EDS
EHLERS-DANLOS SUPPORT UK

SUMMER 2024

FragileLinks

Living with Ehlers-Danlos syndromes and hypermobility spectrum disorders

VOLUNTEER LONG SERVICE AWARDS

MANAGING YOUR EDS & HSD
If you can't connect the issues, think connective tissues

MY STORY:
Turning heartache into hope with EDS UK

THEORY OF CHANGE
Why we do what we do and how we expect to make a difference

MAKING OUR INVISIBLE VISIBLE

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Events calendar

July 2024 – May 2025

July

July 6th – 7th 2024

Peak District Challenge

A wonderful and varied route through Derbyshire's finest scenery.

August

August 17th 2024

Superhero Tri

The Superhero Tri is a triathlon with a difference, it enables those with a disability to take part in a large sporting event.

September

September 14th – 15th 2024

Thames Path Challenge

England's greatest river provides the backdrop for this unforgettable challenge.

October

The Great British Bake Off Sweepstake

Get Set, Bake! Who do you think will be the winner of this year's competition? Join friends, family, neighbours and colleagues for this friendly sweepstake.

November

Strictly Come Dancing Sweepstake

Keep Dancing! Who will foxtrot to this year's final? Join friends, family, neighbours and colleagues for this friendly sweepstake.

December

EDS UK Winter Raffle

Don't forget to buy your tickets to be in with a chance of winning a fabulous prize.

2025

January

January 25th – 26th 2025

London Winter Walk

A great event to walk off the Christmas and New Year celebrations and maybe to kick start a new fitness regime!

February

Organise your own cake sale

From scrumptious scones to a delicious Danish, what will you bake in aid of EDS UK?

March

Take on a Tandem Skydive

Take on an exhilarating tandem skydive and make memories to last a lifetime!

April

April 27th 2025

TCS London Marathon

Are you ready to take part in the most popular marathon on the planet?

May

May Awareness Month

Take part in awareness-raising initiatives.

A word from EDS UK

Welcome to the Summer 2024 edition of Fragile Links. Since the last edition we have been working hard on our new vision, mission and theory of change.

Why do we need these? Well, we need to know where we are going and what it is we are working to change. We also need a plan of how to do this in the coming years and looking further ahead into the future. Our new vision and mission are:

Vision
Across the UK, people with EDS or HSD will be connected, heard and supported, with equitable access to care.

Mission
To be the voice of the EDS and HSD community in the UK.

To bring together people with EDS and HSD in the UK to equitably access diagnosis, treatment and care. We do this through:

- **Awareness** – We will advocate for and empower our community to drive change. We raise their voices, and work with the NHS across the UK in pursuit of services accessible by all
- **Support** – We will provide a platform to support and connect our community, delivering information and advice on living with EDS and HSD
- **Knowledge** – We will build knowledge through information, training and enabling research. We will confront misunderstanding and challenge inequality

We have also created a theory of change for EDS and HSD which centres around three areas:

- **Advocacy and access**
- **Community and connections**
- **Information and knowledge**

Find out more in this edition of Fragile Links.

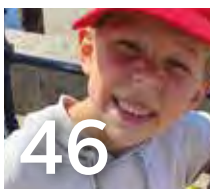
There has been so much else happening over the past few months including all the fantastic Dazzle Walks, key conversations with politicians, education and collaboration with healthcare professionals, wonderful support groups and much more. As we look forward to the new season, I would like to thank every one of you for all you do to support the EDS and HSD community in the UK.

We see you, we hear you and we will raise your voices and connect you. Hope you all have a lovely summer.

Susan

SUSAN BOOTH
Chief Executive
The Ehlers-Danlos Support UK

In this issue



Meet the **team**

Stephen Stacey
Trustee since 2017
Chair

Susan Booth
Staff
Chief Executive

Guy Hodgson
Staff
Head of IT and Digital

Nikki Casey
Staff
Senior Communities Manager

Laura Kyriacou
Staff
Senior Fundraising Manager

Catherine Thurston
Staff
Fundraising Officer

Sabine Bachinger
Staff
Helpline Advisor

Erin Simons
Consultant
Social Media Manager

Leah Mansfield
Trustee since 2013

Jason Pearce
Trustee since 2018
Treasurer

Adrian Steel
Trustee since May 2018

Charlotte Williams
Trustee since March 2020

Sarita Aujla
Trustee since June 2020

Alison Roux
Trustee since Feb 2022

Anne Lavery
Trustee since Feb 2022

Ellie Cannell
Trustee since Feb 2022

Laure Nas de Tourris
Trustee since June 2022

Meet the **medical panel**

Dr. Hanna Kaz Kaz
Rheumatologist
Medical Advisory Panel Chair

Professor Rodney Grahame
Rheumatologist

Professor Qasim Aziz
Neurogastroenterologist

Dr. Jane Simmonds
Physiotherapist

Dr. Nigel Burrows
Consultant Dermatologist

Dr. Alan Hakim
Rheumatologist

Mr Vik Khullar
Gynaecologist

Professor Chris Mathias
Neurovascular Professor

Dr. Glenda Sobey
EDS National Diagnostics Team

Professor Francis Michael Pope
Geneticist

Dr. Kelly Lockwood
General Practitioner

Dr. Emma Reinhold
General Practitioner

Dr. Kate Barnes
General Practitioner

Jason Parry
Specialist Physiotherapist

Dr. Helen Cohen
Consultant in Chronic Pain, Medicine and Rheumatology

Sharon Bunce
Speech and Language Therapist

Contact us

The Ehlers-Danlos Support UK is a charity registered in England and Wales No. 1157027 and registered in Scotland No. SCO46712. Registered Company No. 8924646.

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Getting to know the EDS UK team

Let's meet *Catherine...*

What is your role at EDS UK?

I'm the Fundraising Officer at EDS UK and my main focus is on community and events fundraising.

How long have you been involved with the charity?

I started working for EDS UK in September 2020.

What does a typical day for you look like?

I really enjoy that there is no typical day! Responding to emails and taking phone calls always features but some days I may be researching new events and fundraising trends, others I could be writing content for the weekly newsletter or sourcing prizes for our raffle.

What is the one thing you are most proud of doing during your time with EDS UK?

I'm most proud of how, as a team, over the last four years we have developed Dazzle Walk, our very own inclusive event for the EDS community. From the feedback I have received I can see how much the event means to those who have taken part.

What's the funniest/strangest thing that has happened to you at EDS UK or in your fundraising career to date?

A few years ago I emailed a supporter only to find out that they were my neighbour from the village I lived in when I was 5 years old, it's a small world!

What hobbies do you have or how do you relax?

I'm a bit lost without a book on the go and read whenever I can. Many moons ago I went to art college and I still like to draw and most recently I've discovered abstract embroidery which is a lot of fun. I enjoy walking in our local forest and going to my weekly ballet class, I've made a good friend there who is 80, I find that very inspiring!

What is your ideal holiday?

It's my dream to do a self-drive holiday in Canada with my family. I really enjoy trekking, forests walks and mountains so I would love to go exploring. I'm not sure my seven year old daughter would enjoy it quite so much, maybe in a few years time!

What's your favourite animal and why?

Definitely elephants, I visited an elephant sanctuary in Thailand about 20 years ago and was besotted by them. I think they're beautiful.

What is the one thing you have learnt (or favourite quote) that has stayed with you?

Help yourself by helping others, it's something my mum lives by, she's the most kind and giving person and always makes time for others – I aspire to be like her.

...and hi! to *Charlotte...*

What is your role at EDS UK?

I am one of the Trustees at EDSUK. That means that I am a member of the Board that governs the charity and oversees its legal requirements. The Board sets strategy and makes decisions about the direction the charity takes. The Board also manages the charity's funds and resources and plans how we can best go about achieving our mission and purpose. I am a volunteer like many others who work within EDSUK, and I hope that I can use my knowledge to make a difference for people living with, and affected by, EDS and HSD.

I am also one of the Deputy Chairs on the Board and support our Chair, Stephen, in running meetings, as well as advising staff at the charity. With my background and skills, I can particularly help with matters relating to strategy, research, partnerships, medical pathways and working with the NHS. All Trustees have areas of specialist experience and we work together to help the charity succeed.

How long have you been involved with the charity?

I first became involved with the charity through a friend of mine who had vascular EDS and who was a Trustee at EDS UK. He talked to me about what the charity was aiming to do to support the community, and I expressed an interest in joining the Board of Trustees. That was in late 2019, and I joined the Board in March 2020, just before the COVID-19 pandemic caused the nationwide lockdown. The first couple of years with the charity were largely held online, and focused on how we could transition to a new way of working and helping EDSUK navigate the consequences of the pandemic.

This is now my fifth year on the Board, and there remain a huge number of challenges for charities like ours, both with the current economic climate, changes in charitable giving, and significant deficits in the care available for many people with long-term conditions across the UK.

What does a typical board meeting look like?

At our Board meetings we receive reports from the charity team and fellow Trustees about the progress of our plans as a charity and discuss where we might need to make decisions, act, or find out more information. The Board must understand the risks we face and look forward at where we expect the charity to be in coming months. This can include our budget and finances including fundraising, any changes in policies and developments relevant to EDS in the wider world, such as in politics, in clinical guidelines, the NHS or research.

Our strategy has three areas of focus so we will mainly discuss how we are doing on these: advocacy and access to care, supporting our community and volunteers; generating, sharing and improving information and knowledge about EDS. We have measures and indicators that help us understand how well we are doing, and we will talk to Susan, our CEO, and other staff from the charity for their input, as well as considering what we hear from our community through surveys, feedback and talking with volunteers.

What is the one thing you are most proud of doing during your time with EDS UK?

There are so many things I am proud of about EDSUK's work over the past four years – including our petitions to parliament in England and Scotland, the continuing strength of our volunteering community and support they provide, and the Change Makers programme for our younger members, which I loved attending at their weekend event in Birmingham last March. Personally, I am very proud of the work we have done in understanding the healthcare impact of EDS in working with the NHS and researchers, and the developing Theory of Change that describes our goals as a charity.

What hobbies do you have or how do you relax?

With two school age children and a very energetic Labrador I don't seem to get a huge amount of time for hobbies, but when I do, I love to read fiction and essays, and have a huge passion for fashion, art and history. I am generally to be found dragging my family around a historic building or gallery if I get the chance or creeping off to browse boutiques. Now my son is eight and has taken up the cornet, I also get a chance to play musical instruments again with him, which I have rarely had a chance to for many years.

What is your ideal holiday?

I love old cities with a lot of culture, tasty food and a warm climate, so a couple of weeks exploring somewhere like Italy, Spain or Portugal by train, or maybe Central or South America with lots of time to wander sounds like heaven.

What's your favourite animal and why?

As far as pets go, I am a cat lover really – we have always had cats as long as I can remember, and it never quite feels like a home without one or two lounging around! For wild animals it's hard to beat the majesty of the rhinoceros though. Rhinos are such foreboding, powerful creatures but also gentle. They are hugely ancient, and I feel they somehow connect us to the past. Rhinos really need our support now too, as they are endangered, with only a few species left alive. I love visiting our local zoo which has a rhino family, and hope to see them in the wild one day.

What is the one thing you have learnt (or favourite quote) that has stayed with you?

There is quote from columnist Mary Schmich "Sometimes you're ahead, sometimes you're behind. The race is long and, in the end, it's only with yourself". I've learned that only so many things are in my control, and I need to concentrate on being happy with me and focus on my choices, it's not worth worrying about what most other people think.

Latest news from Annabelle's Challenge

Emergency Preparedness

People with vascular EDS can be vulnerable in an emergency.

If you're living with vascular EDS, it's important to understand the possible complications that can happen because of your condition. This especially includes how to prepare you and/or a loved one for emergencies.

Emergencies can be scary for someone with vascular EDS. Will first responders know anything about your specific symptoms or diagnosis? How will emergency personnel know how to access information about vascular EDS?

Once you're diagnosed with vascular EDS, you'll want to ensure you're treated correctly in a medical emergency. Thankfully, with help from our emergency care project team, your team of healthcare providers and support from Annabelle's Challenge, you can be well prepared for any emergency with the tools and resources that are available.

What tools will help me prepare for an emergency? If you haven't done so already, now is the time to create or update your vEDS Emergency Toolkit!

Example of resources recommended for your emergency toolkit:

- VEDS Emergency Pack.
- Request an Ambulance Marker on your home address.
- Emergency information QR code.
- Download the what3words App.
- Add Medical ID on your smartphone.
- MedicAlert UK & Ireland membership.
- Careline365 SOS GPS Alarm.
- Develop your 'Grab & Go' checklist in case of an hospital admission.

Annabelle's Challenge Counselling Service

As living with vascular EDS happens within the context of your everyday life, it's inevitable that the 'ups and downs' of both impact on each other. You can talk to our counsellors about anything that you are struggling with, and may impact on your ability to live as well as possible with the impact of vascular EDS. This might include:

- Impact on your family
- Anxiety or low mood
- Identity, including feeling different, lonely or isolated
- Your relationship with health care professionals, or navigating systems
- Dealing with difficult, unpredictable or increasing symptoms
- The psychological burden of being the 'vascular EDS expert'
- Coping with unpleasant tests, surgery or treatment
- Worries about the future

It's not always easy to access counselling. Annabelle's Challenge Counsellors provide a safe, confidential relationship to work through difficult thoughts or feelings, think about options that are open to you, and explore new ways of approaching your difficulties.

Annabelle's Challenge is pleased to be working in partnership with Rareminds to offer a new **Free, Confidential Counselling Service** for individuals aged 18+ impacted by vascular EDS in the UK.

8 - 12 sessions can be provided either via Zoom, or by telephone with both evening and daytime appointments available.

The Annabelle's Challenge Counselling Team are **Zubyda Azzam** (Lead Counsellor) and **Louise Brookes**. Both are trained and experienced therapists who have undertaken additional training in Counselling for Rare Diseases.

We aim to respond to your initial enquiry within 72 hours. We are usually able to then offer an Initial Appointment within 5 -10 days, depending on your availability and the next soonest appointment time.

Translated vEDS Emergency Information

The 'Emergency Information for Medical Professionals' document is now available translated into 8 languages, Polish is our latest addition!

The emergency information for vEDS members only is available in:

French, German, Greek, Italian, Polish, Portuguese, Spanish and Turkish.

To request translated vEDS Emergency Information for your next vacation go to: **https://www.annabelleschallenge.org/travel-advice**

Thank you from Annabelle's Challenge

Over the past 12 months we announced 5 new research projects, hosted 2 vEDS retreat weekends, 9 vEDS support groups, launched a new Counselling Service and welcomed 69 new members representing 76 patients.

Annabelle's Challenge now has 539 patients registered on the database across 22 countries, this month we also celebrate 10 years since becoming a UK registered charity.

It has been super busy for the team in delivering the VEDS Support Programme thanks to National Lottery funding. The charity supports over 440 members touched by vascular EDS, since the support programme was launched in August 2021 we recruited new Patient Coordinators and together Team AC have so far achieved:

- 44 x School Visits
- 98 x Medic Alerts
- 130 x EDS Sunflower Lanyards
- 143 x Ambulance Markers
- 244 x VEDS Emergency Information Packs

Thank you to **Christina, Katie, Karis, Danika** and **Scarlett** for their support as patient coordinators since the programme was launched.

We are far away from taking our foot off the gas! In the coming months we will be announcing:

- **VEDS Conference 2025**
- **New publications in journals**
- **Update on vEDS Sunflower Lanyards**
- **Results of the annual members survey**
- **New online vEDS support groups**
- **Additional vEDS in-person support groups**
- **A new science led vEDS research project**
- **International symposium patient day for vEDS, Loeys Dietz and Marfans**

In summary, it has been a highly productive year and we wanted to take this opportunity to thank everyone, who has supported and continue to support Annabelle's Challenge to make all this possible for our community.

And a BIG THANK YOU to all our amazing volunteers, vEDS steering group, emergency care project team, regional coordinators, board of trustees and our colleagues at the EDS Service in Sheffield & London and Ehlers-Danlos Support UK.

Peer Support

Feelings of isolation often accompany the everyday effects of living with vascular EDS.

Frequently, those feelings stem from the perception that no one understands what you are going through. Sometimes you simply need to talk freely about how you're feeling.

Speak with someone who understands. Our peer support community is comprised of patients, family members and carers of all ages affected by vEDS. They are ready to listen to your cares and concerns; offer emotional support; and will share their experiences and offer their understanding.

How do I get involved? It's easy... just contact **Annabelle's Challenge on 0800 917 8495 or email info@annabelleschallenge.org.**

One of the Annabelle's Challenge team will contact you and get to know you and your needs. and plan arrangements for a peer support volunteer to contact you by telephone, text message or e-mail, however you prefer.

Remember - you are not alone. Annabelle's Challenge is here to help.

VEDS Conference 2025

Save the date! 10th – 11th May 2025 is the next vEDS Conference jointly hosted by Annabelle's Challenge and Ehlers-Danlos Support UK. The conference will take place in Bury, Manchester with presentations by the EDS Service. More information will be announced soon.

EDS UK Community Champion Awards

2024 has brought more nominations for Community Champions within the EDS and HSD community. In this issue we highlight our two most recent recipients. The awards are made to people or organisations who have gone above and beyond in either raising awareness, promoting and disseminating education about the syndromes, supporting people with EDS and HSD or other significant contributions such as adaptations and inclusivity. The awards also celebrate innovative products which make a difference to the lives of people with EDS or HSD.

