



HERSTMONCEUX INTEGRATIVE HEALTH CENTRE (HIHC)

Newsletter No. 6

Spring 2020

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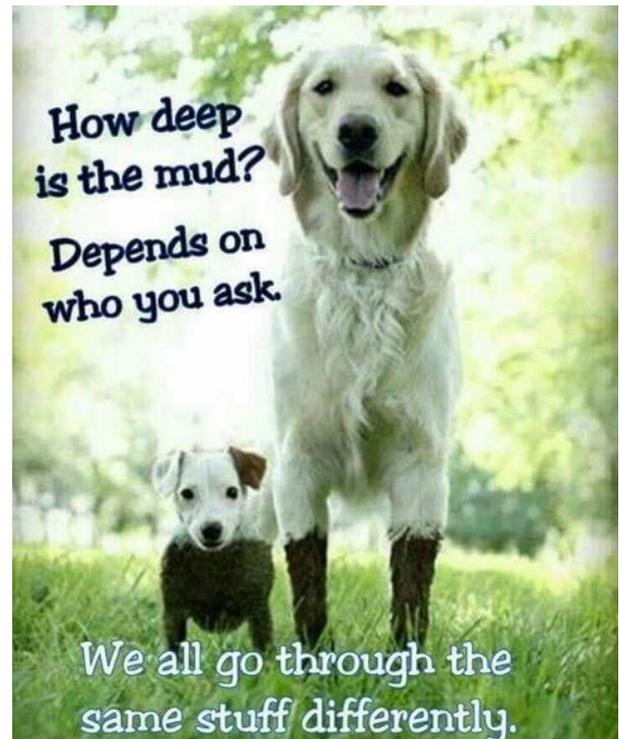
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There is an interesting article on **Hypermobile Ehlers-Danlos Syndrome** on page 14; if there is anyone with conditions and they wish to share their experiences and insights please contact the editor, Lynn Bowman: plg.hmxihc@nhs.net

Cutting back on single-use plastic

In line with our environmental beliefs we are looking to reduce the use of single-use plastic. One way we will do this is that the Practice will no longer provide plastic cups for the water in the waiting area.

We are looking for more sustainable alternatives but it would also help if patients who would like to make use of the water could please bring their own cups or water bottles. Thank you.



Do come to our barn dance on 14th March – see page 4

Our celebrated patient of the month is Mr Martin Jobson. See page 2

Martin recently came to see Dr Andersen to talk about his health concerns; he had low energy, always felt tired, with low motivation and high blood pressure.

Dr Andersen advised him to take the first step and start to build up his fitness levels.

After making excuse after excuse of why he shouldn't go to the gym, Martin finally made the first step and joined the local gym. To start with it was hard but, with the motivation of friends, he stuck with it and pushed through the tiredness.

Martin has now made sustainable, positive lifestyle changes. He now loves the gym, has a good routine, is eating healthily and has a healthy positive mind-set.



STAFF CHANGES

Herstmonceux Integrative Health Centre would like to welcome two new team members:

Kirsty Kane joined our reception team in January. She is new to General Practice but is fitting in well and learning the ropes.

Dr Rachel Harrison joined us this month as a salaried GP and she will be working on a Thursday. Dr Harrison has been working at another surgery in Sussex but has joined us looking to support our holistic and integrative approach to Health Care.

NHS QUESTION

There is more than one version of the NHS in the UK.

True or false?

Answer on last page of newsletter

Don't forget evening and weekend appointments

Evening and weekend appointments are currently being provided at several practices across East Sussex.

