



Sex and Intimate Relations

for people with
Symptomatic Hypermobility,
Ehlers-Danlos Syndromes
and
Hypermobility Spectrum
Disorders +

**"If you can't connect the issues, think
connective tissues"**

Commonly Used Terms

You might hear people with our condition(s) symptoms using a lot of acronyms and acronyms, because some of these classifications are still evolving. It's much easier to shorten them. We appreciate it can be confusing when this is all new to you so we've created a glossary of commonly used acronyms and acronyms below

- EDS - Ehlers-Danlos Syndromes
- hEDS - Hypermobility Ehlers-Danlos Syndromes
- cEDS - Classical Ehlers-Danlos Syndromes
- vEDS - Vascular Ehlers-Danlos Syndromes
- HSD - Hypermobility Spectrum Disorders
- SH - Symptomatic Hypermobility
- POTS - Postural Orthostatic Tachycardia Syndrome
- JH - Joint Hypermobility conditions
- MCAS - Mast Cell Activation Syndrome

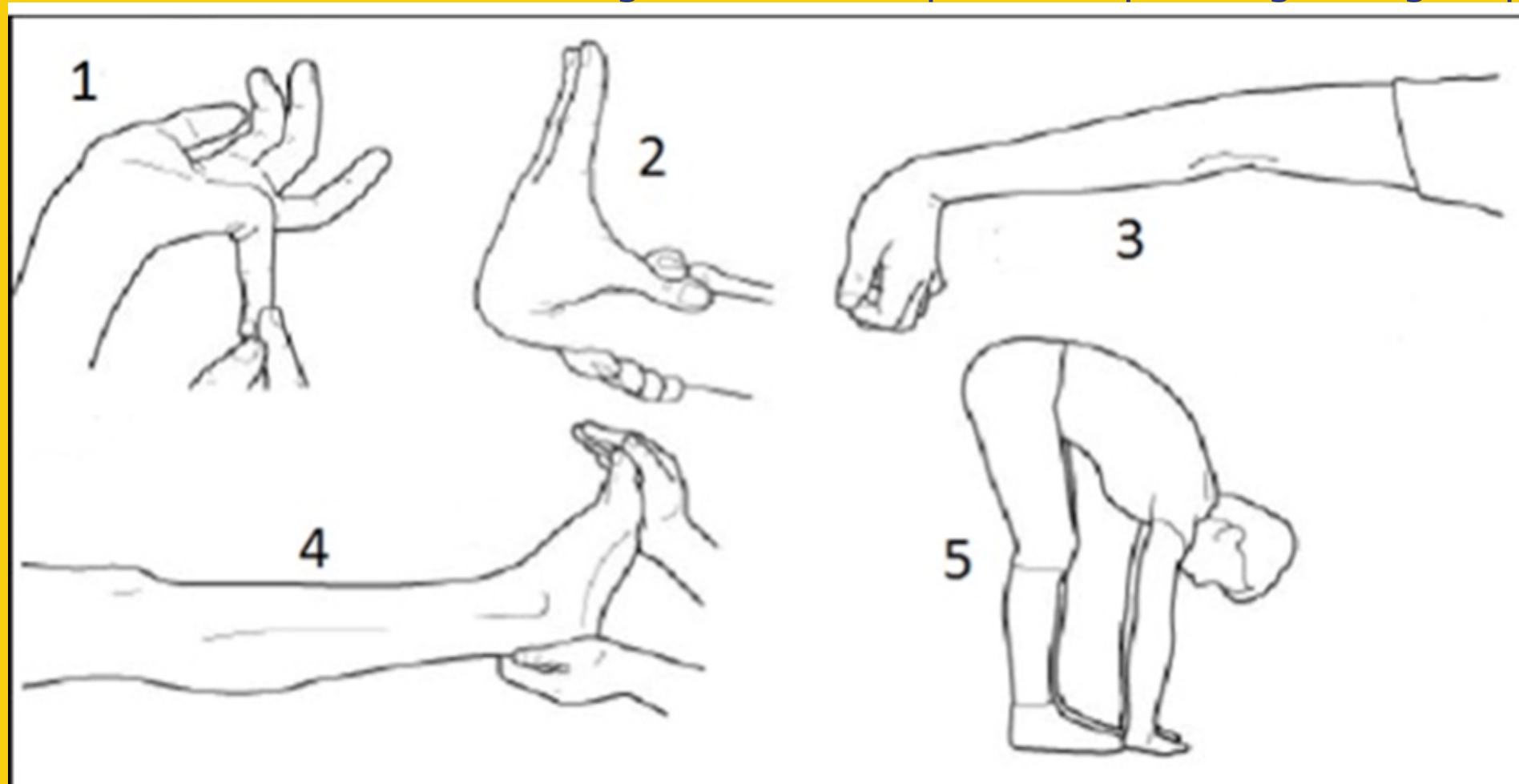
What is Symptomatic Hypermobility?

Symptomatic Hypermobility is a term coined for those who experience symptoms of the multi-systemic issues associated with conditions like Ehlers-Danlos Syndromes and Hypermobile Spectrum Disorder, but have no diagnosis.