The awards are open to public places, businesses and non-profit organisations, education establishments and to recognise individual products. Nominations must be made by someone living with EDS or HSD or a family member, friend or carer. Once a nomination has been received, we will contact the organisation or individual to find out more about them and to discuss the potential award. EDS UK Community Champions will receive a certificate and plaque (if they want one) and be listed in Fragile Links and across our digital platforms.

Dr Audrey Kershaw

The award was presented to Dr Audrey Kershaw by Anne Sutherland our Lead Engagement Volunteer for Scotland.

Dr Audrey Kershaw is a specialist in Oral surgery based in Scotland. Audrey became a volunteer with EDS UK in 2021 and has since helped many members in her professional capacity as well as writing articles for EDS UK. Audrey delivers training sessions to many groups including the dental team, doctors, physios and solicitors on hypermobility within dentistry and is passionate about spreading the word to anyone that will listen.

"Dr Kershaw has been a massive support to EDS UK since joining as a volunteer last year. Her knowledge and expertise in the field has been so useful through webinars and articles that she has produced for us and she goes above and beyond spreading awareness to everone including other dental practitioners."
Nikki Casey, Senior Communities Manager

Fran Healey

The award was presented to Fran by Lisa who met at Physiocure – one of our previous Community Champion Award recipients!

Many people may remember Frans heroic walk 'Pathway to Parliament' as part of the #enoughisenough campaign last year. Fran (and a lot of the time joined by amazing husband Stefan!) walked from Yorkshire to Westminster over 2 weeks – even popping in to EDS UK Head Office on their way past. Fran had a huge social media following with members and non-members far and wide following her travels, raising awareness with everyone she met along the way. A massive thank you to Fran and Stefan for such an amazing achievement!

Lisa said "When I was first approached by Fran to support her in this endeavour as a fellow member of EDS UK, I could not say no. Fran being able to walk the distances she did was something I'm no longer able to do due to my EDS, but being part of her support team meant I could be involved and it was inspiring to see her dedication, tenacity and commitment to completing her mission. I am delighted the charity has recognised what Fran has done to help promote the #EnoughIsEnough campaign; it gave Fran and the team behind Pathway to Parliament a lot of hard work but it has all been so worthwhile." **Lisa Backhouse**

You can make a nomination through our website by going to https://www.ehlers-danlos.org/community-champion-awards/. Alternatively, you can email us at info@ehlers-danlos.org

EDS UK GP conference 2024

We are working with one of our members to plan and host an event for GPs to share latest information on EDS, highlighting the condition and its sub-types and the need for earlier diagnosis and how to make a diagnosis.

We know from the recently published hEDS start study that 83% of people said they had had an encounter with an unknowledgeable health care provider and only 10% of people were diagnosed within primary care. It is critical that we support the NHS in providing the right care for people where there is no defined care pathway. One way we can do this is through reaching out to GPs directly and asking them to come and learn more. We need your help to ask your GP to attend and get your friends and family to ask their GPs to attend as well.

The event will focus on how GPs can support patients with hEDS in particular, given the lack of clear treatment pathways. We have three leading consultants supporting the event and will invite other top experts to speak and share their experiences of best practice. The event will be accredited and held at the Reform Club in London, in November 2024. We plan to create post-meeting educational content to host on the EDS Support UK website after the event so that more GPs can benefit from what promises to be a highly educational and informative event.

If you want to be one of the first to know about this exciting event and get your GP to attend please sign up to become a member and get our weekly e-newsletter here. **https://www.ehlers-danlos.org/ membership-account/membership-levels/**

How to be a campaigner

Last year we saw over 33,000 of you sign our petitions across the UK calling for dedicated services for EDS. As a result of the #EnoughIsEnough campaign we led a debate in Westminster, delivered the English petition to 10 Downing Street, held a briefing for MPs in London, have welcomed MPs to support group meetings, have had questions asked on our behalf in parliament and have secured exhibitions and information stands in Holyrood and the Senedd. We delivered a petition to Stormont too. Important conversations have been had, and your voices have been heard by decision makers within the government and the NHS.

Campaigning can be like a marathon. There are lots of steps we need to take collectively in order to create change. As the EDS/HSD community in the UK, we know that there are many challenges within healthcare for EDS and HSD and all of its co-morbidities. That's why after years of being unheard, misunderstood and even gaslit we said "Enough Is Enough".

Why become a campaigner?

Because you want change, because we need hope and because to make the change we want to see we often need to influence people in power.

How do I campaign?

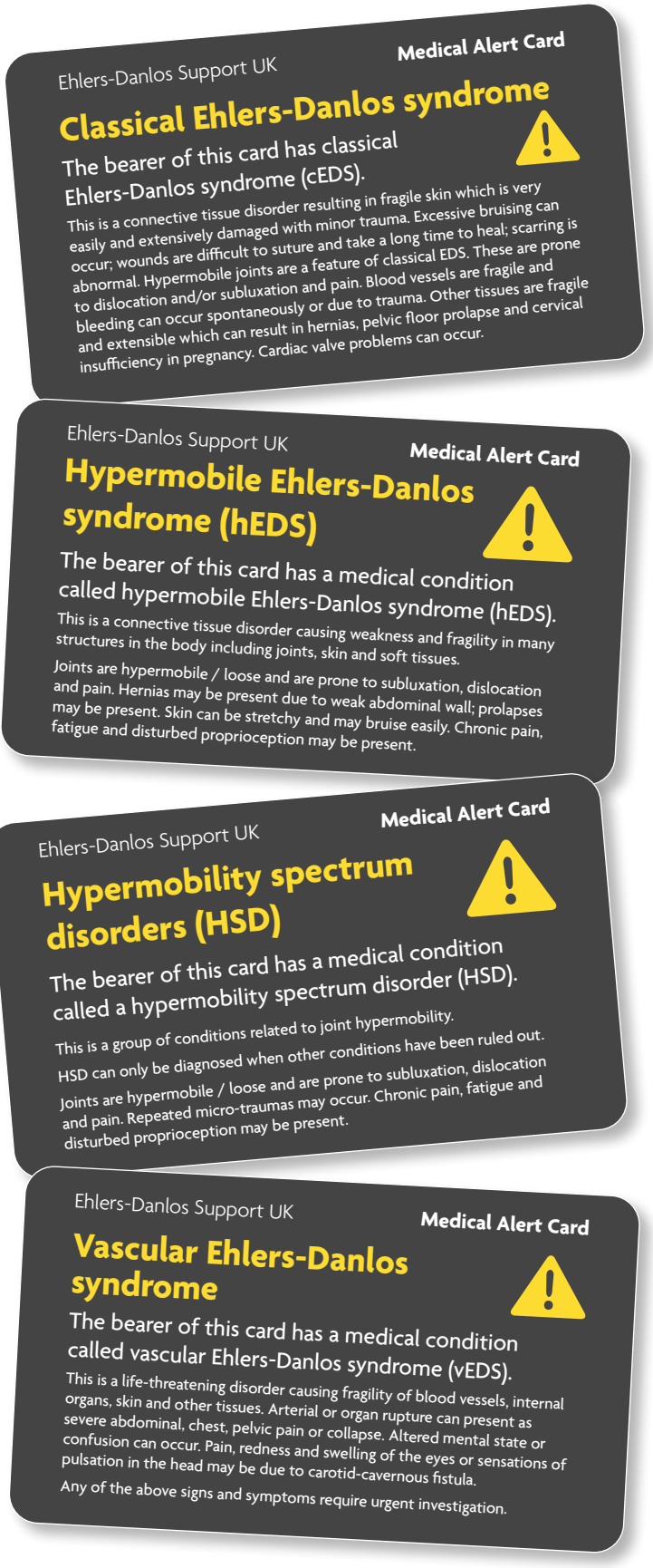
Email your MP and tell them your story and the barriers you are facing locally to accessing the right care and support you need. Send us any responses you get so we can get a better idea of the bigger picture.

Sign petitions – we had a fantastic success in 2023 with record numbers signing. Keep your eyes peeled in our e-newsletter for future actions we can take.

Share your story. Write to your local newspaper or post on your local community Facebook group and share your story. Explain the issues you are dealing with and what you think needs to change. Don't forget to tag us too.

All Party Parliamentary Group

Update on our involvement from Alison Roux, Trustee



EDS Support UK was invited to attend an All Party Parliamentary Group meeting on Rare, Genetic and Undiagnosed Conditions to discuss the need for medical alert cards for people with rare conditions. We went along to Portcullis House to join the discussion.

Hosted by **Liz Twist MP** and chaired by **Genetic Alliance UK (GAUK)**, the meeting kicked off with GAUK providing the context for the discussion. In 2018, NHS England committed to give every patient with a rare disease an alert card, but this has not been progressed because of "capacity and budgetary constraints", according to the Department of Health & Social Care. But we know all too well that people with rare conditions require frequent interactions with a range of healthcare services, often with healthcare professionals who do not know about their condition. This can result in care being given which may be damaging and even life-threatening. Alert cards can provide critical information.

A round table discussion was conducted with the 12 charities present, all of whom support people with rare conditions, including our friends at Annabelle's Challenge. We were asked about our experience of, and challenges with, alert cards. There was a lot of common ground. Every charity agreed alert cards are a useful asset for people with rare conditions and many already provide them through their websites, but very few of these providers have access to NHS-validated alert cards. Nearly everyone present was frustrated by accounts of health professionals who either ignore alert cards or refuse to take them seriously, even the NHS-validated cards. Anecdotally, the same is true for medical bracelets and letters from specialist consultants.

In spite of the frustration, many charities are looking at developing alert cards with QR codes which access comprehensive information about the relevant condition and give details of specialists in the field, as well as exploring the possibility of links to NHS Digital. There was also a general consensus that educating the healthcare profession about the use of alert cards in their current form should be a priority.

Genetic Alliance UK has emphasised this is a priority topic for them and all the charities present expressed their enthusiasm for taking this initiative further in order to help our communities.

If you have any experiences with alert cards that would help to further this debate, please tell us by emailing **voices@ehlers-danlos.org** by including Alert Cards in the subject line.

If you would like to buy your medical alert card please visit **https://shop.ehlers-danlos.org/product-category/medical-alert-cards/**

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Theory of Change

The EDS UK Theory of Change is our map to explain why we do what we do and how we expect to make a difference for people with EDS/HSD in the UK.

Across the UK, people with EDS or HSD will be connected, heard, supported and have equitable access to care.

Long term outcome

Advocacy and Access	Amplifying the voice of the EDS UK community	Raising awareness of EDS / HSD within primary care	Training and empowering GPs to diagnose and refer to the multi disciplinary team	Engaging with gatekeepers to primary care	**EDS / HSD diagnosed and managed appropriately through primary care: a fairer start**
Community and Connections	Supporting the community through a network of groups across the UK	Providing advice to the EDS / HSD community	Educating institutions on diagnosis and care of EDS / HSD	Proving support and connection through our membership programme	**Improved health outcomes for EDS / HSD**
Information and Knowledge	Supporting the community to navigate the NHS	Supporting the research community in building the evidence base	Creating materials for people with EDS / HSD to increase their knowledge	Increasing the number of subject matter experts	**Better access to information and care for EDS / HSD**

COMMUNITY

Spreading Christmas cheer

Our thanks go to Fullers Family Food Hall in Essex who held their Christmas Hamper raffle for the second year running. They raised the fantastic amount of £355 in aid of EDS UK.

Jazz's incredible art

Jazz Turner kindly sold her beautiful art prints and raised £1,349 to help support people living with EDS. Each exceptional hand drawn picture used a combination of paint and ink and took Jazz roughly 4-8 hours to complete.

"I decided to sell my drawings to raise money for EDS UK as EDS is the condition I continue to battle with that has led to me having a shortened life expectancy. EDS is complex, poorly understood and often isolating. My condition has now progressed to the point where I am on palliative care with likely less than a year to live. Now more than ever it is important for me to raise awareness of this debilitating condition, if I had been diagnosed earlier I would likely not be facing the extremes I face today.

As my condition has been getting worse, I have been spending more days trapped by my body and often confined to bed. Although my body physically hasn't been capable my brain has still very much been active. Drawing is something that I have always loved and it helps occupy my brain but I have never thought my drawings good enough to show people. Since I'm now on palliative care I don't feel like I have anything to lose. My battle has been a long and at times very lonely one. I hope by raising money I will not only make others fighting this battle feel less alone but also raise awareness of this condition."

Go sober challenge!

On 14th January, Mia Dunn and her partner Dan took on a sponsored 60 day sober challenge in aid of EDS UK.

Here, Mia tells us why, "Dan and I love a drink, we would never say no to a bevvy and we're always up for a night out and have thousands of drunken tales to tell! We did this challenge not only for ourselves and our health, but to raise awareness for a condition that is seldom discussed. One of my closest friends has recently come out of hospital after suffering the effects of Ehlers-Danlos Syndrome. The effects of this syndrome are changing her day-to-day life, and will do so forever, as there is no cure." Thank you to Mia and Dan who completed their challenge and raised £500 for EDS UK.

25 hour musicathon

Fiddle Fingers is a small youth string ensemble run by Janet Nicholas and based in Ripon, North Yorkshire. As a celebration of the group's 25th anniversary, Janet challenged the youngsters to a 25 hour Musicathon through which they decided to support two charities, including EDS UK, as two of the group's former members live with the condition.

Janet tells us, "The Musicathon went really well! We were launched by the Mayor and Mayoress of Ripon at midday and during the afternoon we had Ripon String group (for the more mature!), an entire year four class of string players from St Wilfrid's Primary School, and four choirs from Ripon Grammar School. These were all interspersed with young players and alumni from Fiddle Fingers playing either solos or duets. On into the evening, Ripon City Training band played for an hour then a few local professional players did an hour allowing some of the more advanced youngsters to play alongside.

Into the night it was the turn of the secondary school members and alumni to hold the fort. One of our former players even turned up at 3am, played for an hour and a half, then went home again! I won't forget watching two small boys eating their way through an entire packet of Pringles then playing their way through a duet book at 1am, or an 18 year old singing songs from Les Miserables joined by another former player who now sings professionally.

Early on Saturday morning the youngest players returned, plus another former member with her husband and baby. The last few hours were down to the three Fiddle Fingers ensembles performing all the pieces we had worked on since September. The event finished with ABBA's 'Thank you for the Music' with the audience joining in very loudly! The response from supporters all over the country has been extraordinary. We might be a small ensemble, but it just shows how important music is to young and old alike."

Our sincerest thanks go to everyone involved for making the event a great success and for helping to raise £1,543 for EDS UK, an incredible amount!

EVENTS

Amsterdam Marathon

The Amsterdam Marathon is one of the most popular marathons in Europe, it's also one of the fastest! EDS UK is very grateful to Shane Regan who took part in this event in support of his partner Sissy.

"My partner Sissy was diagnosed with hypermobile EDS at the beginning of our relationship but it took more than 30 years of several symptoms – from light to severe – for medical professionals to believe she was in pain and often suffering. Although Sissy is active in many ways (sometimes more like a bouncy bunny!), I have witnessed how debilitating her symptoms can be and how very little support is out there. Her suffering is also invisible and I feel I want to make it visible so that people with EDS can receive the right response from society and not feel they have to hide."

Thank you to Shane and Sissy for raising £1,392 for EDS UK!

The London Winter Walk

Lucia Alonso, who lives with hEDS, bravely took on the chilly challenge of The London Winter Walk and in doing so raised £1,087 for EDS UK.

"When I first got diagnosed, I felt very lost about EDS, I feel very grateful for The Ehlers Danlos Support UK which has given me tools, knowledge and a community to navigate the challenges that come with EDS. Fundraising for EDS UK was a great opportunity to open up to my community and share how EDS impacts me and other people. I was amazed by people's empathy and desire to help. If we start from our own community, we can raise awareness and make visible what is often invisible. The London Winter Walk was a good moment to reflect on the privilege to be able to walk 10 km and how proud I am of my body."

The Great South Run

The iconic Great South Run, which starts in Portsmouth, offers 10 miles of stunning seaside running with guaranteed glorious sea views! Lena Frisk took on this challenge in memory of her dad and raised £160 for EDS UK.

"The festive atmosphere of the race made it feel easy to jog, which running never does for me normally, with a couple of short stretches of walking. I managed to finish the race without injuring myself or pushing too hard and I felt good despite having a cold and general feeling of not being fully healthy. My partner also ran the race we enjoyed a beautiful day in beaming sunshine and biting autumn air.

I proudly wore my EDS UK running vest throughout the race and felt so happy about my little contribution to the visibility of EDS and highlighting the important work done on a daily basis by organisations like EDS UK. Most important of all was participating in something that actively turns my grief of losing my dad (who had EDS) 11 years ago into something constructive, to counterbalance the endless amount of time and energy spent with feelings of grief, loss and regret over the years.

It has been hard and taken a long time for me to learn how to live with and handle all the frustrations related to the fact that me, my dad and none of his family, knew anything about EDS prior to the day we lost him and at the same time come to terms with my own EDS symptoms including fighting for a diagnosis. Being given the opportunity to contribute in this way has been a gift for me, and I am the one to say thank you.

I will continue to spread awareness wherever I go for as long as I live. Even if I wouldn't be able to raise funds again, I will never stop raising awareness and will proudly wear my EDS running vest for my next running race, and again and again."

Dazzle Walk

EDS UK's Dazzle Walk was back for its fourth year in May. We'd like to thank everyone who took part and helped to make it even bigger and better than the three previous years!

Dazzle Walk is an inclusive event. Supporters are encouraged to walk a distance that's right for them and get involved however they can, be that walking it, wheeling it, or using other aids.

This year our walkers donned their razzliest dazzliest zebra attire and collectively raised more than £22,000 for EDS UK. Here are some of their stories...