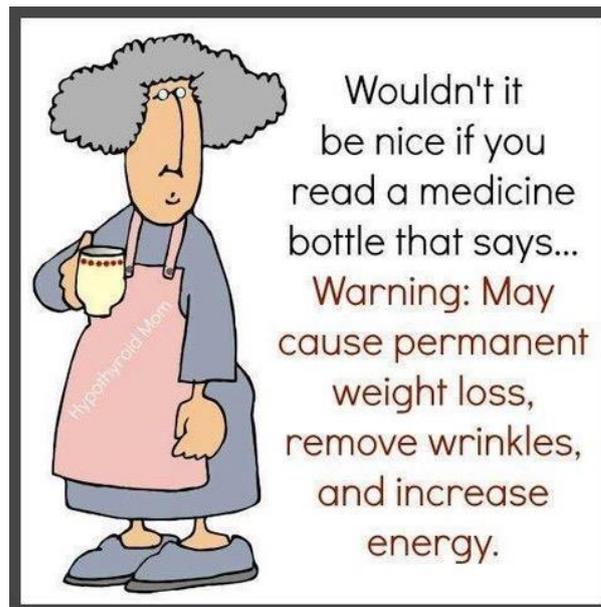
Appointments are pre-bookable and available 365 days a year (every evening from Monday to Friday, at weekends and on bank holidays). They can be booked via Herstmonceux Surgery during surgery hours – just explain to the reception team you would like an evening or weekend appointment. The clinician you see will have full access to your electronic clinical record and will be able to do everything your own GP can do.

LIVI Video Consultations

If you are unable to travel to one of the other East Sussex practices (hubs), there is also the option of a **LIVI video consultation**. LIVI is free to use and HIHC is a participating practice which means that your electronic medical records will be available for LIVI's GPs. <https://www.livi.co.uk/>

The key things to be aware of are:

- This facility is only available via an app on your mobile phone, tablet or iPad (not via a personal computer or laptop)
- You will need to take a photo of yourself when first registering for the service
- You will need to scan in either a passport photo or driving licence photo when registering
- LIVI is not available for children under 2
- The service is available 365 days a year: weekday evenings from Monday to Friday (4pm – 8pm) and at weekends and on bank holidays (8am - 4pm). After these times you can ring 111.
- The app is not transferable between personal devices – you will have to register for each device



PODIATRY SERVICE

We regret to say that the Age UK Podiatry Clinic finished on 31st January. However, we now have a new podiatrist Conneal Clarke.

Conneal works within the NHS, was previously working for Age UK and is now running her own clinic at HIHC

Prices:

Routine: £20 - nail cutting

Enhanced: £25 - diabetic patients and those that need callus debridement etc.

Note: All new clients, except those that are diabetic or at increased risk of infection, will need to purchase a nail kit for £13 which they take with them at each visit. The enhanced group will be provided with a sterile kit at each visit.

Contact details:

Conneal Clarke, Podiatrist
Mobile: 07449929423

BARN DANCE AT HERSTMONCEUX CASTLE

CASTLE CEILIDH

Saturday 14th March 2020, 7pm onwards



We are delighted to announce that Herstmonceux Integrative Health Centre and the Patient Link Group have collaborated to hold our first community event with the aim of bringing people together to have some fun.

Please come along and invite your family, friends and neighbours along. Include others who may just need that extra confidence to come and enjoy a sociable night out. To ensure as many people as possible are able to attend we have kept ticket prices to a minimum at £15 a head to include a buffet. Drinks will be available to buy at the bar.

There is disabled access and we would like to encourage you to come even if you sit and tap your feet to our callers – the Catsfield Steamers.

Tickets are available from the Practice reception or telephone 01323 833535

Come prepared to buy some raffle tickets as we have some very exciting prizes and all profits will go towards purchasing an Ear Micro-Suction Device for the Practice.

**AND SAVE THE DATE FOR OUR NEXT
COMMUNITY EVENT AFTER THIS ONE!**

**Put the date in your diary to join us for a healthy
walk and picnic on Sunday June 14th.**

MORE DETAILS TO FOLLOW

What is an Ear Suction Microdevice?

Microsuction is one of the safest methods to clean the ear. The nurse, doctor or audiologist treating you looks at your ear using a microscope which magnifies the ear, making it easier to assess and treat. A suction device is used to clean the ear without the use of water. Ear microsuction is not provided in the community under the NHS so HIHC are looking to invest in this unit to ensure all patients have access to safe and convenient ear microsuction within the community.

Update on Primary Care Networks (PCNs)

Along with 5 other practices, Herstmonceux Integrative Health Centre forms part of the Greater Wealden PCN.