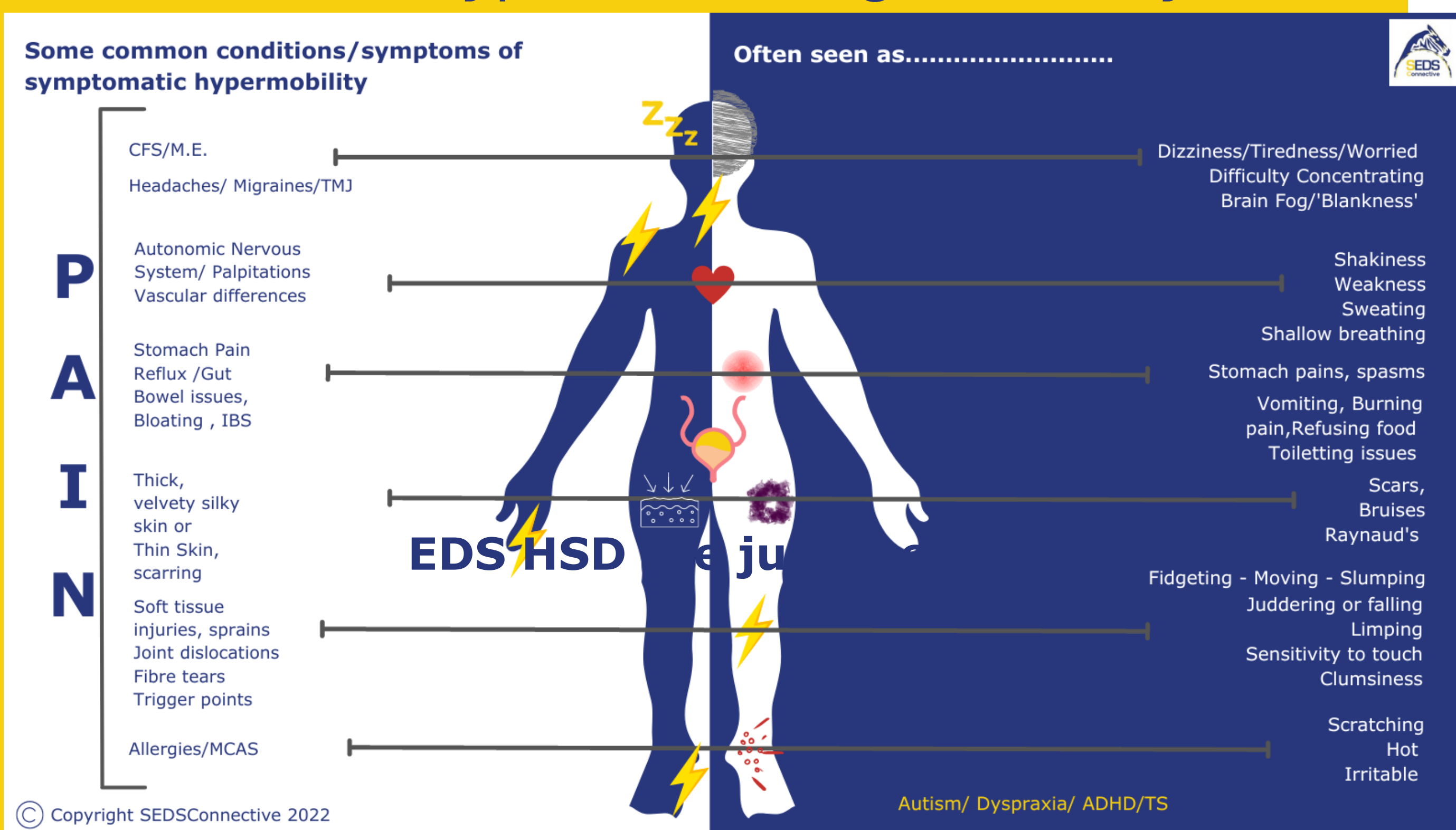
Diagnosis can be very hard to find, as very few doctors or medical practitioners are trained in these conditions and we are often diagnostically overshadowed, misdiagnosed or under diagnosed along with

Fibromyalgia, Chronic Fatigue Syndrome (CFS) / M.E.

