUEST SPEAKERS TO OUR STAGE - ANGUS DRUMMOND OF LIMITLESS TRAVEL AND ROBIN SURGEONER MBE

Thank You

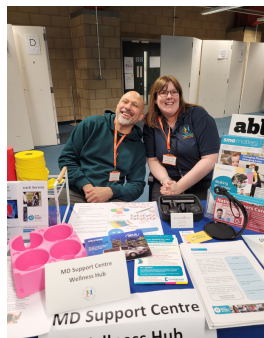
Thank you to Sophie Ali for donating funds for samosas and Amrit Sehmi & family for donating drinks, nibbles, and various Asian goodies.

MDSC WALL OF FAME!



Team members and attendees had some fun posing with our "wall of fame"

A HUGE THANK YOU TO ALL OUR EXHIBITORS AND STALLHOLDERS!



Therapy Update

Recent months have been busy for our therapy team. We have continued settling into our new Westwood House home and everyone has enjoyed welcoming new equipment and trying it out with our service users! Recent additions to our Coventry centre include a new tilt-table, parallel bars, Swedish ladder, massage guns and rollators.

There will be more to come over the summer as we plan to add therapy steps and a brand-new ceiling track hoist.

In January we welcomed a new physiotherapist, Nithin Kunnath, to join Taher, Grace and Mani at our East Midlands Satellite on a Saturday. We are also excited to welcome new therapists Dan Miller (Coventry), Insiya Nagee (Birmingham) and Physiotherapy Assistant Navya Mullapudi (Coventry). Sadly Rewati is unable to continue delivering in-person physio on Saturdays at Coventry but she will still be leading our online Saturday yoga class.

Nithin Kunnath

Nithin is our new Physiotherapist based at our Leicester satellite. Having previously worked with children with MD he is interested in using his experience to support adults, including to help transition paediatric patients into adulthood.



Welcoming our new therapy team members

Navya Mullapudi

Navya is a qualified physiotherapist who is developing her skills and experience, joining us as Physiotherapy Assistant and working at our Coventry HQ from Monday to Friday



Insiya Nagee

Insiya is an experienced physiotherapist who will run Saturday clinics at our Birmingham satellite. Insiya also works with the NHS as First Contact Physiotherapist and recently completed her Masters degree in Physiotherapy at Manchester University.



Dan Miller

Dan is an experienced physiotherapist who will run Saturday clinics for us at our Coventry HQ. Dan is also Centre Manager and Physiotherapist at Daventry-based rehabilitation charity, The Reach for Health Centre, as well as being an Associate Lecturer at Northampton University



Check out below our latest in-person clinic and online class schedule. If you would like to book an appointment at any of our locations, join a class online, or would like more information regarding our services, please contact reception on 02476 100770 or by email at reception@mdsupportcentre.org.

ONLINE CLASS SCHEDULE

Monday

12.00pm - Standing/Seated Cardio with *Dan*

Tuesday

2.00pm - Drop-In Seated Exercise Class with *Ulrike* or *Siobhan*

6.00pm - Beginner Floor Pilates with *Siobhan*

6.00pm - Floor Pilates with *Lynn*

Thursday

10.30am - Drop-In Standing/Seated Mix with *Lynn*

2.15pm - Seated Exercise with *Chandni*

Friday

2.00pm - Drop-In Breathing with *France*

Saturday

12.30pm - Drop-In Seated Yoga with *Rewati*
Every other Saturday restarting 1st July



CURRENT CLINIC SCHEDULE

Coventry

Physiotherapy - Mon-Thurs/every other Fri and Sat

Osteopathy - Every other Fri /one Wed and one Sat a month

Birmingham

Physiotherapy - Every Mon, Tue, Fri and every other Sat

Tipton

Physiotherapy - Every other Mon and every Thurs

Leicester

Physiotherapy - Every other Sat

Complementary Therapy - Sat by appointment

Droitwich

Osteopathy - With Jane by appointment

Upcoming Events

Online Socials

EVERY SECOND
WEDNESDAY OF THE
MONTH - NEXT ONE 12TH
JULY 11.00 AM



MONTHLY ONLINE COFFEE
MORNING ON ZOOM

<https://zoom.us/j/576625802>



EVERY SATURDAY 6.30 PM

SATURDAY COCKTAIL/
MOCKTAIL HOUR ON ZOOM

<https://zoom.us/j/423033181>

In-person Hybrid Coffee Morning

WEDNESDAY 12TH JULY

10.30AM-12.00PM

JOIN US

@

OUR TIPTON SATELLITE
CLINIC (OR ONLINE)

MURRAY HALL
THE BRIDGE
ST MARKS RD
TIPTON
DY4 0SL



Boccia!