What glorious weather we had in Stormont on Saturday! The first NI Dazzle Walk was arranged by our Lead Northern Ireland volunteer Mandy and along with the other volunteers and we had an amazing turnout - over 35 people!

Thanks to the Lottery Awards 4 All funding, Nikki Casey was able to join them and meet NI members, volunteers and members of the public who were amazed by the dazzle of people dressed as Zebras! With three routes to choose from, the Dazzle walked, strolled, rolled, piggy backed and skipped the mile up to Stormont. Joined by Rhoda Walker from the Northern Ireland Rare Disease Partnership, it was a great occasion to meet members, discuss issues and swap stories.

Thank you so much to everyone who came along or donated - so far the NI team has raised over £1,800! Followed by well-deserved refreshments and a lot of cake, we also took the chance to run a social support group meeting afterwards where members had the chance to talk to each other.

Simon's run for Lauren

Thank you to Simon Dewhurst who raised £200 in aid of EDS UK taking on the Dazzle Walk!

Simon's girlfriend Lauren was diagnosed with hEDS ten years ago after a whirlwind diagnostic journey.

"It wasn't long after diagnosis that I found myself turning to EDS UK for advice and resources when I suddenly began to experience more and more symptoms. EDS UK is an incredibly special charity and one that is extremely close to my heart. Without them, I would still be stuck in an extremely lonely and scary place, not knowing where to turn for help. In 2022, I began volunteering with EDS UK as one of their Area Coordinators and, over the last two years, I have seen firsthand just how important support groups for conditions like EDS are. I could not be prouder of Simon. He's been training so hard alongside his running club. Since Simon and I met, my health has declined and we've gone through some pretty scary situations including post-op complications. Yet, Simon has never once left my side. He's my biggest cheerleader and is always there to comfort me when things get hard."

Max Turner

Max challenges herself to walk 100K in May with her collie Tilly by her side.

"My health and fitness has greatly deteriorated over the past 3 years, now suffering from many chronic health problems including joint pain due to instability and dislocations, fatigue and dysautonomia. After 2 years of struggling, I reached the diagnosis of hypermobile Ehlers Danlos Syndrome. I am still seeking answers to assist with my constantly evolving symptoms arising from comorbidities. Only 3 years ago, I was fit and healthy; hill walking, horse riding, cycling and jogging alongside my active job of dog walking and as a groom. Now relying on crutches, having to plan every activity to not push myself too much. Never knowing what tomorrow will bring is difficult, sometimes I won't even manage a flight of stairs and struggle sitting holding my own head up! I very much grieve my old life! And there are many facing much bigger challenges than myself.

EDS UK have helped me learn how to manage my health and cope with this new life, they do great work creating awareness within the general population and among professionals, along with supporting myself and many others live with our chronic illness."

Dazzle Walk

Caitlin Green

Thank you to Caitlin who walked the Tramway Trail Trek at Calke Abbey, surrounded by the love and support of her family.

"I completed my walk today and am very proud of myself! I walked unaided for the majority of the walk and was supported by mum, dad and dog Milo."

RAISED £264

Jeni Neale

Thank you to Jeni who completed her 10-mile Dazzle Walk along the seafront from Swansea to the Mumbles Pier.

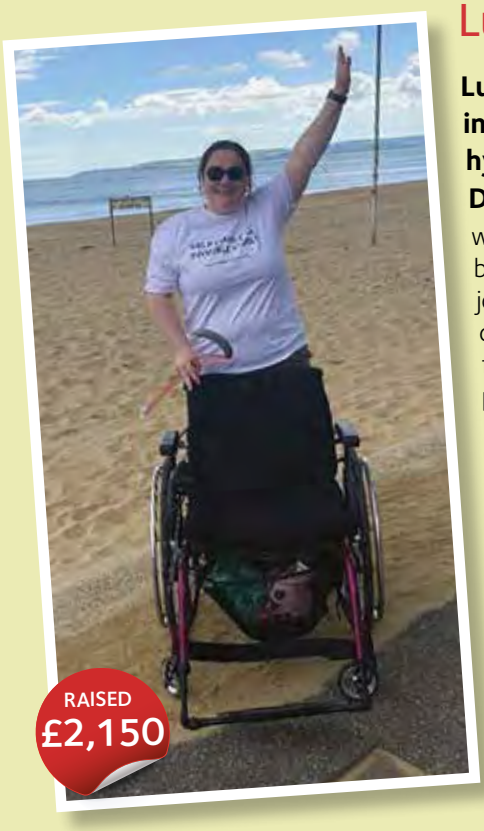
"Walk/Roll completed! The rain stayed away but the blisters didn't! Home for a well-deserved rest now!"

RAISED £645

Lorriane Shirley

Lorriane completed her Dazzle Walk at Boxhill in Surrey, with her two daughters Tia and Kiri.

"We all have EDS and as a family we understand the challenges firsthand. Our goal is to inspire hope and support for those affected by this condition."



RAISED £2,150

Lucy O'keeffe

Lucy was diagnosed in 2021 with hypermobile Ehlers Danlos Syndrome which manifests in her body with: chronic pain, joint subluxations and dislocations, chronic fatigue, Gastro issues, palpations and POTS, immune deficiency, skin fragility, migraine disorder, TMJ disorder and mast cell issues. As an ambulatory wheelchair user Lucy is able to walk but has to limit this to only 6 minutes at a time, even before this time is up she is in a lot of pain with her POTS symptoms kicking in.

Lucy was determined to achieve her goal of walking 10K throughout May, "I did it, I've actually completed my 10km walking challenge. Today I had 13 metres left to do and I walked 54 metres, just because! I was loving walking along the sea and thought I would stop when I felt like it and completed the challenge!"

Georgia Grainger

"I went to my art class in Portobello and treated myself to an ice cream and a coffee on the beach to celebrate hitting 100km!

I'm glad I did this walking challenge but I'm also so excited to have a weekend where I don't have to think about trying to squeeze a walk in. I've been lucky to get mostly good weather and mostly good health, but I've still spent a few days completely in bed and other days very sore. It's been fun though, and I'm glad to raise money for an excellent charity!"

RAISED £464

Get Moving Safely

LEANNE ENGLISH OF MOBILATES

Imagine for a moment: lying in bed, knowing that any second now you will need to get up to walk to the loo and you are dreading it, as any movement will feel like wading through quicksand infused with jellyfish tentacles. Even turning over in bed, you run the risk of leaving a shoulder behind or slipping a kneecap out of place. Knowing your family are downstairs and you're up there alone with only the TV and your phone for company. You feel such longing and pressure to join them but your energy will be zapped just from that trip to the loo...

You may not need to imagine it as this might be you right now or in a not-too-distant memory.

And then you see a doctor and they say in frustration "you just need to exercise and lose weight" as they have no further options for you other than more antidepressants and painkillers. So you push yourself to find a Pilates class - as that's what your consultant told you to do. And you arrive having completed the health forms, maybe you lied and kept things to a minimum as your list of ailments could write a book, and you are greeted by an instructor who looks a bit fearful and says "just do what you can do". You try some moves, you cry as the pain is so bad, you may even injure yourself and then you drag yourself home, back to bed - suffering, embarrassed and dejected and feeling like you never want to move again.

I'm sure you are relating to this right now, or from past experiences. Getting yourself moving is so tough. Finding exercise that can genuinely help you and not set you back with injuries or pain and fatigue flares can feel impossible. I'm here to say that I have been there - where you are, or may have been - spending 22 hours of the day in bed. Only getting up when my mum came home from work to make me lunch. If I was lucky, some days I'd have enough energy to be driven to the beach and sit on a bench to get some sea air. And this was in my 20s when I should have been out working, having fun and being with friends.

Now, amazingly, I work in the fitness industry. I trained to become a Pilates Instructor and set up Mobilates so that I could help other people like me access exercise in a safe and adapted way.

Pilates helped me so much, but I was the one crying my way through a beginner's course. Even getting up the stairs to the studio meant that I needed to lie down until the dizziness and nausea eased. I dislocated my shoulder when I moved on to Lite Pilates and completely freaked out the instructor who was already a bit wary of me!

But - with perseverance, a really knowledgeable and supportive Pilates instructor and time - I managed to find a way to build strength in my muscles so my joints were better supported. I increased my exercise tolerance so that I could walk further and stay upright longer, my pain decreased massively and I started to live life more fully.

I knew that I could use my experiences to teach accessible Pilates and plan classes that would help people with mobility issues and chronic illnesses like EDS, MS, arthritis, fibromyalgia etc with their functional movement, reducing pain and increasing energy. I hoped that if these classes were taught by people with lived experience of pain and disability, people would feel reassured and even inspired to get moving. I wanted people to feel like they could get their lives back and start thriving instead of surviving. I now teach multiple classes a day while running a business and home. I never even imagined this was possible, and somehow, despite my long list of diagnoses and issues, it is my reality.

From my own experiences and those of our marvellous Mobilates members, we have put some tips together to help you get started safely with movement.

Start where you feel safe and supported

This could mean many different things to each of us. It could be from the comfort of your bed or chair or finding a class taught by understanding instructors online or even in person. Whatever your starting point is, even if it is pointing and flexing your feet while lying down or popping into an online class for the first 10 minutes, this is 100% progress from not doing anything at all.

"Being assured that you can stop and rest at any time and still feel that you have had a great class was key for me when I started. Feeling able to ask questions and check on things during class with no judgement or embarrassment was great also. The fact that Leanne adapts her classes to take into account everyone's needs is something I have not experienced before. Mobilates is unique in its approach and supports everyone as individuals." **(Mobilates Member Michelle)**

"I'm doing so much better thanks to your awesome Mob and it's insane that the doctors just don't know what is needed! But physically this is the best I've been since my Chiari surgery 10 years ago and it's all thanks to your incredible support and amazing Mobilates family."
(Mobilates Member Kim)

Mobilates
Accessible Movement and Pilates

Take it gently

When you decide to get started, it can be so tempting to really go for it and push yourself too hard. A gentle and slow approach to whatever you choose to do will benefit you so much more in the long term. Taking breaks, leaving early, dipping your toe in is such an achievement. You may find you are able to do the class fine at the time but if you push yourself too hard, you may take longer to recover, and it could set you back.

"When getting started, which is sometimes over and over again after a flare, I try to remind myself not to go 'too hard' and follow Leanne's guidance - "Just because you can, doesn't mean you should""
(Mobilates Member Rachel)

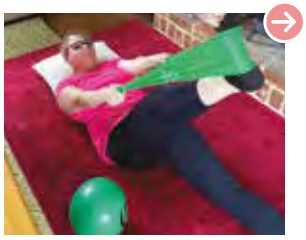
Find the right activity for you

I bang on about Pilates all the time because that is usually what physios and consultants recommend but it needs to be something you will enjoy. You might prefer swimming or horse riding, or even skiing. Whatever it is (hopefully something that will bring you joy so it is sustainable), please make sure you are supported by knowledgeable instructors who know how to keep you safe. They don't have to be experts in working with people with EDS, but a bit of knowledge on how not to hyperextend would be a good start. And if they even whisper the words "no pain, no gain" please walk away!

The right instructor will:

- Give you a private initial consultation
- Listen to YOUR challenges and goals
- Provide reassurance they can adapt for you
- Be honest about their experience and limitations
- Keep an eye on you and remind you to watch your range of movement
- Give you the space you need to rest, adapt or leave early

"Mobilates is the ONLY exercise I have continued doing consistently for more than a few months. Online classes are so convenient, removing the time and effort of travel, as well as much of the self-consciousness of physically being in a space with others. But because of Leanne's care to ensure she can see us all properly, together with the community aspect, I still get the benefits of an in-person class, i.e. the camaraderie of the Mob and the safety of an attentive teacher (particularly important when I have been recovering from injuries)."
(Mobilates Member Sophie)



Consider using braces and props

We can at times feel a bit like Robocop with all the knee, shoulder, wrist and finger supports, and I understand turning up to a fitness class wearing them can feel a bit daunting. Being scared and tense may cause you to move stiffly and hold your breath which can cause injury. If you feel like you have an unstable joint that needs supporting, it won't hurt to use it until you feel more stable. Ask in the online EDS UK support groups for recommendations for braces that could help. Ask the instructor if any props might support. We often use soft balls and bands to help you feel a movement more and let you know when to stop, cushions and extra thick mats for comfort, and belts to enable lifting of legs. You may find all-in-one compression gear can enable you to get in and out of a pool safely, or using a chair in a class can help you stay upright for longer.

Watch your range of motion

"Just because you can doesn't mean you should". We say this a lot in Mobilates classes! Just because you can bend your knees and elbows backwards at the same time as resting your head on your shoulder, doesn't mean it's not going to cause issues if repeated. These are a couple of tips to consider:

- **Neck** - use your hand or a soft small Pilates ball to remind you not to hang it down near your shoulder
- **Arms** – soften your elbows, try not to let shoulders hang out at the socket, keep your hands where you can see them
- **Knees** - keep them soft but not too bent and do sit when needed
- **Back** – try not to hunch, or hang back in your pelvis. Just because you can touch the back of your head to the back of your heels doesn't mean it is safe for your spine
- **Hips** - when standing on one leg, avoiding dropping into or hitching up your supporting hip
- **Keep your moves slow, small and mindful**, so you are less likely to hyperextend and more likely to maintain a range of movement that you can control.

If you would like to start moving safely, Mobilates would be delighted to support you with a FREE consultation and trial for live, online, accessible classes. We have understanding instructors and a gorgeously supportive group of members who we call Da Mob ready to welcome you with open arms. Find out more at www.mobilates.com

And join us for our monthly EDS Support UK class.

If you can't connect the issues...

...think connective tissues

Understanding Ehlers-Danlos Syndromes can make a difference to patients' lives – and that of the dental team

Dr Audrey Kershaw is an Oral Surgeon who qualified in 1987. She worked as an Associate Specialist in Dundee Dental Hospital and School between 1998 and 2017, where she lectured on medicine and surgery in dentistry and helped train more than 1,000 dentists.

A transition to private practice in recent years led to the foundation of Oral Surgery Scotland, Dr Kershaw's own peripatetic service. Through this, she takes her own brand of thorough and efficient patient care to practices across the length and breadth of Scotland.

Alongside, she has been working with the charity Ehlers-Danlos Support UK lecturing several times a year. Her recent work with Ehlers-Danlos Syndromes (EDS) patients has enabled her to highlight the relevance of connective tissue issues to her dental colleagues.

"If you can't connect the issues, think connective tissues," is a common phrase amongst those in the EDS community.

Since 2017, Dr Kershaw has taken an interest in connective tissue disorders and feels this is an area where we can make a real difference to patients' lives. She also stresses that understanding EDS can make the dental team's life much easier too.

In this interview, Dr Kershaw takes us through some of the ways in which a better understanding of Ehlers-Danlos Syndromes can make a significant difference to patients healthcare practitioners alike.

Why did you get involved with EDS patients?

Six years ago, I started seeing a pattern emerge with some of my oral surgery patients. I would often be asked to help with patients reporting a history of local anaesthesia issues, complex multi-system medical issues, or of being of a certain anxious character type; all features that I would eventually discover can point towards connective tissue disorders.

This has allowed me to identify these patients and understand their issues, so I can better help them through their treatment. I pick up at least a handful of these cases organically each month and am often referred several more where these issues are suspected or diagnosed.

What is EDS?

Ehlers-Danlos Syndromes (EDS) is a collective name for 13 different collagen defects of genetic origin, which affect various connective tissues in the body such as skin, joints and internal organs.

The most common type is hypermobile Ehlers-Danlos Syndromes (hEDS), with a growing body of evidence suggesting a much higher prevalence than previously thought. Owing to its multi-system nature, there are close links between EDS and:

- Postural Tachycardia Syndrome (PoTS)
- Mast Cell Activation Syndrome (MCAS)
- Irritable bowel syndrome (IBS)
- Chronic fatigue syndrome/Myalgic encephalomyelitis (CFS/ME)
- Gastro-oesophageal reflux disease (GORD)
- Mood disorders such as anxiety and depression
- Neurodivergency
- Dysautonomia

As dentists we are in a perfect environment to identify these patients, and my hope is to share my knowledge with colleagues so we can better help as many of them as possible.

This interrelation between several concurrent issues is what gives rise to the phrase 'if you can't connect the issues, think connective tissues', and can lead to many patients experiencing a frustrating journey through medical specialties without a single cause ever being identified: it takes the average Ehlers-Danlos Syndromes patient around 20 years to obtain a diagnosis.

Connective tissue disorders are a complex topic to navigate and there is significant overlap in symptoms between EDS and the nearly 200 connective tissue disorders.

What I stress both to patients and colleagues, is that it often matters less what the exact diagnosis is – this is left to medical professionals and genetic testing where it is available. Through a general understanding of common features, we can offer an improved dental experience and signpost towards lifestyle and medical interventions that improve quality of life.

Over the past few years, I have been delivering CPD sessions to dentists and other healthcare professionals with the aim of helping them better understand connective tissue disorders and how they have a huge role to play in identifying possible cases.

What should dentists be looking out for?

If there was one thing that I would ask the dental team to keep in mind in flagging up Ehlers-Danlos Syndromes, it would be persistent failure of local anaesthesia (LA); a widely-reported phenomenon in EDS.

This is what I see most often, and sadly all too many patients report hearing the words "you must be numb" before tolerating a procedure in unnecessary pain. To this effect, a simple enquiry about LA history should take place as a routine part of any patient examination.

Others may present with TMJ issues (particularly myofascial pain, headaches and subluxation), or erosive wear as a result of gastro-oesophageal reflux disease (GORD).