Our Clinical Director is Dr Ragu Rajan. His role includes:

- assessing the needs of the local population
- adjusting the services provided to fit those needs
- co-ordinating all the activities across the PCN
- working towards prevention and encouraging self-care

All the above issues are discussed at monthly Board meetings represented by nominated people from each GP practice.

This could work well if it is kept realistic and services are provided in suitable locations. Some services are best kept to single practices, whereas other more specialist ones (e.g. diabetes or minor surgery, where extra training is required) can be shared within the PCN, giving patients the best possible care as local as possible.

A PCN is classed as an enhanced service and the document from NHSE describing that service is very prescriptive. A GPs new contract will expect them to take on these enhanced services in addition to their existing work, with the practice paid to take part and expected to reach targets.

Funding is mixed. There is some central funding from NHSE for certain staff, (e.g. 100% of funding for social prescribing). Other funding is allocated as 70% from the NHSE and 30% from the core PCN collective to pay for extra pharmacists or physiotherapists etc., with the Board deciding who to employ and where to place them depending on need.

Future of Local Patient Participation Groups (PPGs) and Primary Care Networks (PCNs)

This was seen as an iterative process. Currently:

□

· Each GP practice would continue to have their own Patient Participation Group (our PLG)

· Eventually the PCN directors may see the need for a combined PCN PPG in addition to existing practice PPGs

· There are thoughts that our PCN may need patient input if they are looking at redesigning services and would want feedback from patients. For example, where would diagnostics be best placed within the PCN geography? How could they make a new service work for the patients in that area? Any new service would need a business case for the funding presented to the Clinical Commissioning Group.

Clinical Commissioning Groups (CCGs)

On the 1 April 2020 the High Weald Lewes Havens CCG will be launching a new public website for each of the NHS Clinical Commissioning Groups in Sussex.

On this date:

- the three CCGs in West Sussex are merging into one new **West Sussex CCG**
- the three East Sussex CCGs are merging into one new **East Sussex CCG**
- Brighton and Hove CCG remains unchanged.

This gives the CCGs an opportunity to overhaul their web presence and the way that they communicate and engage with the patients and public across Sussex online.

To help inform them about our priorities and what you would like from their future websites, they would be very grateful if you could spare a few minutes to complete a survey. (link provided below).

If you'd be able to help out in any other way as they get closer to launch, there is a space at the end for you to leave your contact details.]

<https://www.surveymonkey.co.uk/r/XFPH7P>

FRIENDS & FAMILY SURVEY

We would like to thank those patients that have expressed satisfaction with the Practice and praised the staff through the December Friends and Family feedback. Positive feedback is always lovely to receive.

We would like to take this opportunity to respond to some of the more specific comments made in December:

About 6 people “would like to see quicker appointments or less time waiting for them”

- We try very hard to keep to time for all appointments but obviously delays do happen with emergencies, phone calls and other interruptions the clinicians receive. We do inform the patients if there is a significant delay and aim to keep these to a minimum. At each administration meeting we remind the admin team to inform patients if a delay occurs.

“The car park verges were mentioned”

- There was a comment regarding the car park verges. We are not sure what this refers to. We are aware during the winter the verges have been driven over and the wet weather has meant this has caused some damage. Our lovely gardener is aware of this and we look to making this more attractive as the weather improves.

Another person mentioned “the reception door slammed”

- This has been brought to our attention and we understand this may cause disturbance. Unfortunately the door has to conform to H+S regulations and also be secure, i.e. with the number pad lock on it. To ensure the door always closes the door has a “door closer” attached. It is quite strong but we have tried to tweak this but then the door doesn't close as the door is so heavy. We have

reminded all of the team to not allow the door to swing shut but sometimes that gets forgotten when people are in a rush. Again, this will be reiterated to the HIHC team.

Thank you for your feedback

Nic Hone, Practice Manager

PATIENT LINK GROUP SURVEY

Later this year the Patient Link Group (PLG) will be working in the Practice to conduct another bespoke patient survey.

In advance of this, if there is anything you particularly would like us to include in the survey could you please let me know.

Thank you.

Lynn Bowman, Chair of PLG,
Email: plg.hmxihc@nhs.net

Bill Bryson's Fascinating Facts

We aren't built to walk on two legs. When our ape-like ancestors came down from the trees, there was an evolutionary advantage to walking upright: we could cover more ground and see further.