DATE TBC

WE ARE CURRENTLY LOOKING TO
HOST A BOCCIA TASTER SESSION
IN SEPTEMBER, MORE
INFORMATION TO FOLLOW.



Fundraising and Thank You's!

In January this year we were delighted to be joined by our new Fundraising Manager, Helen Hone. Helen has been working very hard with the rest of our fundraising team (Lysa and Nina) to raise the money that we need to continue all our work to support people with MD across the Midlands and beyond – and she is loving working with our team and fabulous service user community!



Helen Hone

Community Fundraisers:

Service users and staff got together for the first 10th Anniversary Celebration Dinner at the Chef and Spice near our satellite location in Leicester.

We all enjoyed a great evening with delicious food and lovely company and managed to raise £348 in the process. Thank you Sheila Hawkins for organising this great night.



THANK YOU!

Thank you to all who donated prizes and sold and bought tickets for the MD Support Centre Easter Raffle. We raised £517.

Paul Dowling and the ABP Club kicked off their golfing season with a fundraiser for the MD Support Centre. They donated a whopping £1,620 after their first tournament this spring. Thank you for your continued support.



Andy Collins held his annual golf day in April 2023. The day was a major success and he raised a fantastic £1,066. Thank you!

Radio Panj hosted a 23-hour, 23 minute and 23 second broadcast radio marathon in support of MD Support Centre, raising a fabulous £1,100. Our Clinical Services Manager Taher and Chief Executive Sarah enjoyed taking part and joining the Radio Panj DJs on air!



On Thursday, 6th July – two key supporters, David Salt and Gary Evans, are holding their golf days once again in support of MDSC and MD charities at South Staffordshire Golf Club and Aston Woods Golf Club. We thank them for their vital and continued support!



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!

Trusts and Foundations

The National Lottery Community Fund
Garfield Weston Foundation
Heart of England Community Foundation
The James Tudor Foundation
The 29th May 1961 Charitable Trust
The Hobson Charity
DMF Ellis Charitable Trust
WPH Charitable Trust
HEARTH Foundation
Birmingham District Nursing Charitable Trust
Archer Trust
Edward Cadbury Charitable Trust
P.F Charitable Trust
Carmela and Ronnie Pignatelli Foundation
Michael Marsh Charitable Trust
George Fentham Birmingham Charity
Edgar E Lawley Foundation
CB and HH Taylor 1984 Trust
Keith Coombs Charitable Trust
Muntz Trust
Leamington Spa Community Fund
Tilehouse Trust
Marsh Charitable Trust
Eric W Vincent Trust Fund
Douglas Heath Eves Trust
Lillie Johnson Charitable Trust
Austin Edward Charity Trust
JC Seccombe Trust

Individual Fundraisers:

Andrew Geoghegan
Andy Collins
David Salt
Edwina Sarkissian
Gary Evans & family
Gayle Armson & family
Trisha & John Saul and their team of Via Francigena walkers -John, Pete, Bridget, Sadie and Lawrence - plus supporters
Neil Corfield & family
Nick Randle
Paul Dowling
Tracey Pratt & family

Volunteers:

Emily Bonner
Grace Kabinga
David Wilson
Nicholas Gibson
Paul Jordan
Terry McDonagh
MDSC Steering and Focus Group participants
MDSC Project Board

Other Companies/ Partners:

Mezei Design
Microsoft
Questionpro
Smugmug.com
Start.me

And last but not least

All our generous individual donors
All those who have run a Facebook birthday fundraiser
All our donors who have donated generously and wish to remain anonymous

A big thank you to everyone who sold goods at our Open Day with proceeds going towards the Centre - Paul Jordan, the Sehmi family and their friends, Tracey and Jennika and Clair and Lee, you made the day extra special! Special thanks to all of those who donated goods to sell in the Centre – we raised £402 to date.

Thank you to our Corporate Donors

**ABP Club
Armson Electrical
Bennett Workplace Solution
Thera Trainer**

We appreciate your continued support!