There are also strong links to enamel hypomineralisation, aggressive periodontal disease and unusually fast and painful orthodontic treatment. Any one of these, in the context of a medical history which alludes to some of the conditions listed previously, could be suggestive of an overarching connective tissue issue.

Interestingly, there is also a possible link between EDS and congenitally missing lingual and labial frenula, and I find noting this incidentally in an intra-oral exam can be a useful early indicator to screen more closely for the dental issues listed above.

Similarly, patients with undiagnosed connective tissue disorders can present unexpected management issues, especially in primary care. Awareness gives us better scope to offer care that meets these patients' needs.

Moreover, with the ability to suggest that features of a patient's presentation fit with a possible connective tissue issue, we give ourselves greater confidence to make higher-quality referrals to secondary care where necessary.

Diagnosis – or a better understanding?

We must stress that, as dental professionals, we are unable to diagnose connective tissue disorders.

However, to a receptive patient a suggestion of the link between their dental issues and general health issues under the umbrella of a connective tissue disorder can give useful encouragement for them to explore the topic further and seek advice from their GP or other healthcare professional.

I have been fortunate to be able to help many patients tie together lifelong debilitating symptoms and find support to make sustained improvements to their quality of life.

There is an EDS GP toolkit which is a very useful resource **https://gptoolkit.ehlers-danlos.org/**.

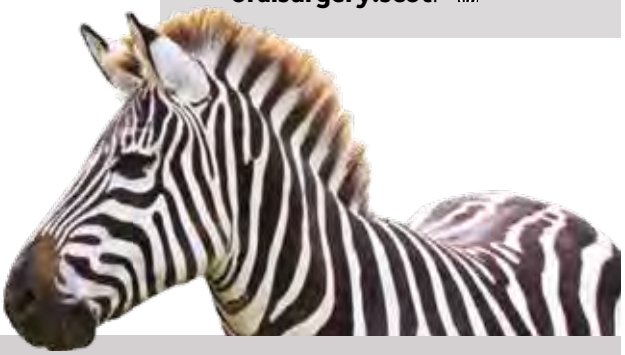
Ehlers-Danlos Support UK is available for patient support.

"We welcome any chance to improve healthcare experiences for people with EDS/HSD through increasing knowledge and understanding. Audrey's trailblazing approach to 'if you can't connect the issues, think connective tissues' in dental practice, is making an enormous difference. Going to the dentist is even more difficult if you know local anaesthetic may not work. To have a dentist who understands and believes you is so important. To also have a dentist who can highlight a possible link between dental issues and other health issues will empower and help people to speak to their GP. Please do reach out to Audrey and find out when the next talk is planned and get your dentist to find out more."

Susan Booth, Chief Executive, EDS UK

Get in touch

"My hope is to raise more awareness amongst my dental colleagues and the wider medical community," said Dr Kershaw. "Dental professionals, along with other healthcare professionals, have a great role to play in identifying some of the signs and symptoms relating to patients who live with connective tissue disorders. I run free CPD talks for anyone interested in learning more about this important area of health and wellbeing. To enquire about the next available talk or to invite me to offer a free CPD talk at your practice, please contact **hello@oralsurgery.scot**."



The zebra is the symbol of Ehlers-Danlos Support UK because those with EDS are often unexpected and, as the saying goes: "Sometimes when you hear hoofbeats, it really is a zebra."

Ask the advice Line

SABINE BACHINGER

Here are a selection of questions posed to the EDS UK advice line to be answered in this edition of Fragile Links.

Question. My four year old son is showing all the signs of hypermobile EDS - he's very bendy and tells me he has pain in his joints. He has slow gut motility and has been on Movicol from a young age. He's just started school and is coming home and going to sleep, he's also struggling with PE due to his flat feet. Where do I start in getting this looked into?

Reply. Thank you for your question, it can be difficult when little ones are voicing that they're in pain and knowing where to start is hard as well. Under the age of five, we do not typically see diagnosis of hypermobility disorders, including EDS. This is because most children are hypermobile and there are also lots of different causes for pain and issues they may be experiencing. Often an early diagnosis can mean that something may be missed instead of it being looked into when they're older.

In 2023 the criteria for children was changed. There are now eight identified hypermobility disorders, but under 18s cannot be diagnosed with hypermobile EDS until they're over 18 or biologically mature.

Management is key. Even without a diagnosis there should be management to help understand and alleviate symptoms. With the symptoms you have described, I would highly recommend a referral to physiotherapy and orthotics as well as to a pediatrician to look into pain management as well. Additional to that, with the gastro symptoms you have described, I'd suggest a referral to gastroenterology to help with those issues in the long run. I would push for this referral, especially when your son has been on Movicol from a young age.

Regarding school and struggling with PE, our school toolkit **https://theschooltoolkit.org/** would help the school to understand your son's symptoms and to implement management. The toolkit has lots of tips and information on how to help pupils and where limitations may lie, such as PE needing to be adapted. Hopefully with a physio this will help build up your son's muscle strength and reduce his hypermobility and pain.

Question. EDS has recently been mentioned to me as a possibility after years of difficulties with my health. I am currently 68 years of age and when I read up about everything online, I'm very worried about the possibility of vascular EDS and whether this might be a possibility. I'm hypermobile with joint pain and healing issues, I bruise easily, and my father had an aneurysm when he was 80 years old. Would you be able to offer clarification?

Reply. It can be scary when first researching EDS and coming across types such as vascular. Often there is a lot of crossover symptoms, or the information online doesn't offer in-depth information. We would be concerned about vEDS if an individual or a family member had experienced a dissection or aneurysm below the age of 40 (usually between the ages of 20-30). Over the age of 40 aneurysms become much more common in the general population. I am sorry to hear about your father experiencing an aneurysm at the age of 80 - this must have been traumatic. Unfortunately, at that age it would be much more common to experience an aneurysm and wouldn't be a cause for genetics to investigate vEDS.

We typically see hypermobility in hands and feet rather than across the body but this does differ from person to person. Additionally, hypermobile EDS patients often bruise easily but not to the extent of vEDS patients, which tends to be very severe. For instance, a bruise covering the entire thigh or spontaneous deep bruising, very different from the bruising we see in other types.

I hope this has helped to put your mind at rest. If you are worried about vEDS and would like clarification you can speak to the GP about symptoms and ask them to go through it with you or, if you are under a rheumatologist or geneticist, they too can look at all your symptoms. If they have any concerns about a rare type, they can then refer to genetics for further investigation.

Question. I'm starting university in September and would like to know what I can have put in place while I am there to make things as accessible as possible. Would you be able to advise please?

Reply. Firstly, congratulations on your place at university! UCAS has excellent resources for students on how to access what the university has to offer. Each university should have a disability advisor that is also able to assist with getting things put in place. Depending on your needs, there can be help with accommodation, providing accessible accommodation if you require it, and help in lectures, eg with note-taking. You may also be eligible to apply for Disabled Students Allowance to help with funding university.

There is usually also a society within the university, often set up and run by students, which might also be worth getting in touch with. Don't be afraid to ask for anything you think may help you or, if things change throughout the semester and you need less or more support, they are there to help, including by supporting you in advocating for yourself.

Good luck with your degree!

Question. I have had issues with my gums from a young age and ended up needing dentures when I was in my late teens. This has affected my life heavily and I've never understood why this has happened, until recently. I saw a new dentist who highlighted how unusual my situation was and whether there is a possibility of periodontal EDS as I am also hypermobile and have fragile skin. Please could you tell me about this condition and how I would go about getting diagnosed?

Reply. I'm sorry to hear about the difficulties you have had throughout your life with your gums, and the impact that this has caused. The prevalence of pEDS is around 1 in a million but from the symptoms you have described I believe it would be worth having this investigated further.

pEDS affects the mouth, especially the gingiva, and causes tissue fragility. This often means that individuals end up needing dentures at a very young age despite any oral health measures in place. Often individuals are also hypermobile and have similar symptoms to hypermobile EDS.

Regarding next steps, I would suggest approaching your GP and asking for a referral to genetics locally, they should then refer on to either Sheffield Children's Hospital to the EDS diagnostic clinic or to Northwick Park EDS diagnostic clinic, depending on what one is closest to you. They will then run a genetic panel if they believe you meet the criteria for a rare type of EDS such as pEDS. If they identify the gene, they will also offer genetic counselling, which often also includes bringing in close relatives for testing if they're displaying symptoms. Additionally, they should look at measures to help with symptoms and discuss a management plan to help guide other medical professionals to manage your symptoms.

Question. I've recently been diagnosed with hEDS through the GP. What happens now with management and who would oversee my care?

Reply. I'm glad to hear you have a diagnosis through the GP. Often this first step can be hard and it's difficult after diagnosis to know what comes next. Ultimately, the GP should be overseeing your care and making referrals when necessary, although patients often end up managing their own care and putting things in place to help. As your GP diagnosed you, they sound supportive and likely to help with relevant referrals, eg if you're having issues with dislocations and joint pain, referrals to physiotherapy and pain management would be advised. If you're having problems with your feet, then orthotics or podiatry can be a great help. Often the referrals work on an ad hoc basis., For instance if you're suddenly having stomach issues a gastroenterology referral may be required. It is also important that any new symptoms are appropriately investigated as they would be for anyone without EDS, as not all symptoms are linked, and they may be caused by something else entirely.

Don't be afraid to advocate for yourself and push for the referrals you believe would be helpful in managing your symptoms.

Call **0800 907 8518** or email **adviceline@ehlers-danlos.org.**

Before contacting our adviceline, we would encourage you to check our FAQ's page as this may help you find the information you need quicker. **https://www.ehlers-danlos.org/what-is-eds/frequently-asked-questions-about-eds-and-hsd/**

The phone line gets very busy. If we don't answer, please leave a message with your number and we will call you back, usually within five working days.

We can help with:

- Diagnosis questions
- Referral processes
- Managing symptoms
- Preparing for appointments
- General support
- Claiming benefits
- School, college and university

Shoulder strength in hypermobility: building resilience and stability

JEANNIE DI BON, MOVEMENT THERAPIST AND CREATOR OF THE ZEBRA CLUB APP

Shoulder issues and pain are a huge problem for the hypermobile population. Four out of five patients with hypermobility experience shoulder symptoms (Liaghat et al 2022), but the evidence supporting the right treatment approach is still sparse. Sadly, there is still no gold standard treatment for the hypermobile shoulder. Treatment is challenging because of instability coupled with the underlying abnormalities of the connective tissue (Brioida et al 2021).

What could possibly go wrong with this joint that is causing four out of five people to have issues? This article will explore the hypermobile shoulder in more depth and aim to offer some exercise and rehabilitation solutions.

Anatomy of the Shoulder

Let's start by looking at the structure of the shoulder joint. Understanding the anatomy can often help us understand what is going on when we are moving.

The shoulder joint is the most mobile joint in the body. It is a ball and socket joint, and this allows for 360-degree range of movement. This sounds great and it can be hugely beneficial for many sports and activities like swimming, cricket, gymnastics, and ballet.

However, the arm bone or humerus that connects to the shoulder joint is the largest bone in the upper extremity. The head or ball of this humerus sits in the shallow socket or glenoid fossa in the shoulder blade. The head can be three times larger than the socket. Basically, it doesn't fit into the socket deeply and 'hangs' from the socket. It sacrifices stability for mobility. It is supported by ligaments, capsules, and stabilising muscles like the rotator cuff. Liaghat et al (2022) found that pathology in a variety of shoulder structures could be responsible for painful shoulder conditions, including rotator cuff muscles and tendons, the shape of the acromion, and the capsular or ligamentous tissues.

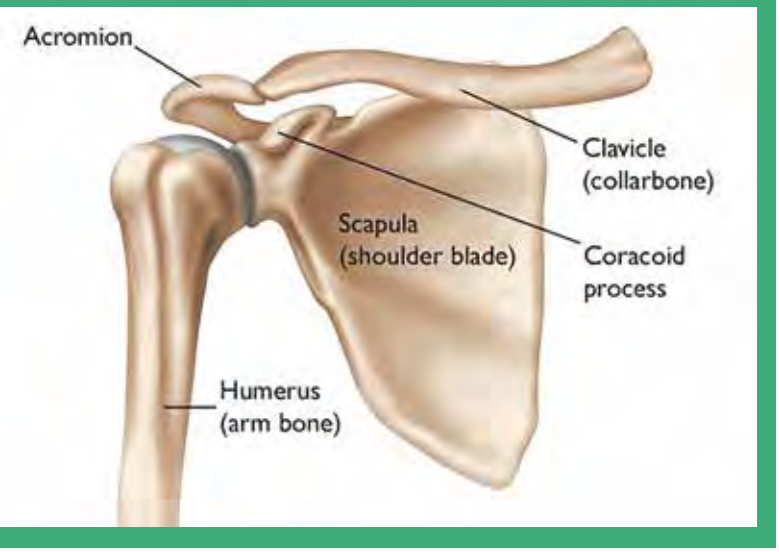
And therein lies our first issue with hypermobility. If the ligaments and muscles are strong and resilient, and have the stability to hold that bone in place, then the structure has integrity. But if you have a connective tissue disorder causing ligament laxity and low muscle tone, we can see how there could be a potential structural and mechanical issue. We need stability surrounding the shoulder joint to hold it in place and to move safely.

Understanding Resilience and Stability

In the book Hypermobility, Chronic Pain, and Fibromyalgia (Hakim 2010), hypermobility stabilisation is described as: "Much greater energy expenditure is required to maintain shoulder stability in hyperlax individuals. These individuals must train consistently to protect their shoulders from overload". In other words, it is challenging work to stabilise hypermobile shoulders. It takes energy and it can be fatiguing. Here are just some of the common issues with hypermobile shoulders.

- Subluxations and dislocations – it's the joint that experiences the most dislocations
- Labral Tears
- Bicep tendon pathology
- Glenohumeral instability
- General Joint pain
- Shoulder Impingement
- Frozen shoulder
- Rotator cuff injury and tears
- Scapular dyskinesia presenting as winging scapula and altered movement patterns
- Upper back tightness – also referred to as Coathanger pain
- Neck and Jaw Pain
- Arm Pain
- Headaches and Migraines
- Nerve Pain

We could also encounter psychological symptoms like anxiety and fear of movement. If you've suffered from recurrent



shoulder issues, it is totally understandable that shoulder movements could be stressful. We may even tense up in anticipation of the pain.

In summary, these are some of the possible causes for shoulder issues in hypermobility – on top of the mechanical and structural aspects.

- **Biomechanical** – misalignment of bony structures, lack of postural tone, faulty movement patterning and environmental such as desk or driving set-up
- **Musculoskeletal** – overall deconditioning, tissue irritability, muscle spasms and repetitive strain could all be contributing to shoulder issues
- **Nerve Impingements / Compression** – if we are misaligned and have low postural tone, nerves can start to get compressed causing pain
- **Stress, anxiety and trauma** may change our posture, leading to misalignment and postural issues. We may hold ourselves differently
- **Environment** – where or how we work or carry out daily activities could impact shoulder pain, especially if we also have ineffective body mechanics

Injury Prevention Strategies

Now we've looked at the issues and causes, we can examine what we can do to help prevent or improve our shoulder pain. There is much we can do to address these issues and improve our shoulder stability.

- **Alignment & posture:** If we can get the bones into a better alignment, then the muscular tissue surrounding the joints has a much better chance of working effectively and providing stability. Look at my Hypermobility YouTube channel for a range of whole-body exercises to start working on postural alignment.
- **Proprioception and control:** Working on specific exercises to really sense and understand the movements of the arms and scapular with control can help. Initially, we want to keep the range of movement small so we can build our sense of control.
- **Laxity of the joint:** We need appropriate local stability exercises for the shoulder. It is important we go low and slow to start. Don't be tempted to jump in with resistance or weight until you have mastered alignment and control.
- **Gravity:** Gravity pulls on the shoulder joint constantly throughout the day. The more muscle tone and muscle mass we can build, the more resilient the joint will be against these forces.
- **Environment / job / home / stress:** Many aspects could be impacting the functioning and pain in the shoulder. It is good to examine your desk setup, your driving position, your sleeping position, and your daily activities to see if anything could be irritating it.
- **Spinal thoracic stiffness:** Many people with hypermobility have quite stiff thoracic spines. This lack of fluidity and bounce in the thorax can lead to shoulder dysfunction and poor movement patterns. Breathwork is a gentle way to start working on softening the thorax and relaxing tight muscles. I have several breathing videos on The Hypermobility Channel you could try.
- **Mobility of scapula:** Scapula movement is key to stability and sometimes the scapula can get stuck on the back of the ribcage. Learning correct scapula movement and control with a movement professional is important.
- **Proprioception and motor control:** As mentioned earlier, these elements are key to reducing shoulder pain. Uncontrolled movements at the shoulder can lead to strain and injury.
- **Breathing:** I often see high-up chest breathing using accessory muscles to breathe as opposed to diaphragmatic breathing. Dysfunctional breathing patterns are common in hypermobility, and these can have an adverse effect on our quality of life (Chohan et al 2021). Learning some relaxing breathing techniques can really help with pain reduction. I've also observed a reduction in rib subluxations in my clinical practice through breathwork.

Exercise and Rehabilitation

Thankfully there are several ways to take care of our shoulders and improve our functionality. Here are just a few ideas.