Beighton Scale 9 points depending on age -physio-pedia.com



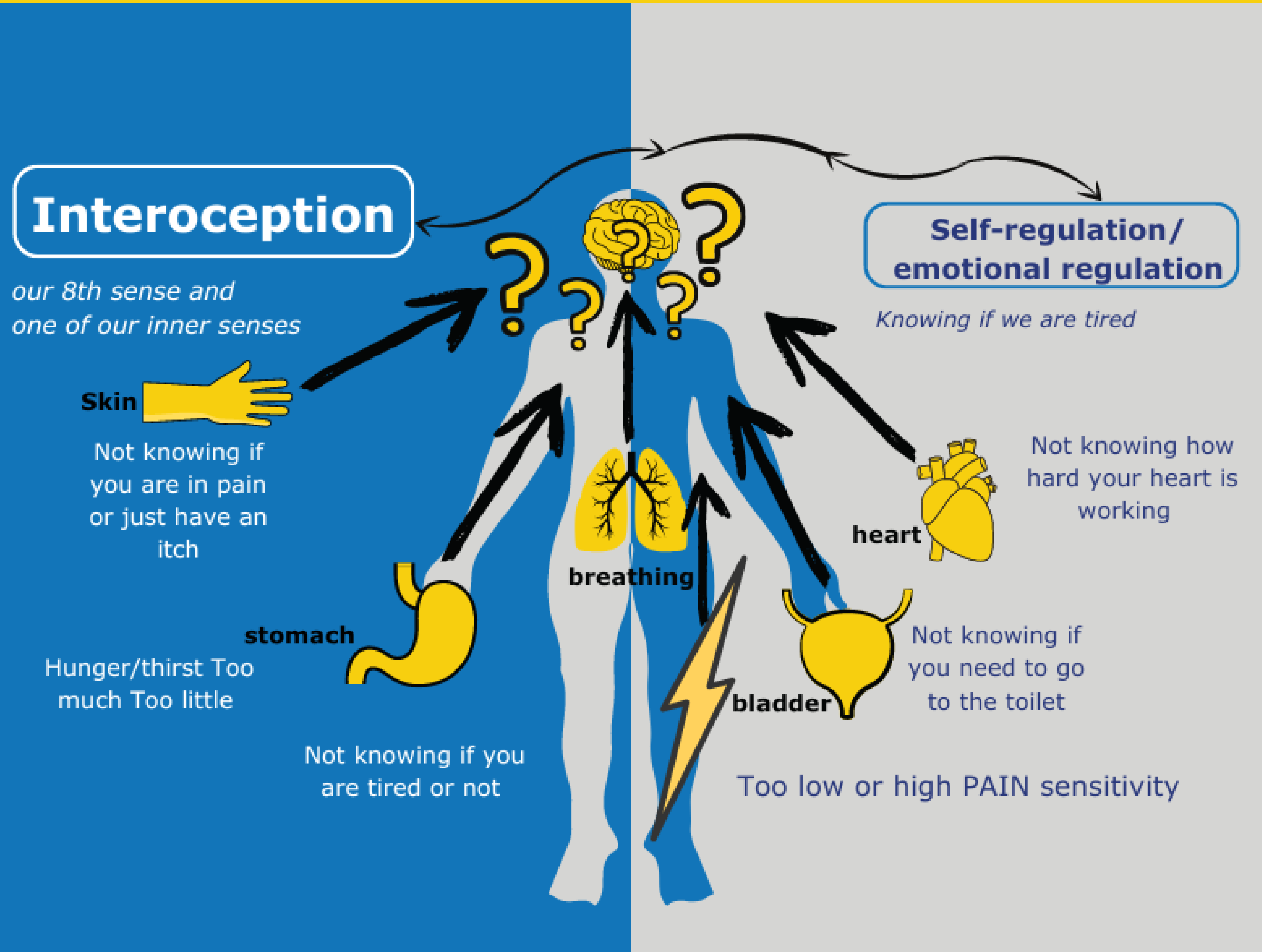
This makes those with the condition even more at risk of trauma, disbelief and being made to think it's all in their head. Diagnosis is usually undertaken by clinical assessment and family history including the Beighton Scale. Rarer types can be genetically tested.



EDS HSD SH are multisystemic heritable, connective tissue disorders which includes the protein, collagen. This can make our tissues very lax and weak sometimes. Connective tissues are found throughout the body in the vascular system, around organs, skin and more.

Interoception

Many people with SH, EDS and HSD, particularly those with neurodivergence have poor interoceptive awareness. This means that this group may struggle with reading hunger and thirst signals, not knowing whether they are tired or not, if they need to use the toilet (until it's nearly too late), or even whether they are in pain.



Ehlers-Danlos Syndromes

There are 13 named types of EDS and most can be genetically tested except the most common one, hEDS. They are a group of genetic connective-tissue disorders.

Symptoms can include soft & velvety skin, pain, extreme fatigue, Autism, ADHD, Dyspraxia, stomach issues and allergies.

The most common type of EDS (90%) is hEDS. This cannot be genetically tested for, and is diagnosed on clinical assessment only. HSD is very closely related to hEDS and should be treated and supported in the same way.

Connective Tissues

Connective tissue is found throughout the body and one of the main components - collagen - is more lax and weak than that of the general population. This means it is not as strong and it bends and stretches easily. It does not necessarily mean hyperflexible - in fact the opposite. It can result in stiff muscles, and muscle spasms.

How can Symptomatic Hypermobility affect my sex life?

If you or your partner has a form of symptomatic Hypermobility it is important to realise that this can affect your sex life. But with a few small adjustments, most people with symptomatic hypermobility can still have a fun and fulfilling sex life, regardless of gender, sexual orientation or relationship status.