A big thank you to our Open Day 2023 and 10th Anniversary Celebration Sponsors Thera Trainer.



Climbing High

by Nick Randle



I went to this place in October 2021 while I was up in Scotland called Ossian's Hall of Mirrors, which is by a spectacular waterfall that the Hall looks out onto from a balcony.

I just wanted to tell you my experience of getting to the Hall, and how my hiking poles and my girlfriend Kayleigh helped me.

I arrived apprehensive as ever as is usual for going any place new, worrying about if I could actually see the waterfall or if it was going to be a complete waste of time if it wasn't accessible.

We then walked along the river which was really nice and made much easier by my hiking poles that I had just bought that day to try out.

I will say they were the best things I've ever bought and completely wiped the fear of me falling over out of my head. After about a 10-15 minute walk we had got to the bottom of the waterfall and it was beautiful with all the autumnal colours adding to it.

That was the easy bit, now I had to try and climb up this really steep slope that had rocks and tree roots everywhere which put me off. That was when I got annoyed with it thinking there's no chance I'm going to attempt that, so I went and sat on the bench upset because I really wanted to see this Hall of Mirrors.

My girlfriend then came over to me and said you can do it with the help of me and your hiking poles.

I was a bit nervous about it for about five minutes or so as I kept having a look at it trying to work out the best route for me to take. I then just went and did it. It must have been quite funny watching me and Kayleigh climb up this hill but it doesn't matter, I did it in about 15 minutes.

The sense of achievement was too much for me, I broke down in tears of joy and gave Kayleigh the biggest hug and kiss, it had made my day. I had an endorphin rush and it felt so good. It also made me feel like anything is possible, and to not listen to the people that tell you can't do things that push you physically and mentally with the conditions we have because we can! It might take longer but we can do them!

The funny thing was I had climbed up that piece to then find a more accessible route after I'd done it but that route was really boring so I'm glad I chose the more challenging way of getting there.



DISABILITY SPORTS

By Jono Whitehead

I'm sure I'm not alone amongst those of us with muscle-wasting conditions, in saying that sports haven't always been my favourite activity. The highlights of my teenage sporting endeavours are coming second-to-last in a cross country race of 150 11-12 year old boys (and the only reason it wasn't last is because someone had a severe asthma attack before the finish line); being moved from the D team to the C team in rugby (because there weren't enough players to warrant having a D team anymore); and joining my brother at boxing training, where I was significantly slower and weaker than the rest.

In March 2020, I had sent an email to David Needham at Leicester Tigers wheelchair rugby asking if I could give it a go. Due to the pandemic, it wasn't until April 2022 that I finally got to give it a go. In the meantime, I'd also seen an article post-Paralympics about wheelchair basketball, and tried that, and loved it. I vividly remember the freedom I felt whilst pushing around the court.

In the year and a half since that first session with Leicester Cobras, I've trained almost every week. I've played for the first team, I've

"With the support of the physio team at MDSC I've been able to make sure I'm not damaging myself too much..."

"I vividly remember the freedom I felt whilst pushing around the court"

supported the women's team at their weekend competitions, and I've been able to train with Paralympians. I've improved so much over the last 18 months; my fitness has increased, I can score baskets far more regularly, and I'm learning to play with a team. With the support of the physio team at the MDSC, I've been able to make sure I'm not damaging myself too much, whilst also pushing myself to the best of my ability.





Alongside team sports, I've been lucky enough to try swimming, parkrun (including being invited to the parkrun conference to give a talk on disability at parkrun), handcycling, framerunning, boccia, and throwing sports. Some of those were at an event run by charity CPTeens: boccia and framerunning are sports dominated by athletes with cerebral palsy, but would often be suitable for people with muscle-wasting conditions. Swimming was great; I was supported by a Paralympic swimmer I met through Instagram, who suggested I'd benefit from a float and a band to keep my legs from flailing. I know other MDSC users use swimming pools just to stretch in the water, or practice walking in a safer environment.

With most disability sports, there are classifications for each athlete. The goal of these classifications tend to be to make the sport as fair as possible. In wheelchair basketball, each team is allowed a certain number of points on the court at a time, and each player is given a classification from 1 to 5 (in 0.5 intervals). Typically a 1 pointer might be someone with a high spinal cord injury, or cerebral palsy affecting all four limbs and core muscles, and a 5 pointer would typically be someone without a disability. This means that a range of people get to come together and play sport.