- **Braces / physical aids** – many people find the use of postural t-shirts or devices like the Body Braid helpful in supporting the shoulder joint. They can help with proprioception of where the shoulder should sit
- **Pain medication** – these can be useful in reducing pain and inflammation, but please do seek medical guidance for this
- **Steroid injection/prolotherapy/surgery** – again, another area where medical guidance and expertise will be required but in some situations these interventions are necessary
- **Taping / Physiotherapy** – physiotherapy is regularly recommended for hypermobile patients. Taping has been found to be inexpensive and can offer temporary pain relief (Tudini et al 2023). You may have to find a tape that works for you as some people experience allergic reactions to taping. You can also try applying a skin barrier like milk of magnesia before taping
- **Awareness Training** – programmes such as Alexander Technique, Pilates, Yoga, and Tai Chi help to bring whole body awareness
- **Meditation / Mindfulness** – there is a growing body of evidence into the benefits of mindfulness and meditation

practices on chronic pain. This, together with breathing practices, can help calm the nervous system and reduce sensitisation

- **Finding a safe and appropriate exercise programme** that is modified for hypermobility is key. We know that exercise can be extremely beneficial if it is delivered and executed in the right way. My Integral Movement Method for hypermobility starts with Breath and Relaxation before moving onto Proprioception and Stability. Balance and Posture come at the end. I've found following this pathway has been extremely beneficial for my clients. Establishing a sense of safety is key before beginning any exercise programme and establishing relaxed breathing patterns is a huge part of this. You can find a whole selection of exercise classes on my Hypermobility YouTube channel or on The Zebra Club app at www.thezebra.club.

Conclusion

The shoulder joint is a highly mobile joint that, by design, presents issues in hypermobility. However, following specific strategies as detailed above can help you improve your shoulder alignment, control and stability. Remember, go low, go slow. Small steps all the way!

Don't forget to check out the special EDS UK offer for an annual membership to The Zebra Club. We are offering a 20% discount for Fragile Links readers.

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Research update

Promoting research studies from across the UK

EDS UK helps researchers to recruit for high quality, ethically approved studies that we believe will be of interest to our community.

If you would like your study promoted please email your request to **research@ehlers-danlos.org**

At this time we are only accepting EDS/HSD specific research requests for promotion to the EDS UK community. This inbox is monitored monthly so please do get int ouch with as much notice as possible. Please do make sure you send all of the following information to help us help you:

- Study name and one or two sentence summary.
- Start and end date of your study.
- Confirmation this is EDS/HSD specific research.
- How many participants you are looking to recruit.
- Information on how you will undertake your research.
- Copy of your ethics approval.
- Copy of your promotional material including text for our website.
- Confirmation that you will send your results and a 200 word summary of your conclusions for us to share with our community once the study is complete.

New evidence that hEDS and HSD are more common than previously thought

A group which includes researchers, GPs and rheumatologists have recently published a new study into NHS data in Northumberland which found the following eye-catching statistics.

People with hEDS and HSD in Northumberland:

- Have twice as many outpatient and mental health appointments
- Cost the NHS 29% more

Dr Ben Frankel, Dr Vadivelu Saravanan, Jeff Powell Davies, Dr Emma Reinhold, Dr Joanne Demmler and **Dr Iain Loughran** aimed to measure the prevalence, pattern of service and financial burden of hEDS and HSD. They used NHS data on GP records in Northumberland and compared secondary healthcare activity and costs between people with and without hypermobility in 2022.

They found that 1 in 227 people in Northumberland had hypermobility in their GP records. If extrapolated across the UK that's approximately 300k people. They also found female patients have a significantly higher usage in acute care, mental health and outpatients especially physiotherapy, rheumatology, orthopaedics and obstetrics and that male patients were young and presented to paediatrics and mental health services.

The group recommended that the NHS explore reasons for healthcare use, develop the workforce to better support hEDS and HSD and provide more coordinated services. They presented their research at a recent Women's Health conference and the British Society of Rheumatology's annual conference. This research provides a vital part of the evidence needed to help inform commissioning decisions within the NHS. Please see here the original article on our website. **https://www.ehlers-danlos.org/news/new-eds-and-hsd-primary-care-study-in-northumberland/**

Anyone who has a long-lasting condition might have questions about exercising and moving safely as well as keeping themselves moving. How often to exercise? Which exercises are safe to try to help keep our mobility?

MOVEMENT

This edition features our members giving their own personal hints and tips to keeping mobile

People with long-lasting syndromes, also known as chronic disease, need to move and keep mobile in a safe way. Exercise can help people with long-lasting conditions cope with symptoms and improve their overall health. Long-lasting conditions can include heart disease, diabetes, depression, back pain, joint pain and many others.

Flexibility exercises, such as stretching, can help joints keep moving, so they can work well.

Another important form of exercise, especially for older adults and people who have trouble moving, is balance. Balance exercises might prevent falls and lessen injuries from falls. Tai chi, walking backwards and practising standing on one leg are examples of exercises that can improve balance.

A healthcare provider might suggest exercises to ease pain or build strength. Depending on your condition, you might not be able to do some exercises at all, or just during flare-ups. Some people might need to talk to a physical or occupational therapist before starting to exercise. People with low back pain, for example, might choose exercises that can raise heart rate without putting stress on the back. Walking and swimming are good choices.

You don't need to have full mobility to experience the health benefits of exercise. When you exercise, or start to use movement, your body releases endorphins that help boost your mood, ease depression, relieve stress and anxiety, enhance your self-esteem and improve your overall outlook on life.

For people with joint issues it is important not to put excessive strain on the joints or cause over-extension or pain.

In this edition we asked our members what they do to keep themselves mobile and moving safely as well as other ideas for sleeping and resting – which helps with being mobile!

Please note – these are all suggestions from members and not medical advice. Please always consult your healthcare professional before starting anything new.

- Orthotics - custom insoles, ankle brace, knee brace, shape wear knickers when i walk outside of my house (but not in my house unless that joint is really bad) plus supportive lace-up ankle boots all help keep me mobile
- Using pillows in bed to support me
- Gentle housework keeps me mobile – in small doses
- The Zebra Club app is excellent and highly recommend
- Our chronic pain team do adapted seated tai chi which is pretty good

> "In bed I am surrounded by pillows to keep me in position and use a moulded memory foam pillow for my head"

- My sleep band which is linked to the cCalm app
- One of the worst things for increasing my pain is getting cold. I use heat pads both inside and outside the house. Electric blanket is amazing

- Pilates & swimming keep me going
- For days when my body just feels too heavy to do any exercises, I get in the pool and it's much easier to move with the water taking the weight off
- I go to a chiropractor. But I make sure the chiropractor has a good knowledge of EDS, as if they don't, they can sometimes do more harm than good
- 'Move it or lose it class' at my local gym – a seated mix of exercise to fun music, balance work and strengthening exercises
- Ring splints to stop my fingers over extending when exercising
- Crutches and aids help me to get up and walk – without them I would be completely sedentary
- I go to physio once a month and also use heat to reduce pain from muscle spasms from the joint instability
- I use Tiger Balm to ease pain and inflammation in my joints
- I use KT Tape to increase stability of my joints, particularly my knees

- I have increased my walking really gradually starting at 5 minute walks and increasing 5 mins per month until I got to half an hour.
- Pilates helps build the muscles to support the lax joints but mostly I continue to follow the exercises I was given from Fibroguy programme. The difference after doing that was amazing. That said it is not available on the NHS, you can only access it privately
- My daily must do is 10-20 mins of light qigong every morning, I can't do anything too strenuous so this really helps to keep some kind of movement going and helps calm my anxious mind too

> I feel better if I am active - doing gardening or housework - rather than exercise, because i tend to overdo exercise, or forget to do it. I just can't get the balance right!

- Pilates used to really help when I was able to do it regularly. And you can do as much or as little as you can on each day. Life is a bit chaotic just now so I'm not doing it and I notice the difference in my joints, posture and general wellbeing
- I find that even if I'm in lots of pain a walk helps. It often doesn't make the pain go but it gets rid of spasms and stiffness and helps realign everything, I think
- My mobility scooter is my freedom to get out and be in nature, and gives me security to have a small walk knowing I can then 'drive' back

- Neoprene knee/wrist supports.
- Pilates helps me a lot as the teacher is EDS/ Hypermobility knowledgeable. Sports massage helps too
- I get physio type exercises from my sports therapist and this helps a lot with stabilisation and pain levels
- When I'm trying to go to sleep but am in pain, putting my hand on my dog and focussing on her breathing helps.
- I have acupressure and Jing therapy every week. I sleep through the night afterwards; I normally wake up about 5-10 times a night in pain. It's a life saver.
- I'm doing tai chi. I do it seated but love that it's slow movement. You never fully extend, only meant to go to 90% so that's good for us and I find it is quite mindful so good for MH too.
- Barefoot shoes. I'm now in Vivobarefoot shoes and OMG the difference! They allow you to spread your toes so you have a more stable base and walk more naturally. They can take a lot of getting used to and you may have to slowly build up how long you wear them for but for me I was able to switch instantly. You can also really feel the ground beneath your feet so gives loads of sensory feedback and the risk of rolling your ankle is massively reduced.

> My Apple Watch tells me when to get up and move around

- For the larger chested ladies - Sugar Candy Bras from Bravissimo - I have a slipping rib so bras are a nightmare. I now only wear SugarCandy. They've got wide straps, lots of adjustment, and most importantly no underwire even in the largest cup sizes.
- Personally for me, that's ballet (which I only started as an adult) and recently found a silver swans class that was happy for me to get involved
- I've tried "everything"(including physio for the last six months). I recently joined an aqua stretch class where we use water resistance for strength training. It has been an absolute godsend and I wish I'd found it decades ago! No overstretching, no weight bearing / strain on joints and core strengthening movements using water resistance.
- Heated throw to sleep on and weighted blanket to sleep under on a tempur mattress, combination is fab, doesn't stop pain nor help sleep but for sure makes for a more comfortable flare up in bed
- I have a knee pillow thing for sleeping and a contoured neck pillow for sleeping. I also do pilates every week to try to keep strong and mobile.

- I make sure I don't reach that extra inch and over extend.
- Sit in chair with knees at 90° and feet on floor. Push up from front of feet, flexing thigh muscles, whilst pushing lower back into chair. That particular exercise can be done anytime as long as knees are 90° or more.

- I use a memory foam cushion in the car for lumbar and hip problems and joint supports to help when they feel particularly "floopy".
- I do the Morning Live on BBC 2 minute seated exercise routine run by Strictly professionals.
- My Apple Watch tells me when to get up and move around...
- I've got some rehab walking poles that Stanmore suggested - they keep me much more upright and can use arms to help with walking.

- I use a wheelchair day to day but also regularly go climbing (bouldering)! It's a combination that often sounds confusing, but climbing has helped me so much - it's a very adaptable sport where I can compensate for my lack of leg strength with upper body strength and go at my own pace. I know quite a few people with EDS who climb!
- My buckwheat husk pillow to support my head neck.
- I would recommend taking a coenzyme Q10 supplement - it helps me feel less fatigued and therefore have more energy (and time, because I nap less) for movement. (I'm not sure what I do can strictly be called exercise, hence, movement!)
- I use a Tens machine, sacroiliac belt and knee braces, pillow between legs when sleeping and magnesium to help sleep
- Massage gun has been helping a lot, as for muscle supplements it's daily vit. B , a banana for potassium, on occasion magnesium, creatine to help flushing away lactic acid when overly tired due to too much activity
- My Ikea rocking chair with extra lumbar support and my office chair also with same type of support (half moon memory foam), a kneeling stool with adjustable height/ angle, and recently a saddle chair with height adjustment
- Mobilates - remote accessible Pilates for all levels run by a lovely lady with hEDS!

> I'm doing tai chi. I do it seated but love that it's slow movement

- I don't let myself sit too long; I walk gently around the home using furniture or walls to keep my balance - I use crutches and splints
- Sitting on a stool while having a shower and gently rubbing the muscles and moving my legs. The worst thing I can do is sit for too long as I get stiff and get too much pain.
- Pacing has been the biggest learning curve taught to me by OTs and physios. I begrudge it but they are so right. I like to potter around my garden as it's my peaceful haven.
- Wheelchair boxing (Great Britain Disability Boxing) - it helps to build up strength in my shoulders particularly when we do work with weights.
- Sports massage on my upper back and shoulders to release tension and knots.
- Gratitude journal - every night I write in three things I am grateful for in the day. This helps me to be more positive. Also if I'm having a bad day with pain, I know I have to find three things to be grateful for so I start looking for the positives in the day.

> Pilates once a week really helps manage my symptoms, it's enough to strengthen my body and lessen pain, without being so much that it causes fatigue

- Knowing when to stop and when to keep going is key - I need the motivation of a friendly group class to get me exercising, but it's vital to let the instructor know I might have to leave half way through
- Osteopath! I'm seeing at amazing one for free via the social prescriber at my GP, I'd always dismissed it as unfounded quackery but it's actually been the best treatment I've tried so far
- K-Tape is helpful when exercising to remind you to keep things in place, I've used knee wraps and braces, wrist brace, back brace to keep things in place
- Best thing I use is my recumbent trike and swimming. Pool and open water help in different ways. Soaking in a jaccuzi or bath also works on some days.

- Walking every day. Keeps everything moving whilst being low impact and good for the mind, body and soul! Perfect destress after a long day at work
- I have slipping rib syndrome, and have switched from wired underwear to very soft but still supportive bras that don't damage my very sore connective tissue. I use good sports bras when walking or stretching.

If you have any other tips you'd like to share, please let us know by emailing: **social@ehlers-danlos.org**

Northern Ireland update

Hi, my name is Mandy and I am the Lead Volunteer for EDS/HSD Northern Ireland. The regional areas we currently cover in Northern Ireland are Belfast/Down, Coleraine/Derry and Dungannon/ Mid Ulster area. I also work with Vivian and Caitronia who are both Area coordinators for Northern Ireland.

Support Meetings

Face-to-face support meetings

In October Vivian hosted our Dungannon/Mid Ulster meeting at Cookstown. In February Caitronia hosted the Coleraine/ Derry meeting. In March Caitronia hosted our Dungannon Mid/Ulster meeting in Cookstown.

Online support meetings

Vivian hosted our online meeting in November and she had 8 attendees. In January due to the weather, we changed our face-to-face meeting to an online meeting. We had 4 attendees at this meeting.

New Monthly Online Meetings

From the beginning of 2024, EDS/HSD Northern Ireland has introduced an online meeting every month rather than every 3 months. Our decision to do this was that our group membership has steadily grown and we can see from our online meeting attendance figures that these online meetings are much better attended. We understand that having to travel to a face-to-face meeting can be a barrier to being able to attend and for our A/C to host too.

New 18-30 Online Meeting

From April 2024 we are going to introduce a meeting for age 18-30 members which will be hosted by Vivian Kirk. We hope to initially run this meeting every 3 months starting on Wednesday 22nd May from 7.00 to 8.30 pm.

Change of venue for Coleraine/Derry area meeting and Dungannon/Mid Ulster meeting

Due to lower attendance numbers at these meetings, we have decided to continue to host face-to-face meetings in these regional areas but we are going to move to meeting in local coffee shops rather than in meeting halls. Coffee shop venues are to be confirmed and will be advertised in advance of meetings.

Most of our meetings were very well attended and after the meetings, we got good feedback too. Thank you to all our group members and their families for attending these meetings.

Dazzle Walk, Stroll or Roll 2024

Last year we held our first Dazzle Awareness event in Belfast to raise awareness and to raise funds. This year we will be holding our first Dazzle Walk, Stroll or Roll on Saturday 1st June at Stormont Estate, Belfast. We have chosen Stormont because of its location with a Translink Glider stop at the entrance so people can travel by public transport or even use the Glider as a park and ride too. Time and meet-up location will be advertised. Nicky Casey EDS UK Senior Communities Manager is travelling to Northern Ireland to join us all on the day.

We hope that many of our EDS/HSD Northern Ireland and your families will join us on the day. It's a wonderful opportunity to meet your EDS/HSD Northern Ireland volunteers and many other EDS/HSD Northern Ireland members and their families.

Engagement

Northern Ireland petition

So far our Northern Ireland petition has had 1,388 signatures and we are very grateful to every one of these but we would like to add to this target before the commencement of the petition. Our next target goal is 1,500. You can still sign and share the Northern Ireland Petition on the EDS UK webpage.

The petition is only the start of the process and one of the EDS/HSD Northern Ireland members and EDS Community Champion Rhoda Walker (MBE) has been engaging with MLA starting talks on our behalf. Rhoda and I have been involved in several discussions together and we have both met with Susan Booth CEO of EDS UK to discuss the next steps for EDS/HSD in Northern Ireland.

Awareness

Independent Living Northern Ireland (ILNI) Event

In November 2023 I attended a conference called the Independent Living Northern Ireland (ILNI) held by the Centre for Independent Living NI (CILNI) as an exhibitor for EDS/HSD Northern Ireland. It was held at the Stormont Hotel, Belfast. The conference had great sessions on all areas of independent living including Direct Payments, Technology and Patient Advocacy. It was also a great networking opportunity with all the other exhibitors.

Caitriona Graham was also attending the event taking professional photographs so I managed to get her to take a quick snap.

'It Takes Allsorts" Programme for Ards and North Down Council

I was asked by Ards and North Down Council to come and speak to their staff, councillor members and council residents about Living with EDS/HSD and Disability at their It Takes Allsorts seminar in December 2023. The popular programme takes a look at topics and issues that staff and residents might encounter in their work and lives. Each seminar will have a different topic and speaker. I spent a few weeks putting together my PowerPoint presentation as it was very important to get across the key facts about EDS/HSD and living with a dynamic disability. On the day there were about 30 people in attendance. My presentation lasted over an hour and I spent approximately 30 minutes answering questions too.

Patient and Client Council (PCC)

The PCC in Northern Ireland's role in Northern Ireland concerning health and social care services is to represent the interests of the public. They also offer an advocacy service to support the public about Health and Social Care.