The most common complaints experienced by people with SH, EDS and HSD are around:

Fatigue

Chronic Pain

Joint Dislocation or Subluxation

UTIs and Interstitial Cystitis

Bruising

Vaginal Tearing

Sensory Issues

Anxiety



First Things First

If you're about to have sex for the first time with a new partner (or partners) it is important to have a chat in advance about your condition and to let them know what might happen and how they can prevent any injury.

So, if (for example) your hip subluxates or dislocates when gyrating too roughly, then avoid positions which put you at risk for that. They might have been fun positions (sorry!) but quite frankly it isn't worth the risk of the damage.

You don't want to over-egg things and scare off a new partner, but it is important that they know that if they're not careful, hips can come popping out, jaws can dislocate, skin can bruise easily and vaginal or anal skin can tear.

Don't forget about keeping longer-term partners up to date with what's happening with your body. Your symptoms may have changed or worsened since you first started having sex with them and they won't know unless you tell them and let them know how it might impact your sex life.

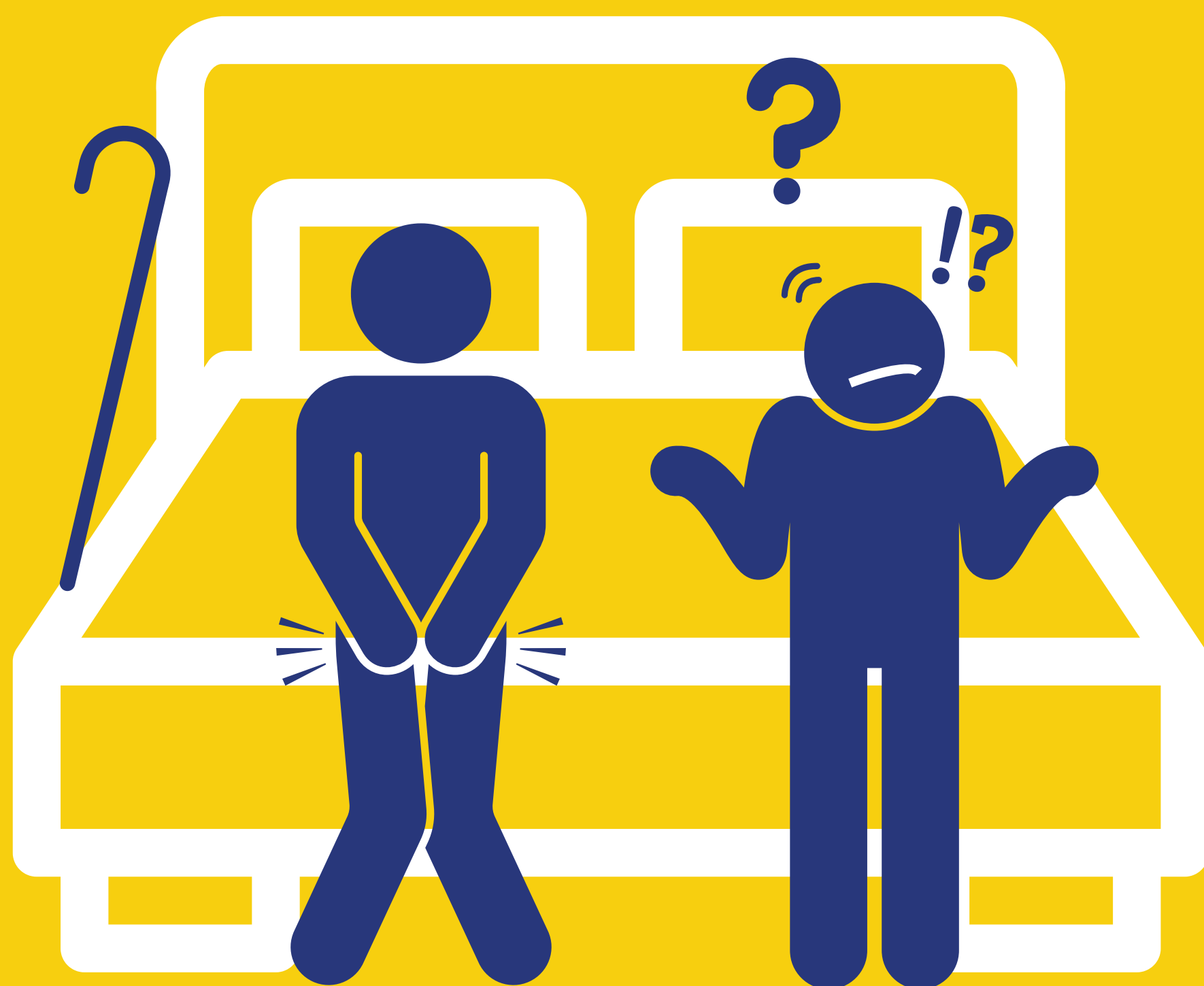
Harsh Reality!

As a person with symptomatic hypermobility, you are most likely going to have some kind of sex-related injury during your lifetime because of your condition.



Your natural hypermobility might have made you extra bendy in the past with an ability to do fantastic gymnastic things in bed - but now that you have SH, it is time to adjust how you do things to avoid injury.

If a sex-related injury does occur, it is important to let your partner know that it isn't their fault (assuming that it hasn't happened due to malicious intent) and to discuss how you can prevent such injuries going forward.