Muscle-wasting conditions affect a wide range of people at a wide-range of times in our lives. From the sports I've tried and experienced, I'm confident that there are plenty out there for us to take part in. The benefits are clear: increased physical fitness, improved mental health, and better social lives. Let me know if you ever want to come to Leicester to try wheelchair basketball!

"Let me know if you ever want to come to Leicester to try wheelchair basketball!"



DID YOU KNOW?

Parasport is changing! Check out Every Body Moves below

John



<https://www.instagram.com/p/CpzlaCbI0fV/>

INCLUSIVE GYM

BY MAURICE COOPER



“EXERCISING
AT HOME IS
OK BUT VERY
LONELY...”

Hi everyone, my name is Maurice and I have a condition called Charcot-Marie-Tooth disease, I inherited it, and it has affected me all my life.

Fortunately, although I have never been a sporty person, I have always tried to maintain an active exercise regime.

My condition really started to show itself when I turned 50 and after the initial shock of how quickly I deteriorated and quite bad depression, I started to settle into a routine thinking this is it and its all downhill from here.

I had to give up my job as an electronics engineer but I managed to retrain and I taught numeracy part time at our local college.

So, from 2001 (when I turned 50) to 2020 I tried to maintain a regular exercise program, seeing different physios and looking on line for inspiration for exercises suitable for me.

I tried the gym route, but with all those fit bodies bouncing around me I found it discomforting so I stopped going.

Exercising at home is ok but very lonely, very difficult to motivate yourself, and are you doing it right, I don't want to do more damage than is already being done by my condition.

Although there was plenty of groups out there, I was trying to cope on my own.

We all know what happened in 2020 and the subsequent results of being able to socialise and mix, and as detrimental as this was it was a wakeup call for me.

A friend who was a volunteer at our local centre (The Portway Health and Leisure Centre) suggested I go back and start training again.

I had attended a few sessions prior to covid but had not embraced the benefits it could offer me.

I now go to several different exercise groups one of them being an inclusive gym group.

There can be up to 25 people in this group who all have different medical issues, but we laugh, and moan, while exercising together for an hour.

The group is led by a qualified gym instructor who takes us through different warm up exercises, and then a round of individual exercise routines using different equipment that last 60 seconds on each piece of equipment.

All the equipment for each routine is laid out in a large circle so everyone gets a chance to have a go at everything, the instructor makes sure you know how to use each piece of equipment properly.

Each routine is designed to accommodate every disability, either in a chair, wheelchair or standing or a combination of all of these.

If you have had enough, you just sit and watch, there is none of this 'no pain no gain' malarkey, everyone goes at their own pace, and you stop if you feel a certain exercise is not for you.

You also get a sense of how best to use the equipment in the gym to suit your personal needs, and how to exercise properly.



BARINDER & TOM SHOWCASING HOW THE GYM EQUIPMENT IS ACCESSIBLE FOR WHEELCHAIR USERS

The main thing is exercising together has given me inspiration, by looking at all the different disabilities of the people at these sessions and seeing how they cope.

Yes, doing a regular exercise routine is something we should all do, no matter what your medical condition; but doing something together just doesn't enhance your physical health, it greatly enhances your mental health, plus you have a good laugh.

Yes, there are the fit bodies bouncing around and sweating with the effort they are putting into their exercise programme, I wonder sometimes when they see us laughing and supporting one another during our gym sessions if they wish they could join us.

I hope by writing this I can encourage some of you to access a group close to you.

Happy exercising!

Maurice Cooper



SOME OF THE GROUP - TOM, GARFIELD (GYM INSTRUCTOR), HARSHA, JULIE, MAURICE, BARINDER & RAJVINDER

Anthony's Story

with MDSC

Anthony who has SMA type 3 has been a service user since 2014 after being directed to MDSC by his then consultant Dr David Hilton-Jones.

Anthony's story although unlikely unique, is an interesting one as it was actually his daughter Caitlyn, who held the key to his SMA diagnosis.

For 38 years Anthony had no idea that he had SMA.

"I had dislocated hips at birth which were corrected as a child but left me walking poorly"

Back in 2009 when Caitlyn was 4 she was referred to the John Radcliffe Hospital in Oxford because her feet were turning in. Her consultant then had Anthony take a blood test to see if there was a link, this in turn led to him being seen by Dr Hilton-Jones.