The event I attended in March 2024 was "Embracing the Public as Assets in HSC: The Role of Advocacy & Engagement". The morning was split into two sessions. Part one was listening to "The Role of Advocacy" and listening to advocacy experiences. Part two was a table group discussion about "Embracing the Public as Assets in HSC. It was a very informative morning and I am much more informed about the PCC's Advocacy service I am now able to pass this information on to any of our EDS/HSD Northern Ireland Group members.

I also had the opportunity to get a quick chat with EDS/HSD Group member and EDS Community Champion Rhoda Walker MBE about ongoing EDS matters as she was also attending the event.

Awareness of EDS in Northern Ireland amongst the medical community and within the general population is key too. We know that the number of people who are diagnosed with EDS/HSD or self-diagnosed is very low so we know that we need to reach many more people.

If any of you know of any other up-and-coming events that EDS/HSD could attend to promote awareness please do get in touch and let us know. Also If anyone works or volunteers for an organisation who would be interested in me coming and talking to them about EDS/HSD please ask them to contact me by email as I would be very happy to have the opportunity to reach more people

nisupport@volunteer.ehlers-danlos.org

Cymru update

It's been an exciting time for the Wales volunteer team! Our petition to the Senedd (Welsh parliament) has been discussed several times the Senedd petitions committee.

The petition is part of the EDSUK #enoughisenoigh campaign calling for a pathway for diagnosis of EDS and requesting better support. The committee agreed that those with EDS/HSD need better care. After the discussions I spoke to MS members including Joel who has family with EDS. Joel stated that we can have a drop in at the Senedd to see if we can get other MS members to get involved with our campaign for better care for us bendies. The Senedd has invited us to present our case to the Senedd in May. Myself and EDSUK are incredibly excited about this, and it's a big step to getting better care for us.

I conducted a focus group along with Susan Booth, EDS UK CEO, with our members who offered feedback about the work we do, and also share ideas for the future. We are also applying for more funding to support those with EDS/ HSD in Wales.

Myself and my fellow area coordinator Jojo have received our long service awards. We have both been volunteering and supporting others with EDS/ HSD for over 10 years!

We have held in person support groups, 1:1 advice and support groups. We have also had a talk from Jo Southall who is an occupational therapist who has lots of experience supporting those with EDS. The talk included tips on how to pace and manage fatigue. We have also had a talks from another occupational therapist called Kim Clayden. Kim has done 2 talks on pain management, with specific emphasis and how to manage EDS related pain. We have had a talk about nutrition by Dr Catriona Walsh. This session was very informative and showed the importance of good nutrition for those with EDS/HSD.

In February the Welsh government released a strategy called- living with arthritis and musculoskeletal conditions in Wales (a framework for the future). This framework unfortunately did not include anything concerning any type of connective tissue disorder. I fed back to the 2 patient advisory groups in North Wales (the JSAG and ARMA), where I shared my concerns at EDS and related problems being ignored. The Welsh government asked for feedback on this framework, so I have also raised my concerns with them. I am awaiting a reply. I also shared this with many of our members via our Facebook group, as it is incredibly important that all of our voices are heard.

We have also had some great awareness being spread by our members. Including Tracey Hanks being on radio Ysbyty Gwynedd (Gwynedd hospital). Tracey and her mum have CEDS and shared the struggles that many of us experience living with EDS and comorbid Raynaud's phenomena.

BY TASHA, WALES LEAD VOLUNTEER FOR COMMUNITY AND ENGAGEMENT

If you live in Wales and want support please email the below:

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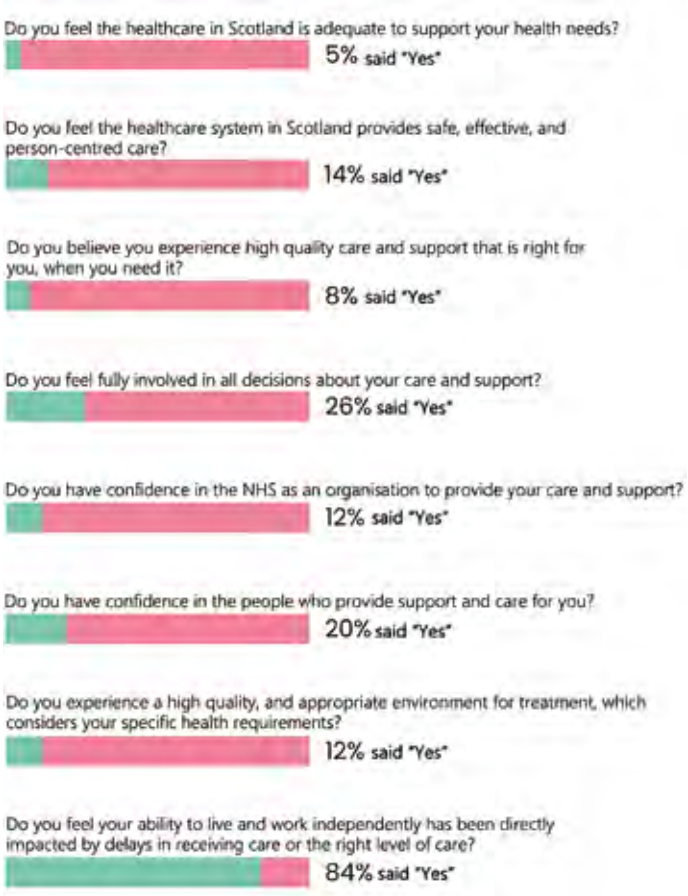
wales@volunteer.ehlers-Danlos.org
Sarah - Aneurin Bevan
Aneurinbevan@volunteer.ehlers-Danlos.org
Emma - Swansea bay
Swansea@volunteer.ehlers-Danlos.org

Emily - Ceredigion
Ceredigion@volunteer.ehlers-Danlos.org
Kat - Llanelli, Camman and Taf
Llanelli@volunteer.ehlers-Danlos.org
Jojo - North Powys
Northpowys@volunteer.ehlers-Danlos.org

Scotland update



It has continued to be a busy but very productive time since our last Fragile Links update with volunteers, Michele and Anne, heavily focused on supporting the preparation work to bring together some of our members to take part in the first Patient Engagement Day in Scotland.

The day was organised and hosted by The University of Edinburgh in February, and formed part of the hEDS-START project, which aims to detail the lived experiences of people with hEDS/HSD living in Scotland. This project involved a nationwide survey of EDS UK members living with hEDS/HSD, but this patient engagement event focused on Scotland members only.

Twenty-five of our members attended and it was a very enjoyable day, albeit overwhelming. We can't thank those who volunteered their time and precious energy enough; we know how much it takes out of you. Most members were meeting in person for the first time and within an hour or so you'd have thought they had been friends for years. Several members commented that it felt good to be in a room with others just like them, who understood what they were going through.

The day was led by researchers from the University of Edinburgh, **Kathryn Berg** and **Dervil Dockrell**, who have been working closely with EDS UK and conducted the hEDS-START Survey on patients lived experiences. Professor Stuart Ralston, of the University of Edinburgh and professor of Rheumatology stopped by to welcome everyone and to say he was very much onboard with finding a way to support people with EDS and HSD.

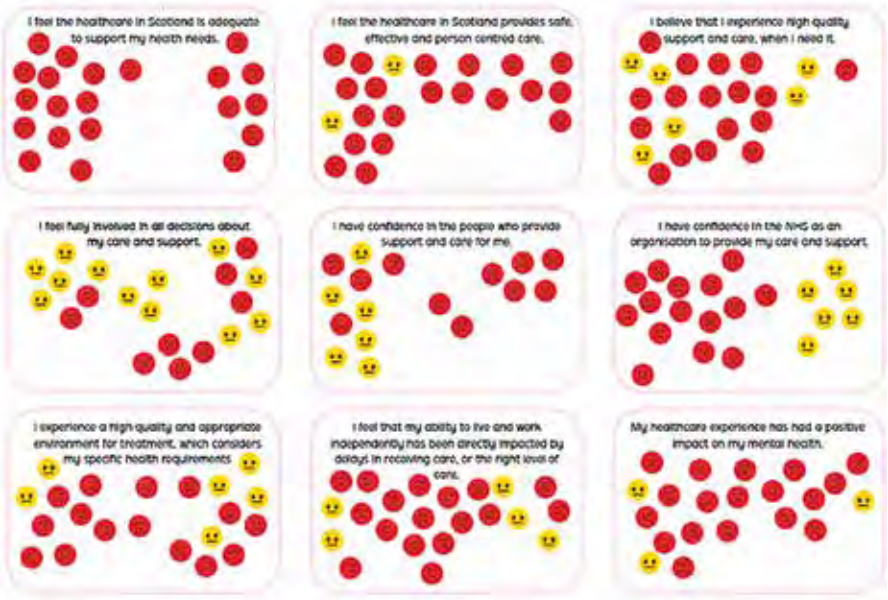
Although this piece of work has focused on the hypermobile type of EDS and HSD, please know that the needs of everyone with EDS, regardless of type, are considered when it comes to raising awareness and calling for improved services for our members.

To open the day and set the scene the researchers presented a paper they had written titled Mind the gaps: therapists' experiences of managing symptomatic hypermobility in Scotland **https://academic.oup.com/rheumap/article/5/2/rkab046/6325096**

They then went on to present the results of their hEDS-START Study which was an online survey distributed to all members of EDS UK between September 2023 and January 2024 and completed by over 2000 people from across the UK. They also presented the findings of the EDS UK Scotland members survey, which used the Scottish Government's Health and Social Care Standards to form the basis of the questions and asked members about their experience of healthcare in Scotland.

The format of the day comprised of two workshops, the first examining the Current Lived Experiences of patients with hEDS/HSD, and the second discussing what an Imagined Future could look like.

Set questions were asked, and attendees discussed and shared their thoughts and feelings using speech bubbles, photographs of their lives and chose smiley, sad, or neutral emoji stickers to capture their current lived experience, not one smiley face was used on the day!



Throughout the day we had an incredibly talented illustrator with us, Rose Matheson, who listened to everything that was said and captured it in picture format. At no point did Rose have to ask for clarification or confirm what was being said and with 25 people in the room, that is not an easy task. Below is one example of many pictures we have that will help depict the challenges and highlight some of the key areas needing to be addressed. This type of medium can be difficult to decipher for some people, but it can also be a great way of communicating

for others. The outputs of the day will be a combination of written word, videos, and pictures. However, I'm sure you will agree Rose has produced beautiful illustrations using members voices that will benefit us all.

The members told us what they would like the future of healthcare in Scotland for hEDS/HSD to look like. They were asked to not only answer for themselves but to consider the 800+ members with EDS in Scotland, and what they might want to see. There was also a discussion about what we hope to achieve in Scotland and how this can be used as a blueprint for the rest of the UK.

As part of the exercises, we were upfront with people, explaining that there is no new money available to the Scottish NHS (SNHS) and that we must think about what we can do with what we have and be realistic in our expectations, the group did exactly this.

The day finished with a discussion about what would be nice in an ideal world, when it came to medical support for hEDS/HSD and what was felt achievable in the current environment. These perspectives will be shared in the report and with Members of the Scottish Parliament in May, to ensure that patient voices are heard in the development of any pathway of care.

As part of the day, attendees who had earlier submitted photographs that represented their experiences of living with hEDS/HSD, came together to produce a scrapbook. This will be professionally published and used for further Engagement work, by the University of Edinburgh and EDS UK. It will also be showcased at the Exhibition in the Scottish Parliament in May.

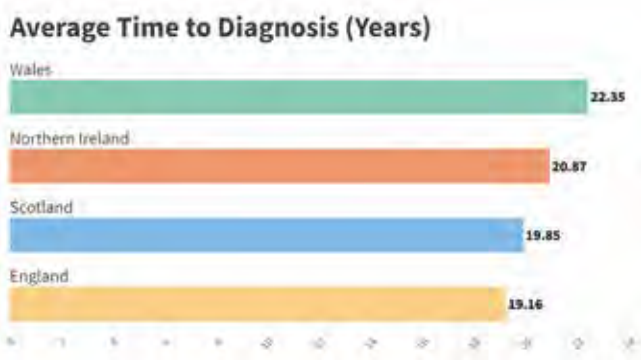
Several attendees also took part in the making of short video clips, talking about their lived experiences which is being made into a professional film. This is a very powerful and emotional medium, which allows people to tell their story in their own words and show the true impact of what it is like living with EDS in Scotland. This will also be used widely at future engagement events.

Kathryn Berg and Dervil Dockrell have produced a comprehensive report based on the focus day and their research from the hEDS-START project.

Some of the key messages are:

- People with hEDS/HSD face almost 20 years between symptom presentation and diagnosis in Scotland.
- Despite the introduction of the GP Toolkit in 2018, only 8% of respondents reported a diagnosis in primary care. All healthcare professionals should feel empowered to identify and diagnose hEDS/HSD, and education is sorely needed to reduce the diagnostic journey.
- Many patients report misdiagnosis of other conditions, often leading to poor management or the experience of other negative impacts on their care.
- People with hEDS and HSD exhibit many symptoms beyond those limited to the musculoskeletal system.
- People with hEDS/HSD report significant psychological distress, though this is not reflected in reported access to clinical psychology.
- Gaps in healthcare access are also evident in Gastroenterology and Pain Management, though there appears to be good access to Cardiology for those reporting cardiovascular symptoms.
- Primary care HCPs should consider which symptoms have the greatest impact on hEDS/HSD patients and refer accordingly.
- People with hEDS/HSD are more likely to report diagnoses of Autism, Attention Deficit Disorder AD(H)D, dyslexia, and dyscalculia.
- People who have hEDS/HSD in combination with Autism are significantly more likely to report co-occurring conditions and symptoms of hypermobility.
- 27% of the hEDS-START Scottish survey population reported that they currently had a carer. Of these, 91% reported that their carer was a family member.

The formal report will be published and shared widely, which is fantastic news as it will be a formal paper written about the experiences of people living with hEDS/HSD in Scotland. However, the data exists for all four nations, which the researchers hope to publish more widely to ensure every voice from across the UK is heard.



To view the report go to: **https://books.ed.ac.uk/edinburgh-diamond/catalog/view/ED-9781912669837/38/473**

We truly hope the results of the day will encourage further research and interest from across the UK and beyond. Working with the University of Edinburgh provides real scope and opportunity for EDS UK to improve care for members in Scotland and the wider UK.

May Awareness Month

As previously mentioned, we have been granted an Exhibition in the Garden Lobby, of the Scottish Parliament on the 7th, 8th and 9th of May 2024. This is a closed exhibition, which means it is only available to MSPs and staff.

This is a follow-up from our successful event in the Scottish Parliament in May 2023 (Ehlers Danlos Syndrome Awareness Session). After which Anne applied to hold an exhibition and was approved and given a date in May 2024. At the time of writing this we are still to hold the event but by the time you read this it will have been held.

The exhibition is sponsored by Emma Roddick MSP and was granted to EDS Support UK on the basis that we would share the outputs and showcase the work we have undertaken since the event in May 2023.

This will be the perfect opportunity to launch the research undertaken by Kathryn and Dervil and it gives us the opportunity to discuss and share the research with the MSPs who choose to stop and chat.

We are delighted Susan Booth; EDS UK CEO will be joining us at the Scottish Parliament Exhibition. This will be Susan's first visit to support the work of EDS UK in Scotland.

As part of our campaign for change before the event we asked all Scottish members to write to their MSPs and ask them to stop by our exhibition and talk to us about EDS/HSD in Scotland and how it affects their constituents. With support from Michael Marra MSP and his team we were able to arrange for a motion to be heard in the Scottish Parliament requesting the creation of a Patient Care Pathway for EDS/HSD patients in Scotland. Michael and his team also arranged a round-table debate for 30th May, which provided the platform for Kathryn and Dervil to share the 2023 research findings and for Professor Stuart Ralston to highlight what a Patient Care Pathway delivers for patients and what patients with EDS/HSD are missing out on.

The motion was submitted by Michael Marra MSP North East Scotland. This is being supported by 14 MSPs with 22 having a registered interest in this. For more information you can read the motion reference S6M-13095 **www.parliament.scot/chamber-and-committees/votes-and-motions/S6M-13095** We're hopeful this motion and the discussions at the forthcoming round table debate will deliver the care pathway that people need.

We'd like to thank Kathryn, and Dervil, University of Edinburgh researchers, for their continuous support and hard work as well as their commitment to research into EDS/HSD and providing support to Anne and Michele. We are extremely fortunate to have them collaborate with us.

They were awarded the Community Champion Awards from EDS UK in 2023 and at the time said "We are delighted to have won the EDS UK Community Champion award. We are the first Scottish winners of the award which is a real honour but may also highlight the need for more hEDS/HSD research in Scotland. This project started and remains to be a labour of love. We have had great support throughout from Professor Stuart Ralston to allow this work to happen."

We recently presented our second Community Award Champion award, in Scotland, this was given to Audrey Kershaw, for her tireless campaigning to raise awareness of EDS/HSD in Scotland. Audrey is a specialist Oral Surgeon and has spent the last few years raising awareness of EDS/HSD to dentists, doctors, nurses, physios, and a host of other medical professionals from all over Scotland and beyond. Audrey has had several articles published and has been asked to present at the Scottish Dental Show in May, where EDS UK will have a table to help raise awareness. Audrey has also recently become a volunteer with EDS UK. **https://www.sdmag.co.uk/2023/10/11/ehlers-danlos-syndrome/**

As part of our Engagement work in Scotland we continue to represent EDS UK on three Scottish Parliamentary Cross-Party Groups: Rare, Genetic and Undiagnosed Conditions; Arthritis and MSK conditions; Chronic Pain. We have recently re-engaged with Genetic Alliance and look forward to more collaborative working in the future. We are also in talks with a major UK charity, with the aim being to provide greater support to members across Scotland and support our Engagement work through greater visibility.