You both need to be able to move past the trauma of an accidental sex-related injury and both parties should be able to remain confident enough to initiate sex with each other. Who knows...it may even be a funny story in years to come!

As a hypermobile person, talking about your physical requirements isn't an indulgence - it's a necessity.

Fatigue

Fatigue is big issue for pretty much every person with SH, EDS or HSD.

There are usually a number of drivers behind the fatigue we experience, particularly inflammation. Navigating the world as a neurodivergent person (which most of us are) can be mentally fatiguing and having chronic pain is physically fatiguing.

Many of us also have issues around sleep and melatonin production which can also make us tired.



A number of commonly prescribed medications which help relieve pain also contribute to grogginess and fatigue, making day to day activities extremely difficult, if not impossible.

This also can apply to sex, because it's really hard to get in the mood when all you really want to do is lie down, zone out and sleep all day (and night).



Tearing and Bruising

The delicate skin which comes with all types of Ehlers-Danlos Syndromes and are present as well as HSD and SH, means that there is a higher risk of bruising and damage.

Vaginal tearing is something many people with these conditions experience.

"...any treatment [for vaginal tearing] is...hard fought for...as there's an expectation that as a wheelchair using, mostly bed-bound person, that I don't have a sex life..."

Anal tearing can also be an issue for particularly delicate skin. In either case, find a lubricant which you aren't allergic to as this will help reduce damage.

Skin elsewhere on the body can also be easily bruised, so be careful about rough grabbing, biting or sucking which can leave skin black and blue and a bit tender for days afterwards.

Dysautonomia

Dysautonomia affects the Autonomic Nervous System which means that blood pressure and body temperature regulation, amongst other things, are impacted.

Hot weather can make POTS worse, so you might find sex in a cooler room a bit more comfortable. If you're 'in the mood' but know that your symptoms are likely to be triggered, maybe on these occasions, take a more passive role with your partner.