But our skeleton is still largely engineered to cope with life on four feet, not two.

As Bryson writes: “Becoming upright put extra pressure on the cartilage discs that support and cushion the spine, in consequence of which they sometimes become displaced or herniated in what is popularly known as a slipped disc.”

General back pain is ridiculously common: some 60 per cent of adults suffer from it. Our knee and hip joints are nothing to brag about, either, giving out with dispiriting frequency.

Extract from Bill Bryson's Book “The Body”

Which service do you need?



NHS emergency services are there for you in emergency and life-saving situations. But many people are going to A&E with problems that are not emergencies. This makes A&E very busy and means you and other people have to wait longer for treatment.

You should go to A&E if you need immediate, emergency care and have symptoms of serious illness or injuries that could be life threatening. You can read more about when to go to A&E on the NHS website.

If you need urgent care that is not an emergency, you can get quicker treatment closer to home. There are many services available:

NHS website

Visit www.nhs.uk to:

- Check your symptoms to see if you need further treatment
- Better understand your health so you can stay well
- Find out what services are available if you need treatment

Call NHS 111

NHS 111 is available 24 hours a day, 7 days a week and is staffed by a team of fully trained advisers. Depending on the situation, they can connect you to a nurse, emergency dentist or even a GP, and can arrange face-to-face appointments if they think you need one. Calls are free from mobiles and landlines.

Visit your local pharmacy

There are many local pharmacies on the high street, in supermarkets and shopping centres. You don't need an appointment and they can offer expert advice on bugs and viruses, minor injuries, tummy troubles, skin conditions and allergies. Find your nearest pharmacy.

Visit your GP

GPs help with treatment and advice for health problems. You may not be able to get an appointment immediately but practices will see you as soon as possible. Evening and weekend appointments are available, so contact your GP to find out about available appointments.

The reception team may ask what the problem is so that they can refer you to the most appropriate healthcare professional or service, such as a physiotherapist or mental health support, saving you time.

Visit a Minor Injuries Unit

Minor Injuries Units (MIUs) provide assessment and treatment for a wide range of minor injuries in both adults and children.

They can be found at Crowborough and Uckfield community hospitals and are open from 8am – 8pm, seven days a week.

Walk in services

Walk in services are available 8am-8pm at:

- Eastbourne Station Health Centre – 01323 726650
- Station Plaza Health Centre, Hastings – 01424 884410

A consultation is currently taking place on the future of the Walk In Service at Eastbourne station. If you want to have your say, here is a link:

<https://www.eastbournehailshamandseafordccg.nhs.uk/get-involved/the-future-of-eastbourne-station-health-centre/>

/continued overleaf.....

Mental health crisis support

Support services are available for people suffering from mental health problems who are at risk and may not be able to keep themselves safe, or who are considering attending A&E for help with their mental health.

- The Sussex Mental Healthline is a telephone service offering support and information to anyone experiencing mental health problems including stress, anxiety and depression. The service is also available to carers and healthcare professionals. You do not need an appointment.

Call 0300 5000 101, Monday to Friday 5pm to 9am, and 24 hours at weekends and Bank Holidays. Visit www.sussexpartnership.nhs.uk/sussex-mental-healthline

If you are in crisis and need urgent support [visit this web page](#) for advice.

- Samaritans – 116 123. Call free for emotional support any time day or night www.samaritans.org
- You can also find more information and advice in the [East Sussex mental health directory](#).

Emergency dental

If your own dentist cannot help or you don't have a dentist, call the NHS Dental Helpline on 0300 1231663, Monday to Friday, 8am – 4pm, for an appointment.

If you need help outside these hours, call NHS 111 or contact the [East Sussex Emergency Dental Service](#):

- **Eastbourne:** (01323) 449170 from 6.30pm – 10.30pm weekdays or 1pm – 5.30pm weekends and bank holidays.
- **Hastings:** (01424) 850792 from 6.30pm – 10.30pm weekdays or 9am – 1.30pm weekends and bank holidays.
- **Lewes:** (01273) 486444 from 6.30pm – 10.30pm weekdays or 9am – 1.30pm weekends and bank holidays.