Michele, one of our volunteers has recently been appointed, in a personal capacity, to the Scottish Government Pain Management Task Force; The Task Force was established in 2022 to oversee the implementation of the Framework for Pain Management Service Delivery in Scotland. **https://www.gov.scot/groups/pain-management-task-force/** The Taskforce will meet bi-monthly, and it will be good to have one of our volunteers representing lived experience of chronic pain.

We hope you all have a great summer and look forward to having more to update you with in our next edition of Fragile Links.

UPDATE!

Since writing this article we held the exhibition in Holyrood and here are some pictures from the event. Many MSPs and their staff were spoken to and the new First Minister John Swinney even wore an EDS UK pin badge for his very first questions session!

Above: Lead Engagement Volunteer Anne and Lead Area Coordinator Michele with Chief Executive Susan.

Above: University of Edinburgh researchers Kathryn and Dervil.

Emma Roddick MSP.

Below: The EDS UK team with MSPs.

John Swinney First Minister wearing an EDS UK pin badge in his first set of Minister's Questions.

For up to date information on Scotland support meetings, please go to **https://www.ehlers-danlos.org/support/support-groups/scotland/** or join our Scotland Facebook group (closed to EDS UK members only) **https://www.facebook.com/groups/edsukscotland**

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Anne
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Volunteer long service awards

This year for the first time we have introduced our volunteer long service awards to recognise those who have now given 5 years or 10 years of service to the Charity. We are so proud of our volunteering team and we have now grown to over 95 volunteers in various roles across the UK which is amazing growth!

Last year our volunteers ran 323 meetings supporting over 3,300 members, as well as running information events, fundraising events, hospital and GP open days, awareness days – the list is endless - AND answering emails and helping to moderate the Facebook groups!

We thank all our volunteers for their selfless time and energy supporting members, and special thanks this year to those who have earned long service awards.

Our Chair of Trustees, Stephen Stacey, said "Volunteers are not optional add-ons to the service we offer but its indispensable core. Simply put, we could not do what we do without our loyal and committed volunteers. We are deeply grateful for the time they give to our work. Thank you to every one of them!"

Everyone here at EDS UK couldn't agree more and I am especially proud to manage and work with this incredible and inspirational team of people who, despite their own challenges, put supporting others first.

Thank you everyone. **Nikki Casey, Senior Communities Manager**

10 years

Tasha – Wales Lead volunteer and North Wales Area Coordinator

Jojo – North Powys Area Coordinator

5 years

Sarah – Leicestershire and Rutland

Graham – Nottingham

Zandra - Truro

Lisa - Leeds

Jos - Canterbury

Michele – Scotland Lead Community Volunteer

Anne – Scotland Lead Engagement Volunteer

Krissie - Bristol

Rachel - Bath

Mel – Parent group

Caitriona - Belfast

Lynette - Hayle

Debbie - Cumbria

Tasha's story

Tasha, one of our 10 year long service award recipients, started with EDS UK when the charity started its first pilot project to provide support groups around the UK.

Tasha said "My names Tasha and I've been volunteering for EDS UK for the past year 10 years. I started the role in 2014 as the area coordinator for North Wales and Cheshire back when the Charity first started providing support through local volunteers. My background is a degree and master's in psychology and I'm currently finishing off my master's in social work.

When I started we had over 35 people come to our first meeting. The role was completely new and we didn't know what to expect... We found a huge community of bendies wanting to meet others like them, and many of us had never met another bendy before!

Over the past 10 years I've held fundraisers, liaised with other professionals, spread awareness to anyone and everyone , and supported 100s of bendies. Many new bendies have been diagnosed from the advice given by myself and other area coordinators.

There has been lots of change over the last 10 years: 2 new CEOs for EDS UK, a GP toolkit and a new criteria for hEDS and HSD. When I started the role I set out to not let others struggle as I did. I was diagnosed at 19 after a childhood with chronic pain, recurrent dislocations, gastric issues, autonomic problems and skin issues. I didn't want others to struggle like me: I wasn't believed and hate the thought of others going through the same. I set out to support others, and found an incredibly strong and resilient community who now feel like family!

For the past year I have taken a lead role in Cymru. I am now the lead engagement and awareness coordinator for Cymru, as well as the area coordinator for North Wales. Over the past year we've petitioned the Senedd (Welsh Parliament) for better care for those with EDS in Cymru. Things are progressing nicely, and we will be doing a drop-in at the Senedd to raise the issues us bendies are experiencing in Cymru.

A big change is that more people are being diagnosed with hEDS and it's not classed as a rare disease anymore. This has meant lots more people needing support from EDS UK. Myself and EDS UK are determined to get better care for us bendies. If you need support please do get in contact with your local area coordinator or contact the office. "

We are stronger together

Check out the picture above of Tasha at her first meeting in 2014 with the old branded T-shirt on and one from this year on page 35.

Life-changing moments

I am **Sharon Birch** and I have hEDS, along with comorbidities – osteoarthritis, MAST Cell disorder, hiatus hernia, gastric issues, dyspraxia and others.

In 2004 my son was suspected to have Von Whilem's disease. He and his two sisters were formally diagnosed at the RVI in Newcastle with hypermobile EDS. As a result, I went to see the wonderful Dr Hakim in London where he diagnosed me and, later, my siblings.

It was one of those life-changing moments, and I expressed all the same emotions that I suspect most people have when first diagnosed – relief, confirmation, validation, anger at years of unjustified treatment – and more. It was a true lightbulb flash, the jigsaw complete, finally justification. I had spent years being dismissed, mocked for clumsiness all my life, called a hypochondriac, accused of making things up or exaggerating. I'd spent a week in hospital under investigation for Multiple Sclerosis, maybe I had Guillian Barre, or a pituitary tumour and other things, all of which were checked. I was kicked out of hospital having been told I had hypermobility, which was nothing, get on with it. I was just different, felt different, and made to feel a fraud.

I'd been born with right sided talipes and wore a built-up shoe until I was 12 when I refused to wear them anymore. I've had chronic gastric issues all my life, was ultra-bendy (definitely not now!) dislocated my shoulder, my neck, my right knee a few times, my left big toe more times than I can count, snapped my left hamstring, had an awful labour resulting in hysterectomy, two bladder and bowel repairs, and more again.

Once the dots were joined, diagnosis gave me a different perspective. I took medical retirement from policing after 20yrs. I'd had many injuries on duty, not all deliberate, but I was no longer eligible for front line duties. I'd spent years on the beat, on various squads, as a detective working on major incidents and in child protection. I loved my job, all of it, but it was time to move on.

I went on to become a safeguarding consultant and opened my own early years nursery. We won many awards, including national nursery world awards, and Outstanding from Ofsted. I worked with the EDS UK charity for a couple of years as a volunteer for the Edinburgh group when I lived in Scotland, and as a safeguarding advisor. I spoke at a couple of EDS seminars and at one of the vEDS conferences. I also worked with a number of families as their advocate.

My passion has always been writing. When asked what I wanted to be when I grew up, I used to say, "I want to write books". I was told people like us read books, we don't write them. That was then, at a time when children were seen and not heard.

Since 2004 I have written earnestly. I started to be placed in short story competitions and had many published. In 2012 I won the first Bloody Scotland Pitch Perfect for a novel I was writing. In 2013, under a pseudonym, I wrote Confessions of an Undercover Cop, with Harper Collins. Then life took a turn. I was running my business, my children were teenagers, and I was coping with a myriad of health issues. When my mother-in-law came to live with us to be looked after, there was only so much I could do. Something had to give, and it had to be writing. I still wrote the odd story, still went to some crime writing festivals, but novel writing had to stall.

Finally, in 2023 the crime novel that I'd won the pitch for, 'She's Not There', was finally published. I realised a life dream when I appeared back on the stage at Bloody Scotland in Stirling, spotlighting for the Queen of Crime Fiction, Val McDermid, hosted by Abir Mukherjee. For any crime fiction fans, this is bucket list stuff. I'm appearing at Cromarty Crime Festival in May alongside Sir Ian Rankin, my crime writing ultimate hero!

The sequel to She's Not There is 'Last Train Through Pitlochry' and it is due to be published later this year. I have self-published two collections of my award-winning short stories – 'Bowl of Cherries' and 'Rather Like Marzipan', and the third, 'Blood Oranges, My Love' is due to be published in July.

'MAMAN', the book I've long wanted to be published, my novel with EDS at its centre, is due to be published on April 20th.

I now walk with a stick and my mobility isn't great. I've recently had one joint replacement and I'm waiting on another three. I'm not allowed to have my hernia fixed for health reasons I don't understand. I've now given up my business and work predominately from home as a safeguarding consultant. Thanks to Covid, it's now acceptable to do this. And I write.

I'm a firm believer in doing what you can with what you've got. I'll never be a fitness person, though I was once fit. I'll never be a size ten, though I once was. I'm 60 next year. I'm not giving up anything I love just yet, though we are downsizing our house.

About MAMAN

MAMAN is a standalone suspense novel that I first started writing in 2006. I spent a few years completing it and it stayed there, on my computer, loitering with intent, teasing me over the years to find the right time to do something with it.

That time is now.

MAMAN is a story relating to the miscarriage of justice that surrounds some families who have Ehlers-Danlos (and other conditions) who are wrongly accused of fabricating illness and/or hurting their children, often with tragic consequences.

EDS is a theme in the book, it is not the whole story. It is not a true story, though it contains truths that some can understand. It's not a handbook for EDS, it's not supposed to be a guide for those looking for a defence, it's story that uses narrative to explore and explain pertinent issues that we don't often see portrayed in fiction.

MAMAN is a story about justice and injustice, of power and how it corrupts willingly and unwittingly, as professionals collude in a system that is unrelenting and unforgiving and, at its worst, flawed.

This is a story. It is a story that is a reality for some. It could be for you.

What would you do for truth and justice?

Turning heartache into hope with EDS UK

My name is Millie and I'm an Area Co-ordinator for The Ehlers-Danlos Support UK within the Surrey and Sussex region. As with so many others, my EDS journey is full of grief, pain and great sadness, all of which have given me the drive to help others throughout their own journeys.

My life used to look very different. I spent years training full-time at two of the most prestigious dance colleges in the country, somehow able to push through the endless symptoms that I blamed on the physical demands of my training. It wasn't until I woke up in the resuscitation area of A&E following a ballet class that I realised something was very wrong. I desperately tried to continue my training, enjoying every single second while terrified that it could be my last. But after dozens of hospital admissions far away from my family, and major operations leaving me lifeless in intensive care for weeks, my hopes and dreams shattered right in front of me.

After years of feeling uniquely broken in every way of the word, I was diagnosed with EDS and it all made sense: the years of suffering from relentless symptoms that never seemed to add up, along with dozens of hospital admissions due to medical complications. I never thought being told I had a incurable illness could bring such relief, but that's exactly what it did.

My diagnosis opened up a whole new world full of answers I didn't even know I was looking for, along with co-morbidity diagnoses such as PoTS, gastroparesis and intestinal dysfunction. Due to this, I rely on multiple medical tubes to administer artificial nutrition as well as medication in order to stay alive; a surgical jejunostomy tube, a nasogastric tube and central lines when necessary.

So, life's pretty different now. My days are mostly spent going from one hospital appointment to another, mostly in pain, suffering and living life one day at a time. But instead of pushing through the pain and longing for that 'magic wand' to make everything better, I make the most of the days I am able to be a part of the world instead of watching it though a hospital window. Spending months and months in hospital has made me be able to truly appreciate the days when I am able to go outside, dance to my heart's content and spend time with the people I love.

Stumbling across EDS UK was one of the biggest turning points in my journey. My heartache turned into hope and I finally found my place in a world I never thought I'd fit in to. So after a long gruelling battle between grief and acceptance – I came to terms with the harsh realities of living with multiple chronic illnesses and subsequently became fixated on the idea of helping others.

In Summer 2022, I began my role with the charity and never looked back. I hold regular support groups with the goal to create a safe space for people to open up about the harsh realities of EDS, inspire friendships, give hope to those along their journey and ultimately support people through the highs, lows and all the in-betweens. I also organise seasonal socials, offer support and advice as a fellow EDSer, get involved with charity projects and help sufferers navigate the healthcare system in order to get the support they so desperately need.

I owe so much to Ehlers-Danlos Support UK; from the knowledge they have given me which has enabled me to get the right support as well as give support others, to the wonderfully inspirational people I have met who've given me strength on the darkest days.

So if you find yourself or a loved one struggling with the effects of EDS, please get in contact with us... because "nobody should be left to fight on their own" – EDS UK

Instagram: @_milliebridger

MILLIE BRIDGER

EDS opened many doors for me

SHARON (PARENT)

The path to diagnosis of an illness can be a long and hard journey particularly when the symptoms lead you to consider something as rare as EDS. It was when Megan was 11 years old that a young, newly qualified Osteopath related Meg's collapsing ankles, gastrointestinal symptoms and hyper mobile joints to Ehlers Danlos Syndrome. We had never heard of EDS and after doing our own research, it did appear to make sense.

For several years despite asking for a referral from her GP to explore this diagnosis, Meg experienced worsening symptoms, misdiagnosis leading to psychiatric hospital admissions before, at the age of 18 years Megan finally received a diagnosis of Ehlers Danlos Syndrome hypermobility type through a referral to an NHS geneticist. At no time were we able to get a referral to an NHS rheumatologist. During this time. Megan was traumatised, we as her parents were traumatised and her brother Olly who was caught up as the 'well' sibling was traumatised.

At this point, we had a diagnosis but no support. We were all bewildered, jaded and still no further forward with helping our poorly child.

Megan used this diagnosis to find support. She asked me to come with her to an EDS UK support group in the nearest town to where we lived. It was here that we met Sarah Steele who was beginning the journey to setting up the support group that we still attend today. Megan and I arrived and sat quietly whilst others shared the story of the path to diagnosis. Parents shared the names of consultant rheumatologists whom they had been able to see privately and understood this seemingly impossible diagnosis.

As a parent, I felt hope in the stories that I heard from other parents that they were able to find enlightened healthcare professionals and took notes so I could contact these same people to help my own daughter. I felt encouraged that we were not alone anymore, Meg was indeed a zebra but no longer in a herd of one. I felt empowered to find the right sort of help and felt blessed in the support of the people in this group who wanted to use their journeys to inspire and teach others through their own lived experience.

Today, we are five years down the road, Megan has seen several consultants named in that support group and can now add MCAS, POTS and a number of other diagnoses to her record. These have helped to stabilise her and understand her body so she can live a life although still challenging, in a more informed way.

Even now we hold the trauma of the mis-diagnosis days and are learning to deal with it. Meg and I still attend meetings and I have used my lived experience to support other carers, my husband Jon has raised funds for EDS UK by taking part in Ride London and my son Olly has graduated university.

I too am now a diagnosed zebra and attend the support group for myself finding support amongst my peers and will continue to do so, supporting and being supported by the wonderful people around me.

MEGAN

My diagnosis of Ehlers Danlos Syndrome changed my life. It opened many doors for me, from further diagnosis and treatment, to meeting new friends through support groups.

After a particularly difficult year of being ignored and constantly being told I was making everything up for attention, I came out of that year with a constant feeling of being an imposter and lost all my trust in the health care system. It wasn't until my diagnosis came that the relief set in that I had the answers for something that had been affecting me my whole life. Though diagnosis was helpful, it unfortunately led to more question that were unlikely to be answered.

We are told not to google symptoms, but it felt like my only option, and I'm glad I did. Without this I would never of found the support that has made the biggest change. The online search led to the EDS UK website and then to the Facebook support group. With the nearest support group to me being around hour away, we reached out to the group for support and to meet someone in the group who was trying to set something up closer. We jumped at the opportunity to start exploring these options more.

Sarah and I met, with my mum coming along for support, we had a brilliant and fulfilling first meeting. From there the Market Harborough and Draughton group began. Meeting and listening to other people's stories about their diagnosis of both EDS and the co-morbidities that commonly come with it, we started to learn about what available support was out there. We began creating our own list of doctors with an understanding of EDS and how they could support us. Coming out of this first meeting had changed my perspective of what life could be and all the possibilities that could be out there for me.

Having the opportunity to discuss, listen, and vent if needed, has made a huge difference to both my physical and mental wellbeing. I didn't realise the support you can receive from just being in this environment. Being able to now share my story with others and give others the support back in a way I have received is, and continues to be, very rewarding.

The Wobbly Cyclist

My Wobbly Cyclist Facebook bio is "50+ cyclist and mobility scooter user and neurospicy spoonie with Ehlers-Danlos Syndrome & fibromyalgia", but the bigger picture is that I'm 57 years old, married with 3 (adult) children, work part time for a local youth charity and am lucky enough to live on the Moray Firth coast in North East Scotland. I have hEDS, fibromyalgia, Raynaud's, Sjögren's, Ménière's, Autism and ADHD.

Over the years, my health issues slowly reduced my mobility and cognitive skills, leaving me crippled with anxiety. In 2016, I was lucky enough to be awarded a scholarship through Flying Scholarships for Disabled People, and spent three weeks out of my comfort zone, learning to fly in Gloucestershire.

My scholarship changed my life and my mantra of "Well, if I can fly a plane..." has been getting me into trouble ever since, including abseiling off the Forth Rail Bridge, despite being absolutely petrified of heights and bridges.