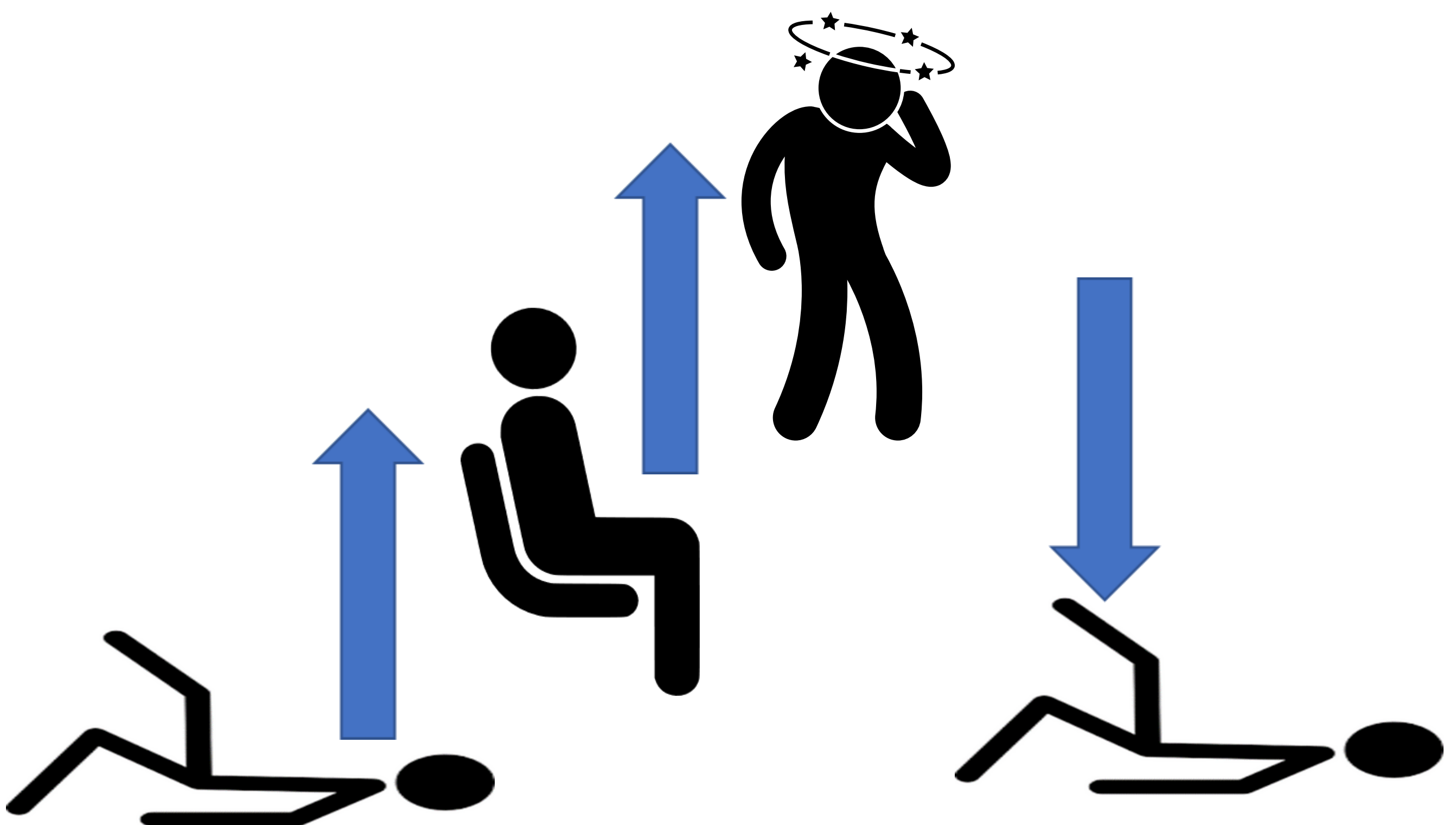


Dysautonomia

People with PoTS often feel that their symptoms increase after eating - particularly after large meals - as the blood moves to the digestive system. So avoid having sex soon after eating.

Allergic to Gravity

POTS and Orthostatic Intolerance can also cause dizziness due to lack of oxygen to the brain, so you may find a lying down position less symptom-triggering and when changing positions, be mindful of moving too quickly. No one wants to faint mid-orgasm!



Allergies

Many people with SH have allergies, ranging from hay fever to multi-systemic Mast Cell Activation Syndrome (MCAS).

People with allergies will want to be mindful of condoms if they have a latex allergy and the ingredients in lubricants and spermicides which can often exacerbate allergies and allergic-like reactions in people with sensitivities.

There are brands of organic and natural lubricants which some people will find they don't react to.

Some people even have allergic reactions to semen or the fragrance on their partner's skin.

Allergies like hayfever can also just leave you feeling like you don't fancy sex for long periods of time while you're suffering.



Remember that allergic reactions
can be directly IgE mediated,
such as a
reaction to licking chocolate off
your partner's skin or an
allergy to a lubricant

OR



Allergies can be indirect IgE mediated,
where something in the body/environment
triggers a reaction, such as stress
a room perfume scent or the detergent
used on the sheets

Medications can also affect allergy response
and libido

Pleasure or pain?

Be careful with your positions as they may cause pain or put pressure on weak joints. Discuss your higher risk joints or other tender areas with your partner in advance, and be sure to have a pain signal to let them know if you are uncomfortable. Moans & groans can equal pleasure as well as pain, so perhaps a 'tap' or clap instead.



Many people with badly affected joints will use a variety of supportive specialist pillows and cushions during sex, to ensure they're in a good and comfortable position.

If you have TMJD (Jaw) issues, be careful not to lock or overextend your jaw when having oral sex. Your jaw can dislocate quite easily in these positions.

If you have any form of SH, then rough sex may not be the best choice for your body. If you're into S&M then it is probably safer for you if you take on the dom/sadist role rather than the sub/masochist role. Bonus - the leather catsuit might reduce PoTS symptoms, like compression-ware!

Bladder Issues

For those with bladder issues, it is important to be aware of sexual intercourse that could cause UTIs.

Although women and people with vaginas are more likely to suffer, men and people with penises can also experience UTI infections. Be careful about using lubricants as they can also increase the risk of bladder infections, especially if you have MCAS or are allergy-prone. Contraceptives such as the diaphragm and/or spermicides may also contribute to exacerbating allergic symptoms.

Make sure you clean before and after sex, and be sure to urinate as soon as possible after intercourse.

If your mobility allows, have a bit of fun and try having sex in the shower for a change...this will keep things clean and clear of bacteria! Don't try this if you feel there's a risk you could slip or fall over, or faint from the hot water.

Pelvic Floor

Weak pelvic floor muscles can often cause issues with orgasms but you can use tools like:

- Pelvic floor trainers— this ensures you are doing pelvic floor exercises properly, engaging muscles at the right time and some of them even make the exercises more interesting by allowing you to use them to play angry birds!

- Perifit Smart Kegel Exerciser

- Elvie Pelvic Floor Trainer

- Pelvic floor muscle toners (both internal and external ones)