"I was seen by Dr David Hilton-Jones who after a biopsy was taken of muscle sample in my left shoulder and marching it with a sample taken back in 1975 of my right thigh I was finally diagnosed me with Spinal Muscular Atrophy type 3"

Fast forward a few years and after a subsequent visit with Dr Hilton-Jones, Anthony was referred to MDSC (then NMC Midlands) for an assessment with Lynn. Since October 2014 he's been having regular physio once a month.



Anthony with his daughter Caitlyn

"...the help I've received from all the staff has been wonderful and truly helpful"

In 2016 it was genetically confirmed that both Anthony and Caitlyn have SMA type 3.

Whereas Caitlyn isn't showing any real signs of the condition Anthony is keen for her to get the help and support that he missed out on early on.

"I've been having problems with my mobility for a while firstly with my legs and more recently with my arms but the help I get from the physio is so helpful despite the pain I suffer the fact that once a month or more if I need it there is help here for me to access.

Take the time last September when I had a bad fall on a day out causing my knee to balloon and left me unable to walk on it. I was able to get a physio appointment within a few days for treatment and for it to be checked. The help I received was excellent and I'm so grateful for all the help I got"

REMEMBER

As soon as you turn 18 MDSC is here to support you! You can be referred by your GP, Consultant or Care Advisor. We have more information available on our website at <https://mdsupportcentre.org/contact/referrals/>



In the Trustee Spotlight Anna Terry



For this edition we are popping Anna in the spotlight to talk about one of her passions - skiing and how she's had to adapt along with the progression of her muscular dystrophy.

For those of you who may not know, Anna has been on our Board of Trustees for over 7 years. Prior to that she managed the office for some time, coming to work with the MD Support Centre from a fundraising background.

Moving back to home turf, Anna now lives in Jersey with her family but we are thrilled she's still able to be part of the Centre in her trustee role.

Anna with her knowledge, hard work and dedication has always been a valuable asset to MDSC.

Last ski season Anna enjoyed her second adaptive ski holiday through Oxygene Ski.

"I had a great instructor and actually made quite good progress. I wasn't convinced after last year that I'd ever be able to do it on my own but I seemed to get the hang of it a bit more this year"



Anna has always skied but knew that when her MD condition meant she was struggling to even put her boots on, it would probably be the last time she did so.

But then, after having children and once they were old enough Anna thought it would be a great opportunity for them to start skiing, so after a gap of some years it was either miss out on the experience altogether or embrace the "sit ski"!

A lot of research led Anna and her family to a suitable resort called La Plagne Centre.

"The company (Oxygene Ski) have developed a lot of the equipment and they had a big group there from Blesma, the military charity, and they had double amputees and blind people skiing and snowboarding, it was amazing"



As with anything new or different and after skiing the traditional way for many years Anna mentioned that adaptive skiing takes a bit of getting used to and that it can be frustrating because you are back to being a beginner.

The sit ski direction of travel and braking is essentially controlled by the arms and you don't need a lot of strength but being tense can make it more tiring. Luckily the instructor can take over if you get tired and whizz you down the slope at a hair-raising rate of knots!

Anna isn't just stopping with her skiing though. Living on Jersey, you simply have to embrace the sand and surf! Hence Anna has recently acquired an off-road wheelchair that can cope with the beach and has also started adaptive surfing through the charitable organisation, Healing Waves.

Surf boards are adapted to contain a seat and there's plenty of volunteers to help out!

Check them out:

<https://healingwaves.org.je/>

FANCY ACCESSIBLE SKIING?

<https://www.oxygene.ski/la-plagne-ski-school/>



Anna on the sand with one of her sons in her beach-friendly wheelchair!



Anna practising with the indoor surf machine before hitting the waves!

FEELING INSPIRED?

Then check out Disability Snow Sports UK for more info around adaptive snow sports, local groups and accessible ski holidays!

<https://www.disabilitysnowsport.org.uk/>

Thank You
Anna!

WELLNESS HUB

Nutrition

Our most recent Wellness Hub event focusing on nutrition featured star guest Ian Taverner who has a great approach to cooking easily, quickly and healthily.

Here we share his Cookfulness Steps and the recipes that Ian cooked for us.
Why not have a go yourself at home!