This isn't a drop-in service so you'll need to call to make an appointment.

“Which Service do you Need” was published on 16th December 2019 by [Health and Care News East Sussex](#).

Bereavement Drop in Mornings

From Friday 28th February, the surgery is starting a monthly coffee morning.

It will be hosted by volunteers from St Wilfrid's Hospice and is for anyone wishing to talk to the volunteers about bereavement.

The volunteers have received training and can also signpost to further services at St Wilfrid's.

The sessions will run from **10am to 12noon** and will be held in the Great Space.

You do not have to book or let them know you are coming - it is an open drop in session. The volunteers will be with us **on the last Friday of every month**. If you would like further information please speak to Bea at the Surgery.

Next few sessions:

Friday 27th March
Friday 24th April
Friday 29th May

NHS Abdominal Aortic
Aneurysm Screening
Programme
SMaRT



NHS

Screening Programmes

Have you been screened for an Abdominal Aortic Aneurysm (AAA)?

If you are a male aged 65+ and have **NOT** been screened before, you are eligible for a screening examination.

We screen locally in
VARIOUS LOCATIONS

NHS Screening Programme we also screen nationally.

**Please call the AAA Screening Office on 01903 843834
for an appointment or for further information.**

Information can also be found in our leaflets or by visiting
[https://www.gov.uk/topic/population-screening-
programmes/abdominal-aortic-aneurysm](https://www.gov.uk/topic/population-screening-programmes/abdominal-aortic-aneurysm)

Sussex Community 
NHS Foundation Trust



VITALITY VILLAGES NEWS

Men's Shed

The Herstmonceux Men's Shed now has 19 members, some are working on individual projects, some supporting Herstmonceux Castle projects, some making ladder stiles for the Vitality Villages Community Footpath scheme and others who pop in for a chat and a cup of tea.

Come along and meet the members on Wednesdays 1pm until 4.30pm in the Science Block at Herstmonceux Castle. Entrance is via the main entrance off the Wartling Road; the Men's Shed is located near Bader Hall.

Phone Alan on 01323 833306 or 07946 604201 for more information.



Community Choir

The community choir invites you to join them; they sing for fun, with no auditions.

They meet on Wednesday evenings from 6.45pm until 8.45pm at the Herstmonceux Integrative Health Centre.

Phone Laura on 07905 745384 for more information.



Allotment

Work on the community allotment will start in a few weeks, if you would like to join us and try your hand at growing vegetables, fruit or flowers, we have small boxes and areas where you can come along and have a go.

Phone Janet on 07889 159824 for more information.



Walking and associated activities

Over the past few months, fundraising, grants and donations have resulted in the installation of five kissing gates in the parish and the construction of two ladder stiles. The stiles, made by the Men's Shed, are due to be installed soon. The funds have also allowed for the continued publication and distribution of the local walking guides around the parish.

Twenty Walks in 2020

Last year Steve Burke, accompanied by a number of other walkers, raised over £600 in sponsorship and donations when he walked the parish boundary

This year he hopes to go even further by encouraging more people to join him and hopefully donate, when he tackles **Twenty Walks in 2020**. The walks will vary from very short strolls to longer more challenging endeavours, giving everyone a chance to join in. The walks will take place from the latter half of April through to the beginning of June. He is busy preparing the programme of walks and will advertise them widely once they are finalised. Meanwhile get ready.

Phone Steve 01323 833473 for more information.



See next page for coffee morning dates.