- Kegel8 Ultra 20 Electronic Pelvic Floor Toner

- vSculpt Pelvic Floor Toning and Vaginal
Innovo Non Invasive



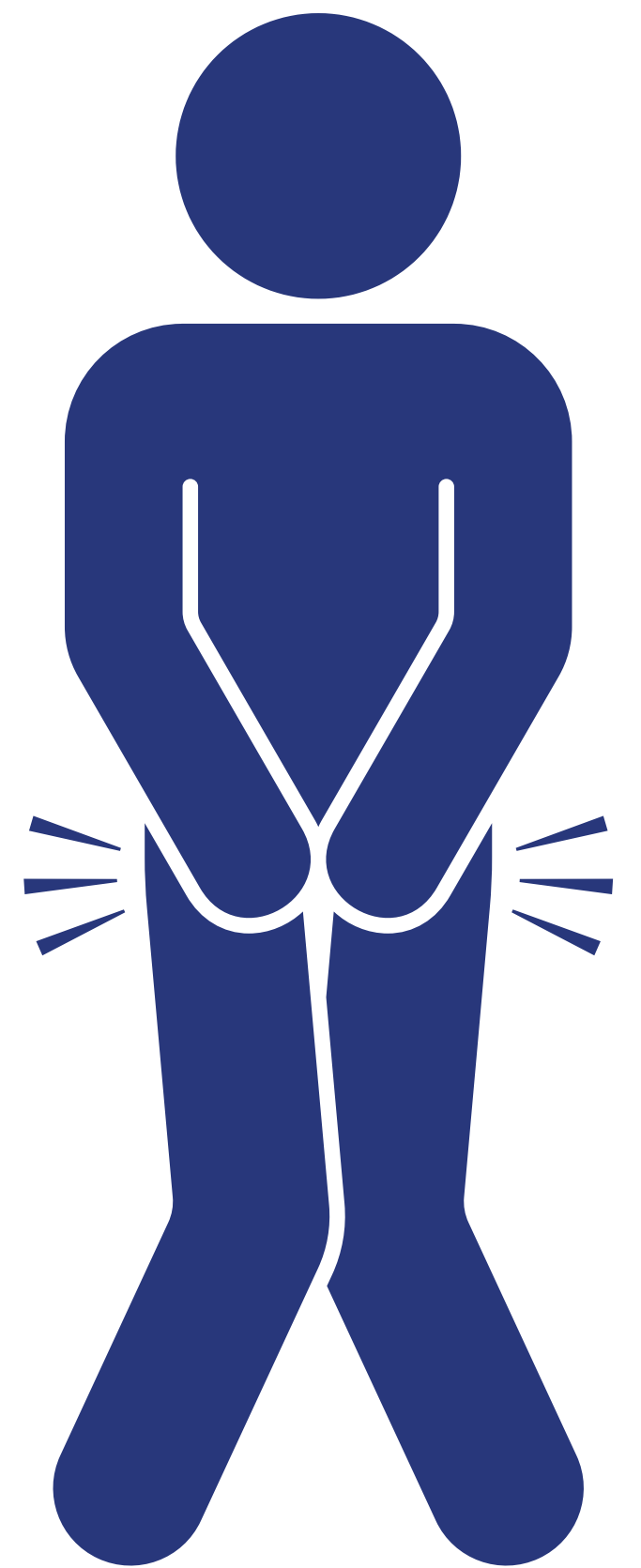
Interstitial Cystitis

Interstitial Cystitis (IC) differs from Urinary Tract Infections in that it is not caused by a bacteria, but rather is due to a chronic condition which causes bladder pressure and severe bladder and pelvic pain.

Having IC can potentially cause pain both during and after intercourse, and sometimes even during foreplay, although many people find that they're pain-free during sex and it is only afterwards that symptoms become exacerbated.

Although IC is not driven by bacterial infection, you are still at risk for UTI and you may find, particularly if you have a vagina, that if you clean yourself both before and after sex, this might help reduce symptom flare up bladder pain will be further exacerbated with any infections.

Some people find that using a lubricant which they can tolerate helps to reduce any pain from the friction inflammation.



Sensory Issues

People with sensory issues might find that touch is more heightened or can feel uncomfortable. Some people prefer a firmer touch, whilst others prefer a soft touch.

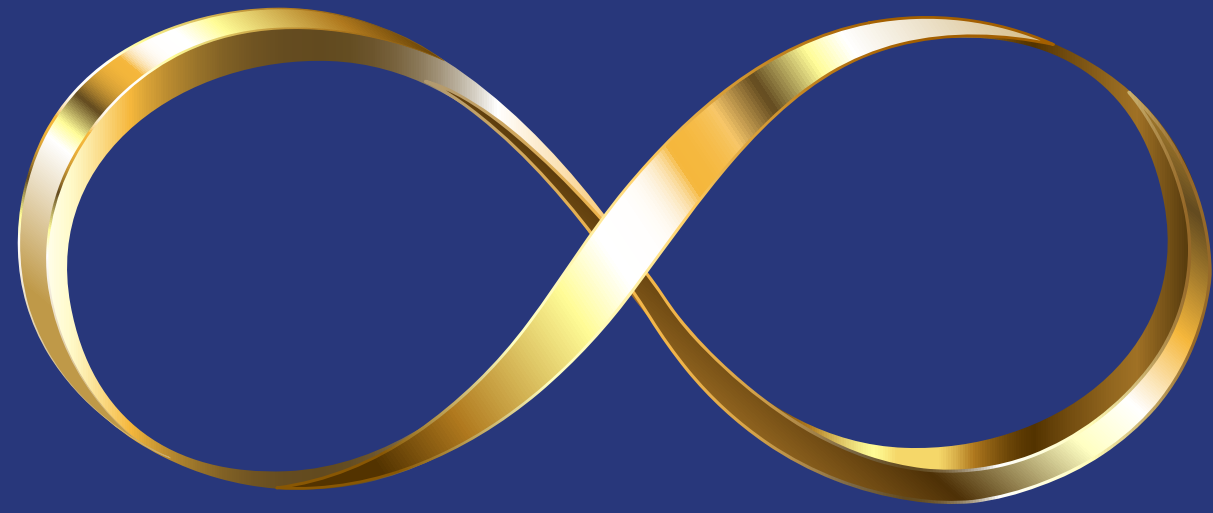


To others...either of these can be spooky and creepy = so be sure to talk to your partner about your likes and dislikes.