Ian also showcased some really handy kitchen equipment such as the knuckle duster peeler and right-angled knives!

DON'T MISS OUT!

You can watch the replay on our YouTube channel! [Click here](#)

Easi-Grip knives shown below were one of the adaptive pieces of kitchen kit that Ian uses



COOKFULNESS 12 STEPS TO THE HAPPY STUFF!

1. Breathing & Visualisation
2. GIVE YOURSELF TIME
3. Cookfulness Playlists
4. Widen Your Kitchen
5. Smart Equipment
6. SMART INGREDIENTS
7. Little Extra Cooking
8. PLAN FOR THE UNPLANNED
9. Try Something New
10. Whatever You Make, It's Right
11. CREATE NEW MEMORIES
12. Celebrate Everything!



COOKFULNESS

THE RECIPES

COOKFULNESS & MDS
Coconut & Herb Curry Sauce

2 cans full fat coconut milk
1 big handful fresh basil (incl stalks)
1 TABLESPOON GINGER PUREE/CHOPPED
Juice 1 lime
1/2 TEASPOON TURMERIC

For all the recipes on this page just pop the ingredients into a food processor and whizz until well combined

COOKFULNESS & MDS
Flapjacks

100g soft butter
2 tablespoons maple syrup
200G PORRIDGE OATS
100g sultanas
2 MASHED SOFT BANANAS

COOKFULNESS & MDS
Oat bites

120g porridge oats
1 tablespoon coconut flour (or dessicated)
120G CHICKPEAS
120g fresh blueberries
1/2 TEASPOON CINNAMON
1/2 TEASPOON VANILLA EXTRACT



YOU CAN FIND IAN TAVERNER AKA MR
COOKFULNESS ONLINE HERE:

[HTTPS://WWW.COOKFULNESS.CO.UK/](https://www.cookfulness.co.uk/)

TRAVEL BLOG SERIES!



Feature in our blog!

DO YOU HAVE A
TRAVEL STORY TO
SHARE?

ARE YOU
GOING ON
HOLIDAY?

Then we'd love to hear from you!
Please contact Emily at:
emily.bonner@mdsupportcentre.org
We'll be delighted to feature your story in
our website blog!

DID YOU KNOW?

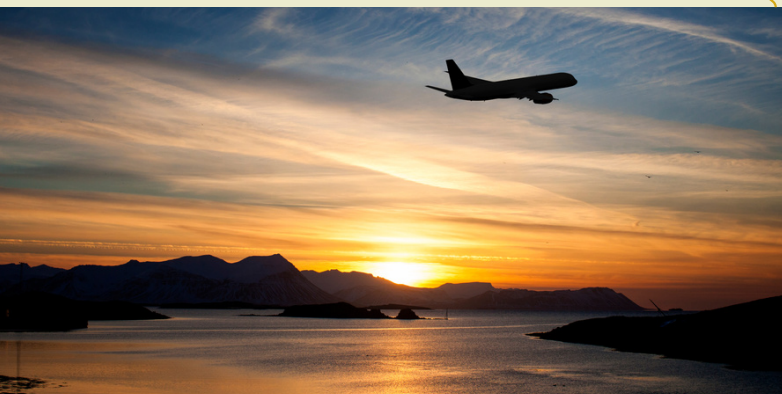
You can apply for grants to help cover the cost of going on holiday!

Here are some websites to have a look at:

C S Disabled holidays
<https://www.csdisabledholidays.co.uk/>

The Victoria Convalescent Trust
<http://victoriaconvalescenttrust.org.uk/>

You can also use the grant search tool on Turn2Us
<https://www.turn2us.org.uk/>



Keep in Touch



Follow us:
@mdsupportctr



Follow us:
@mdsupportcentre



Find us on Facebook here:
www.facebook.com/mdsupportcentre/



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://bit.ly/MDSCsubscribe>

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

Would you like to contribute? We are always on the lookout for content for our magazine and blog and we'd love to hear from you if you have a story to share or an exciting experience you'd like to tell the world about.

Do you have a creative hobby? Participate in sport? Or could you recommend a life changing piece of equipment or adaptation that would possible benefit others?

Please reach out to Nina or Emily to register your interest on
nina.hanks@mdsupportcentre.org / emily.bonner@mdsupportcentre.org