VITALITY VILLAGES COFFEE MORNINGS



Every third Monday in the month, 10.00 am to 12.00 noon

**IN THE GREAT SPACE (UNDER THE SURGERY) HERSTMONCEUX HEALTH CENTRE
HAILSHAM ROAD HERSTMONCEUX**

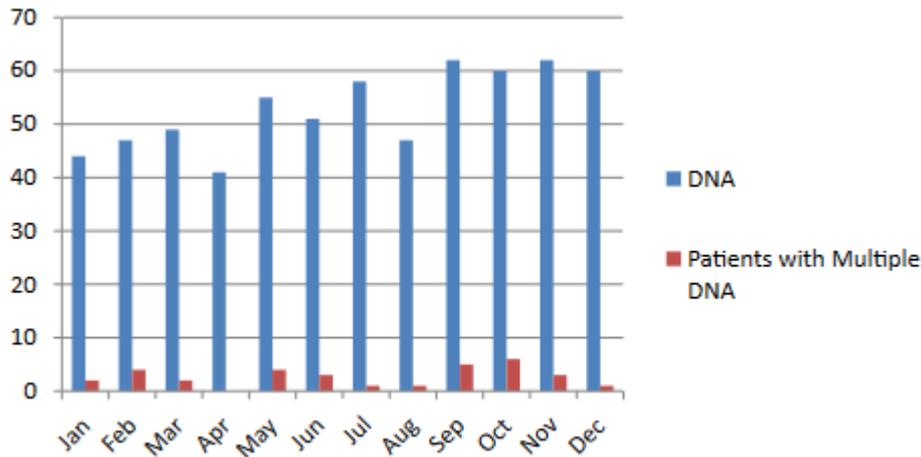
PROGRAMME FOR 2020

- | | |
|-----------------------|---|
| Monday 16th March | Steve Saunders and Rosie from the East Sussex Association for the Blind and partially sighted |
| Monday 20th April | Talk by Trevor Weeks MBE on the work of East Sussex Wildlife & Ambulance Service |
| Monday 18th May | Di Arndle - "Cooking for One" - |
| Monday 13th June | Pam Clatworthy - how to make birthday cards |
| Monday 20th July | Heather Goodsall – Hedgerow Magic |
| Monday 17th August | Visit to St Wilfrid's Hospice |
| Monday 21st September | Diana Gould - Pearly Kings & Queens |
| Monday 19th October | Older People's Day - a celebration of this day |
| Monday 16th November | Suzanna Jones - craft session |
| Monday 21st December | Christmas Singalong |

Contact Sheila Charlton on 01323 833673 for further details

HERSTMONCEUX INTEGRATIVE HEALTH CENTRE

NUMBER OF DID NOT ATTENDS EACH MONTH (DNAs) - 2019



Compared to other practices cross East Sussex, our Did Not Attend rate is quite good. However, the Practice is in the process of producing a DNA policy. Details will be in the next newsletter.

HAILSHAM FOODBANK – THANK YOU

Thank you for your donation of food to Hailsham Foodbank. We weigh all our donations for our records and I can inform you that your donation weighed 40.10 kg

Without the generous support of those within the community we would struggle to meet the needs of those who use the foodbank. Especially as we have seen a significant increase in use of the foodbank.

In the run up to Christmas we gave out almost 400 emergency food parcels - a food parcel provides 3 days worth of food - this was nearly double compared to last year.

We also gave out over 70 Christmas treat bags; these contained savouries, stuffing, sauce and biscuits/chocolates to provide a few extra treats.

When we ask those who use the foodbank what impact it has upon their lives, the response is very similar that without the foodbank being available they would not have known how they would have managed. It is not only those without work that are requiring the support, but also those who are on low incomes.

Without the support of people like yourselves we would not be able to help those in food poverty; so please could you pass on our grateful thanks to all who donated.

Kind regards

Tracey Bond, Community Liaison



Herstmonceux ACTIVE

Sport | Health | Community



MUSIC, EXERCISE, FUN!

A one-hour gentle exercise class with our qualified instructor Andrea. We welcome all ages and all abilities. This class is a great way to ease yourself back into exercise.

ALL SHAPES AND SIZES NO SURPRISES

Your first 4 sessions are free, No excuses! 😊

If you wish to continue the fun we suggest a £2.50 donation per session

WHEN? Friday evenings 6.30 – 7.30pm

WHERE? Herstmonceux Integrative Health Centre,
Hailsham Road, Herstmonceux BN27 4JX

If you can't make Fridays you can join us at the Hailsham Active sessions on Saturday mornings at 9am and/or Tuesday evenings at 6.30pm at the James West Community Centre, Brunel Drive, Hailsham.

Contact us: AndreaAttilane@gmail.com Steve@pro-eco.co.uk

Hypermobile Ehlers-Danlos Syndrome

The Rare Condition that isn't Actually Rare?