In Oct 2017, I got a part-time role with Outfit Moray, an outdoor learning and adventure organisation for youngsters, their families and communities. In 2020, my colleagues turned my life around again by convincing me to try an electric bike. As a mobility scooter and wheelchair user, it was amazing to be able to move so quickly under my own steam and I was immediately hooked.

A month later I purchased my first Volt e-bike and was soon reaching previously inaccessible places, including getting up the highest hill in Moray. As my cycling confidence grew, I upgraded to a hybrid Volt Pulse LS for more off-road cycling and took part in Cairngorm to Coast, a 100km challenge event.

Spending more time outdoors increased my confidence and last September I finally took the plunge and have been sea-swimming at least 4 times a week since then. I love the buzz! I continue to share my Wobbly Cyclist stories and promote accessible adventure, in the hope of encouraging people like me to try something new. This July, I plan on cycling up Cairn Gorm, the sixth highest mountain in the British Isles. I can't wait to see what it feels like to be 1,244.8m above sea level!

All this from a three-week flying scholarship and 5 minute e-bike trial. It just goes to show you never know what you are capable of until you try it.

If this article has inspired you, you can follow my Wobbly Cyclist adventures at **https://linktr.ee/wobblycyclist**

Finding friendship can sometimes be tricky. This is especially true when you need a friend who can be understanding of having a chronic illness and all that goes along with that (the needing to change plans or even having to cancel last minute). However, we've found friendship can sometimes develop from a chance meeting into something quite special...

Finding friendship

SIAN GOSWAMI AND CHLOE SMART

While attending an EDS face-to-face support meeting in Leicestershire some five years ago, my mum met Chloe. They chatted at the meetings and eventually swapped contact details. This led to myself messaging Chloe and our friendship began. The two of us not only realised we had much in common healthwise but incredibly found out that we shared the same birthday and were born in the same hospital just two years apart!

As our friendship developed over the years, we've spent a lot of time together discovering EDS-friendly activities, which we could both enjoy. Chilled pottery sessions, picnics in the park (occasionally even on a sunny day!) and the odd spa trip have added to our enjoyment of our blossoming friendship – having someone who understands the myriad of issues and demands that EDS presents in everyday life has really helped.

Having become close friends, I was delighted for Chloe when she announced her engagement and forthcoming wedding. To my surprise, Chloe also asked me to be one of her bridesmaids! The two of us spent many hours deep in discussion preparing for the big day and - in October 2023 - it finally arrived. It was an amazing day, as you can see from the huge smiles on our faces.

Sharing such a special life event together has brought us even closer, and we continue to plan chilled EDS-friendly activities for the future. Both of us agree that having a best friend who understands and can relate to the struggles you're having is a huge help in daily life and has been a positive element in both of our EDS journeys.

Who knows who you may meet at your next EDS meeting – it may be the start of a truly special friendship too.

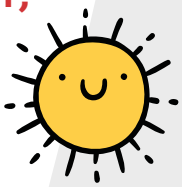
You can find your local group meeting here:
https://www.ehlers-danlos.org/support/

Junior Ezra Club

Welcome to Junior Ezra Club for the under 12s!

In every edition we have pages just for our younger members so when your parent or guardian has finished reading all the boring stuff, you can look at the fun bits!

Summer is back! We have some fun activities for you to do and can't wait to see how creative you are!



Kids' corner

This edition, as well as some new pictures we wanted to go back and find some of our first Junior Ezras from Winter 2021 and Summer 2022 and see what they are doing now! They are certainly growing up fast!

Harry then and now

Harry was 11 when he appeared in our first Ezra Club article back in Winter 2021! He is now 14 and loves to dance and perform Michael Jackson songs. He has just picked his GCSE subjects and looking forward to starting that in September.

Ada then and now

Another Winter 2021 Ezra clubber – Ada is now aged 12 is still a junior dragster. Here is a picture of her from last race season. She won some trophies and finished 7th in the national championship.

Sullivan aged 7 – Berkshire

In Weymouth crabbing – lovely day. Then at a skate park – EDS doesn't hold him back.

Layla aged 13

Layla is 13 and loves playing rugby!

Lily and Bret – then and now

Lily (and her twin Bret) are now 7 and this was a picture from World book day today, with Lily as Minnie Mouse and Bret as Funnybones. Both of them are very active with swimming and playing rugby.

Lucia – then and now

Lucia from South West Scotland is 9 now. She loves swimming, singing, art, playing the piano, reading and all things magical.

Abi then and now

Abi is 13 now. Her two passions are reading and crocheting and she is currently working on a brilliant blanket.

Amara aged 4

Amara lives in Cheshire and has hEDS and loves baking cakes.

Tao – then and now

Tao is now age 13. He loves to play the piano too and is very good This picture is in St Pancras train station where the programme 'The Piano is filmed.

Lennie then and now

Here is Lenny in London after a basketball match now 11 years old and ready to start Secondary school in September!

He kept at it with his basketball and tried out for Essex Rebels juniors U12 and made the team as one of the youngest players and is playing his first season in the Junior National Basketball League! He spends his time at basketball practice and games and working at the Essex Sport Arena helping out at the adult national basketball league games.

Wren-Hollie then and now

Wren-Hollie is nearly 11 now and in year 5. She now has a full hyper-mobile Ehler-Danlos syndrome diagnosis from the geneticist. From some of the tests the hospital did because of EDS we found out I also have a heart problem called Wolf Parkinson white syndrome. I'm on the waiting list for an operation to take away the extra pathway.

I'm doing really well in school as I'm getting lots of help but I've had to temporarily stop doing things I enjoy because of my heart. I still get lots of pain and regularly see a physio but I struggle to remember I need to take things easy. I still want to run at a 100 mph and forget this causes lots of pain there after.

I'm going to get a back brace too for my spine as it's curving more and causing more pain. I still always have a smile on my face though and love cuddling my cats willow and Luna when I feel sad about things.

Junior fundraiser

Postbox Piglets

12 year old **Rhys**, who lives with hEDS, has been creating colourful piglet ornaments since he was 10 years old. He sells them on his website Postbox Piglets to raise money for charity to "bring a smile to people's faces and give something back." Rhys created a fantastic 'zebra pig' and very kindly donated 20p from every sale to EDS UK raising a total of £75 so far. Senior Communities Manager Nikki even bought one for her office desk! 'I absolutely love it – it is so cute and sits on my window sill and makes me smile'

Thank you Rhys for supporting EDS UK, we think your zebra pig is wonderful!

If you want to buy your own zebra pig then go to:
postboxpiglets.co.uk

Beware there is a whole set – they might become addictive

Zebra crafts

Make a Zebra Z for your bedroom door!

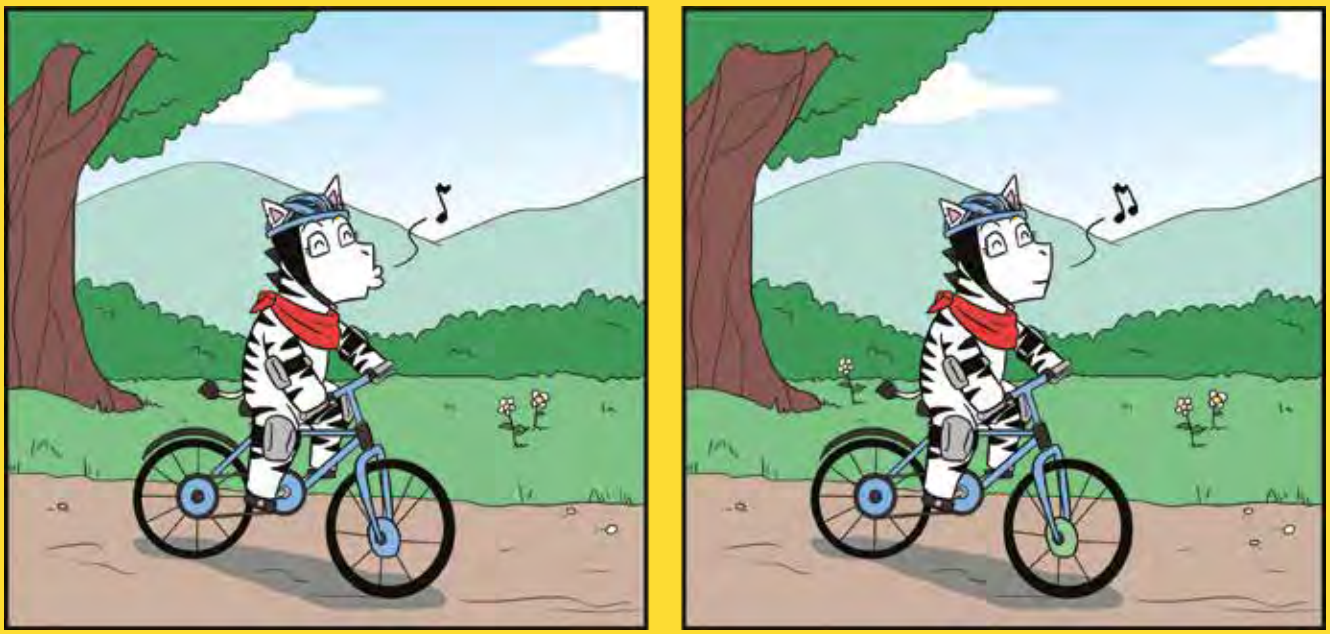
Here is what to do.

1. Get a cereal box and draw the shapes you can see opposite (you can get an adult to help you)
2. Cut out the shapes and glue them together
3. Colour or paint the shapes. You can even add black and white wool for the mane!

There are loads of zebra crafts out there to try – why not send yours in to us to feature in the next magazine! Take a picture and get your parent or carer to email them to **nikki@ehlers-danlos.org** or whatsapp them to **07904 216063**

Spot the difference

Can you spot the six differences between the two pictures? Answer on the next page.



Interesting Zebra facts

White-colored stripes can be 18 degrees cooler than their dark counterparts.

Zebras use their stripes to camouflage themselves in tall grasses.

What did the zebra tell the vet at his hospital visit?

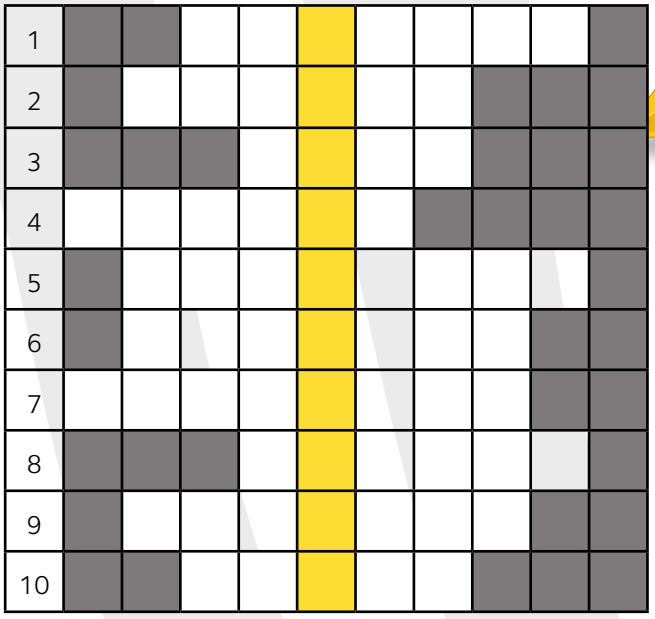
"I'm feeling a little horse."

Ezra Tails

Word puzzle

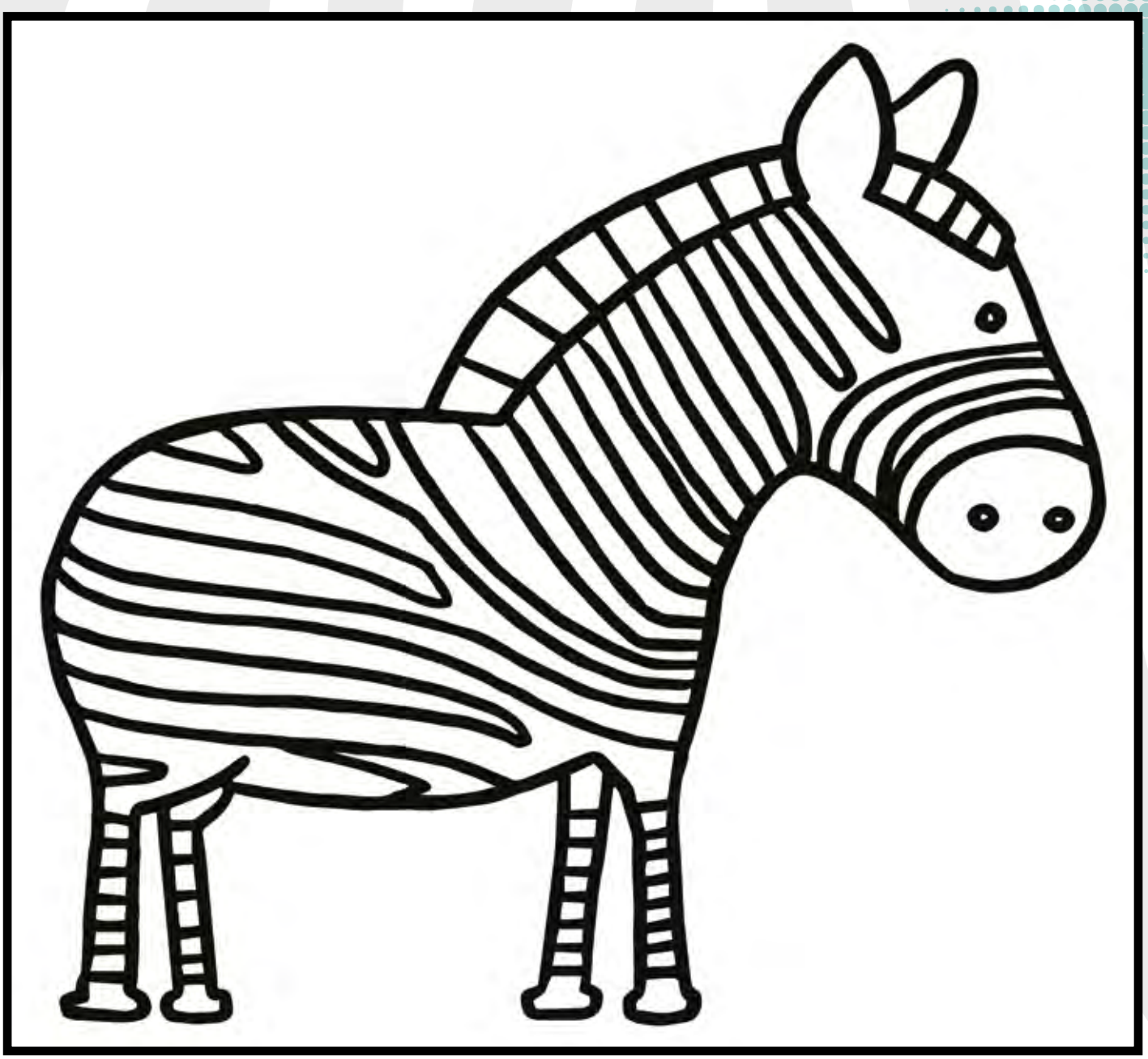
1. Look at the EDS UK staff team pictures. What is Guys surname?
2. A yellow fruit with a curve
3. The name of our Zebra mascot?
4. Olympic third place medal
5. A giant who went travelling to Lilliput
6. Football team known as 'The Gunners'
7. Someone who always has their head in a book is known as?
8. Superhero with a best friend named Robin
9. Another word for a really huge rock. And a place in the USA
10. The best type of tinned bean

Fill in the blanks and find the hidden words



Answers on next page

Let's colour in!



WE WOULD LOVE TO SEE YOUR PICTURES, PHOTOS AND ACHIEVEMENTS AND FEATURE THEM IN THE JUNIOR EZRA CLUB.

Send in articles and photos to Junior Ezra Club by getting an adult to send them to: **EDS UK, Junior Ezra Club, Devonshire House, Manor Way, Borehamwood, Herts WD6 1QQ** or by email to **ezraclub@ehlers-danlos.org.**

SOLUTION TO SPOT THE DIFFERENCE:

SOLUTION TO WORD PUZZLE:

1. Hodgson
2. Banana
3. Ezra
4. Bronze
5. Gulliver
6. Arsenal
7. Bookworm
8. Batman
9. Boulder
10. Baked

Hidden words: **DAZZLEWALK**

Your legacy. A future where EDS / HSD is understood.

Too often we hear that you are not believed, misunderstood and dismissed for trying to get help with your symptoms. Imagine a future where we have trained a wide variety of healthcare professionals so they recognise, understand and can help diagnose and manage EDS/HSD. A gift in your will can help us to confront misunderstanding and challenge inequality and ultimately achieve this vision.

After making provisions for your loved ones please consider leaving a gift to The Ehlers Danlos Support UK to help others yet to be diagnosed or treated. Across the UK we will help people to be connected, heard, supported and have equitable access to care. Help change the future through what could be the biggest gift you will ever be able to give.

Please remember, a gift does not have to be large to make a difference. Anything we receive is important, appreciated and will help improve lives.

If you would like to talk to someone about leaving a gift in your will, please call the fundraising team on **020 8736 5604**, or email **fundraising@ehlers-danlos.org**

To find a solicitor in your local area, who will be able to advise on leaving a gift to EDS UK when making a will, visit the Remember A Charity website: **www.rememberacharity.org.uk/find-a-solicitor-or-will-writer**

Don't forget you will need to give your solicitor our name The Ehlers Danlos Support UK and charity numbers England and Wales (1157027) and Scotland (SC046712).

EDS

EHLERS-DANLOS SUPPORT UK