If you're playing host to a person with sensory issues, use soft, natural bed linens and adjust the lighting and any background music or sounds and any smells to suit their preferences so they can fully enjoy the experience too!

Do make the effort to ask about their preferences as they might be too polite to volunteer what's bugging them, but it will distract them during sex and be a bit of a turn off for them.

Neurodivergence & Intimacy



Recent research has confirmed what many of us have always suspected - that there are strong links between neurodivergence and hypermobility. In particular Autism, ADHD, Tourette's Syndrome and Dyspraxia.

Many neurodivergent adults may remain undiagnosed, by circumstance or choice, but being aware of your particular needs can be helpful for enhancing a positive sexual experience with your partner (and indeed for overall harmony in intimate relationships).

Below are some things to think about in relation to different neurodivergent conditions, but these will not apply to everyone, so make sure you have a frank discussion with your partner about your individual needs and preferences.

Autism

Autistic people may find that they prefer a firmer or lighter touch during sex and can get "creeped out" by the wrong touch pressure. Be sure to make sure other factors, such as bed linens texture, lighting levels and/or smells in the room are all okay, as otherwise the autistic person can get distracted or even potentially distressed and that is definitely a mood killer!

ADHD

People with ADHD can get easily distracted during sex, and their minds can quickly wander elsewhere to think about other things, so keep things fun and interesting!

Tourettes

People with Tourette's may find that their tics can increase or decrease during sex, but often if they're having really good sex and they're focused on what they're doing, the tics might be fairly infrequent. On the other hand, if they're not particularly enjoying sex, their tics may substantially increase. If you have any physical tics which might harm or surprise your partner during sex, be sure to discuss these in advance.

Dyspraxia

A history of clumsiness and poor motor control may impact a dyspraxic person's confidence, so let your dyspraxic partner know they're doing things right!

DIY Sex - Do It (for) Yourself!

By choice or circumstance you might not have someone else in your bed when the mood for sex comes upon you. The best part about masturbation is that when you're having sex with yourself, you know you'll do it right and there's less chance of getting hurt...who knows your body better than you do? Have fun and don't be afraid to try some toys to reduce the strain on delicate wrist joints!



Best of all, masturbation is linked to a number of health benefits and when you orgasm, your brain releases serotonin, oxytocin and a huge surge of dopamine!

Specialist Supportive Pillows

There are a variety of specialist supportive pillows such as those shown below which are designed for pregnancy, sports recovery, arthritis and various disabilities. They can be very helpful for people with SH to help support joints and reduce risk of pain, injury and bruising while having sex.



Specialist pillows are available from a variety of shops. These ones we sourced from : <https://rb.gy/civetn>, <https://rb.gy/ydywas>, <https://rb.gy/qk7axb>, <https://rb.gy/khb4x7>, <https://rb.gy/7hxfkv>, <https://rb.gy/2x5jtr>

About Us

SEDSConnective is a voluntary, neurodivergent symptomatic hypermobility charity actively supporting Ehlers-Danlos Syndromes (EDS) and Hypermobility Spectrum Disorder (HSD) or symptomatic hypermobility. Many of our members have one or more forms of neurodivergence (Autism, ADHD, Tourette's Syndrome and Dyspraxia). We know, thanks to the research led by our Patron, Dr J Eccles and team, that these conditions co-occur. We are the only charity to specialise in supporting both SH (whether diagnosed or undiagnosed) and neurodivergence.

We were founded in 2018 in Sussex, UK as a small, grassroots community group, but have grown exponentially. We now actively support in education resources, in health, social care, transport accessibility and business. We are a multi-award winning charity and most recently, our Founder and current Chair, Jane Green, was awarded an MBE in the first King's New Year Honours List.

We are run entirely by volunteers, the majority of whom all have a form of SH and neurodivergence.

About Us



We actively support members with
symptomatic hypermobility / EDS/HSD/JH,
Neurodivergent

www.SEDSConnective.org
general@sedsconnective.org

Find us on



Pain hypermobility Ehlers-Danlos or Hypermobility Spectrum Disorder or neurodivergent ? Find out more ...

- Skin: Soft & Velvety | Thin & Easily Bruised
- Pain: Acute | Persistent, Fibromyalgia, Dislocations, Sprains, Hypermobility, Double Jointed, Fat cell issues
- Extreme Fatigue: M.E | CFS
- Autistic | ADHD | Dyspraxia (ND)
- Clumsiness
- Dizziness | Fainting | Racing Heart
- Bowel | Bladder Issues
- Stomach pains, Vomiting, Reflux
- Headaches | Migraines | Brain Fog
- Anxiety
- Allergies/MCAS

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Join us**



You can learn more about the work of SEDSConnective by following us on social media and on our website.



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