(Testimony from a Herstmonceux Patient)

I am a patient at the Herstmonceux Integrative Health Centre and I have a condition called hypermobile Ehlers-Danlos Syndrome (hEDS). The Ehlers-Danlos syndromes are heritable connective tissue disorders, meaning they run in families. They can affect the entire body from joints to skin to cells and everything in between.

Hypermobility/double-jointedness

Hypermobility is a key feature in both hEDS and HSD. However, just because someone is hypermobile it does not necessarily mean they have hEDS/HSD, as other key features and symptoms also have to be present. (1) Also the hypermobility does not have to be extreme and the extent of the hypermobility "is not related to extent of multi system symptoms" (1) and hypermobility will often actually reduce as a person ages.

Symptoms

Due to the fact hEDS can affect so many parts of the body, the number of symptoms and severity can be different from patient to patient and even at different points in life. Some people with hEDS are able to work full-time, others can be severely unwell and bed-bound. I have one of the more complex presentations. Just some of the symptoms and ones I personally manage on a daily basis are:

- wide-spread pain and injuries from dislocations/subluxions (basically joints slipping out of place far more easily than they would for most other people. The joints can often just as easily slip back into

place without medical intervention, but not always).

- hypermobility (being double jointed) is a key feature for this type of EDS and HSD because the ligaments and tendon aren't able to hold the joints in place as well as they should. Muscle pain and spasms go hand in hand with this as the muscles tighten in order to try and do the job of the ligaments/tendons and hold the joint in place.
- chronic fatigue
- dizziness and fainting
- non allergic anaphylactic reactions to all manner of things
- spinal cord or other neurological (brain) issues (for me this has resulted in becoming a fulltime wheelchair user)
- issues with bowel and bladder
- migraines
- fragile, stretchy skin which easily bruises
- gastrointestinal dysfunction (digestive issues)
- vision issues
- instability of the neck
- heart rate issues

Delays in diagnosis/misdiagnosis

There is commonly a long delay in diagnosis. The median time to diagnosis has been found to be 10 years-(1). This was true for me as I was misdiagnosed with ME for twelve years before I was referred to a physiotherapist who queried that diagnosis and suggested I displayed signs of hEDS, including hypermobility (double-jointedness). Other common misdiagnoses are fibromyalgia, IBS, medically unexplained symptoms, conversion disorder and CFS amongst others.

- Most of the 13 types of EDS are rare. The type I have however, is more common and along with its sister condition Hypermobile Spectrum Disorder (HSD- previously Joint Hypermobility Syndrome),

was found to be more common than previously thought (2). HSD can display the same or similar symptoms and severity.

- For information about other types of EDS (as well as hEDS and HSD) I recommend contacting EDS UK (3) and The Hypermobility Syndromes Association (4) or visiting their websites.

Diagnosis

Awareness of hEDS and HSD amongst the public is vital so that patients can be diagnosed promptly. It is thought that the earlier someone can be diagnosed the better their prognosis, as the GP toolkit states “there may be potential to reduce long term disability” (1). Unfortunately my diagnosis came quite late in life (late 30s) and my condition was very severe by the time I was diagnosed. I was told by the doctor who diagnosed me that my life could have been very different if I had had an earlier diagnosis and I agree.

EDS is a genetic condition, so you will usually see other family members with the same or similar symptoms. Even within families, the condition can present in different ways and with varying severities. There have been reports of some people with the condition with no family member affected, this is referred to as a spontaneous mutation and is possible particularly in the case of HSD.

Early diagnosis is imperative. Physiotherapy is a key treatment for managing EDS/HSD but the earlier this can be started in life the better. Ongoing specialized physio from an early age to strengthen in the right way, along with understanding how to look after your body to minimize injury and therefore pain, can help prevent deterioration as you age. However, it is important to note that the physiotherapist must be a specialist in EDS as standard physio can actually make things worse. Early diagnosis also means that if the patient begins to experience symptoms they can be managed early before they get too bad. Also many things often have to be done differently for people with EDS, for example in terms of surgery,

childbirth, medications and anesthesia. It's important that medical professionals are aware of the diagnosis so that any treatment does not make things worse for the patient.

I have heard of some patients (not at HMxIC!) who have been asked why they want a diagnosis of EDS/HSD as there is no cure and little in the way of treatment. However, although that may be true from the doctor's perspective (who may feel there is little they can do, except in the more severe and complex cases), it is the patient who does the lion's share of the work in managing their condition. Without clear information about what is happening in their bodies it is very difficult to them to make day to day decisions in terms of lifestyle, activities, choosing holistic treatments etc. I speak from experience when I say that when I had a diagnosis of ME I had no idea how to treat my body and made decisions which resulted in a severe deterioration of my health. On top of that, when new symptoms began or worsened, I was unable to understand what was happening and seek appropriate help. My doctors didn't have that information either, so I did not have the medical care and knowledge I needed to optimize my health in the way I do now.

Treatment

Since my diagnosis I have spent six years seeing specialists for the wide ranging issues and am finally getting treatment to help my condition as well as vital knowledge and understanding that I need to best manage it. Currently hEDS patients have to travel to London or even further afield to find specialists due to the complexity of the condition. Hopefully, now that awareness of EDS and HSD is increasing amongst both the public and the medical profession, there will soon be more local specialists. There is even a toolkit for GPs (1) so that some patients can be diagnosed and managed by them.

It is becoming increasingly apparent that there are a number of other conditions which go hand in hand with EDS that may also require treatment.

The major ones include Postural Tachycardia Syndrome (PoTS) which can cause many symptoms

- fast heart rate on standing and fainting/near fainting being the primary ones, Mast Cell Activation Syndrome (MCAS), an immune system dysfunction where the body has regular allergic reactions to things it is not officially allergic too, gastrointestinal dysfunction (stomach and bowel issues) and more unusual things like abnormalities in the brain and/or spinal cord, bladder issues and instability of the neck amongst others (1).

In conclusion, hEDS/HSD are more common than previously thought and often not diagnosed correctly or diagnosed late. The symptoms can affect the entire body and can vary in severity. It can run in families (particularly hEDS). Hypermobility (double-jointedness in a number of joints is a key feature but having hypermobility does not necessarily mean you have hEDS/HSD). Early diagnosis is important to help manage the condition but diagnosis at any age will help in terms of managing specific symptoms.

If you have EDS or HSD and you feel you might need more help please see your GP and refer them to the GP toolkit (1). Also please visit EDS UK (3) or The Hypermobility Syndromes Association (4), to find out more information. If reading this has reminded you of your own issues, or someone you know has issues, then please visit your GP and ask them to look at the GP tool kit (1).

1. The Royal College of GPs developed in partnership between the RCGP Clinical Innovation and Research Centre and Ehlers Danlos UK. "The Ehlers-Danlos Syndromes Toolkit" www.rcgp.org.uk/eds
2. Joanne C Demmler, Mark D Atkinson, Emma J Reinhold, Ernest Choy, Ronan A Lyons, Sinead T Brophy "Diagnosed prevalence of Ehlers-Danlos syndrome and hypermobility spectrum disorder in Wales, UK: a national electronic cohort study and case-control comparison"- (Nov 4 2019)
3. EDS UK www.ehlersdanlos.org
Tel: 0800 907 8518

4. The Hypermobility Syndromes Association- www.hypermobility.org
Tel: 0333 011 6388

ANSWER TO NHS QUESTION

TRUE

Whilst we talk about *the NHS*, in reality there are four versions of the NHS in the UK (although the health service is not called the NHS in Northern Ireland, rather the Health and Social Care Services).

When power was devolved to the four nations in the UK, responsibility for the NHS also was passed over to the government of each nation. Consequently, Scotland, Wales, England and Northern Ireland all have a version of the NHS which works independently and differently to other nations.

This accounts for differences between health care across the nations, the abolition of the prescription charge in Scotland, Wales and Northern Ireland being an example of this.

JOKES - Please email any suitable jokes you might have to Bea Simmons:
bea.simmons@nhs.net

FUTURE NEWSLETTER ARTICLES

Please email to:

Lynn Bowman (Editor) at plq.hmxihc@nhs.net

or lyndaprimrose27@talktalk.net

