



# Sex and Intimate Relations

Neurodivergence (ADHD  
Autism Dyspraxia TS +)  
Symptomatic Hypermobility,  
Ehlers-Danlos Syndromes  
or  
Hypermobility Spectrum  
Disorders and associated  
conditions

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

# Commonly Used Terms ⓘ

You might hear people with our condition(s) and symptoms using a lot of acronyms and different terminology. It might seem like alphabet soup. We appreciate it can be confusing when this is all new to you so we've created a glossary of commonly used acronyms below



[www.sedsconnective.org](http://www.sedsconnective.org)

## Alphabet Soup



# Commonly Used Terms

- EDS - Ehlers-Danlos Syndromes
- hEDS - Hypermobile Ehlers-Danlos Syndrome
- cEDS - Classical Ehlers-Danlos Syndrome
- vEDS - Vascular Ehlers-Danlos Syndrome
- HSD - Hypermobility Spectrum Disorders
- JH - Joint Hypermobility
- SH - Symptomatic Hypermobility
- POTS/OI - Postural Orthostatic Tachycardia Syndrome / Orthostatic Intolerance
- pGJH/pgHSD - Paediatric Generalised Joint Hypermobility/ pgHSD
- MCAS - Mast Cell Activation Syndrome
- M.E. - Myalgic Encephalomyelitis
- ND - Neurodivergence / neurodivergent
- CFS - Chronic Fatigue syndrome
- ND - Neurodivergence
- UTI - Urinary Tract Infection
- IC - Interstitial Cystitis
- IBS - Irritable Bowel Syndrome
- Dysautonomia - Dysfunction of the Autonomic Nervous System

# What is Symptomatic Hypermobility?

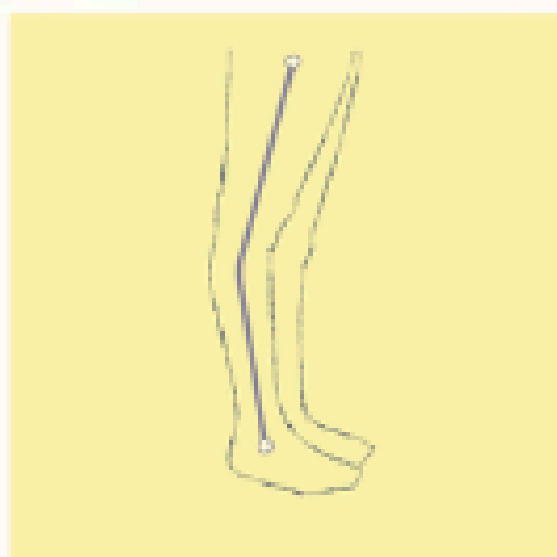
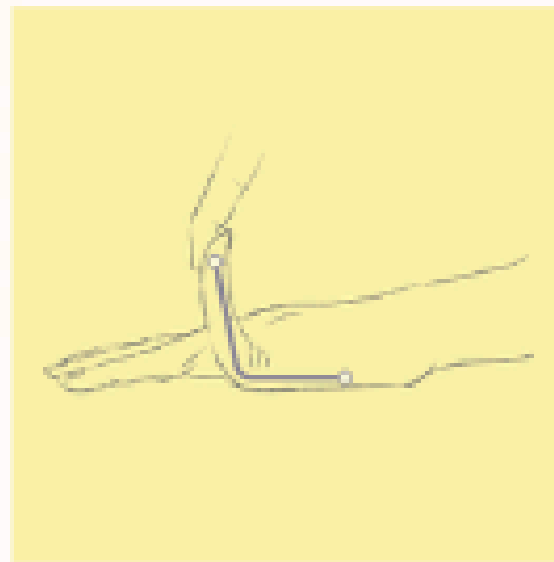
Symptomatic Hypermobility is a term coined for those who experience symptoms of the multi-systemic issues like EDS or HSD or other conditions but have no formal diagnosis.

Very few health practitioners are trained in these conditions. We are often diagnostically overshadowed, misdiagnosed or under diagnosed. Sometimes older diagnoses are used but not recognised. Children are rarely diagnosed.

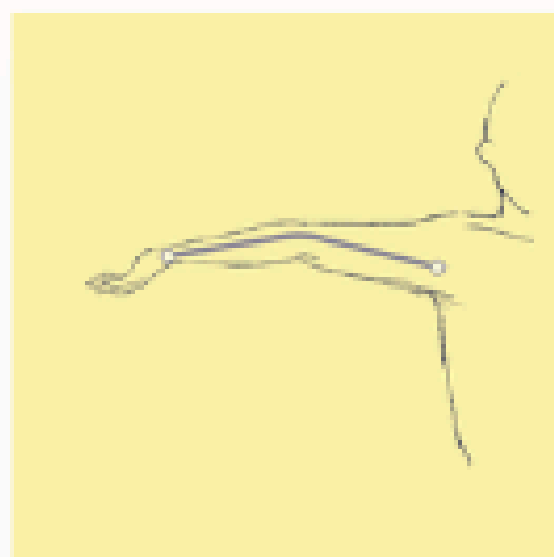
## Beighton Scale



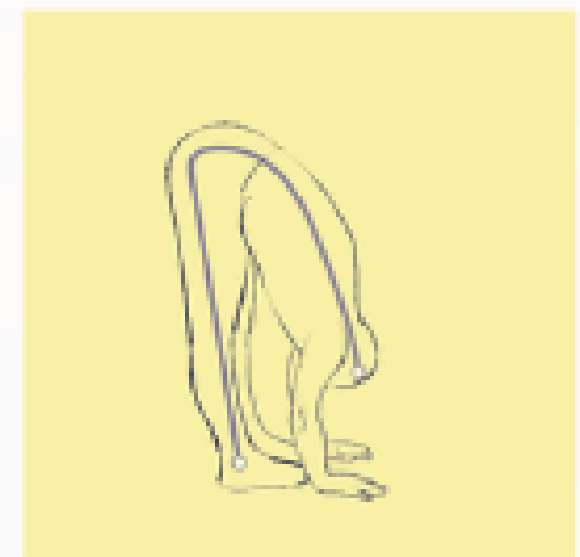
**1**  
point  
(per hand)



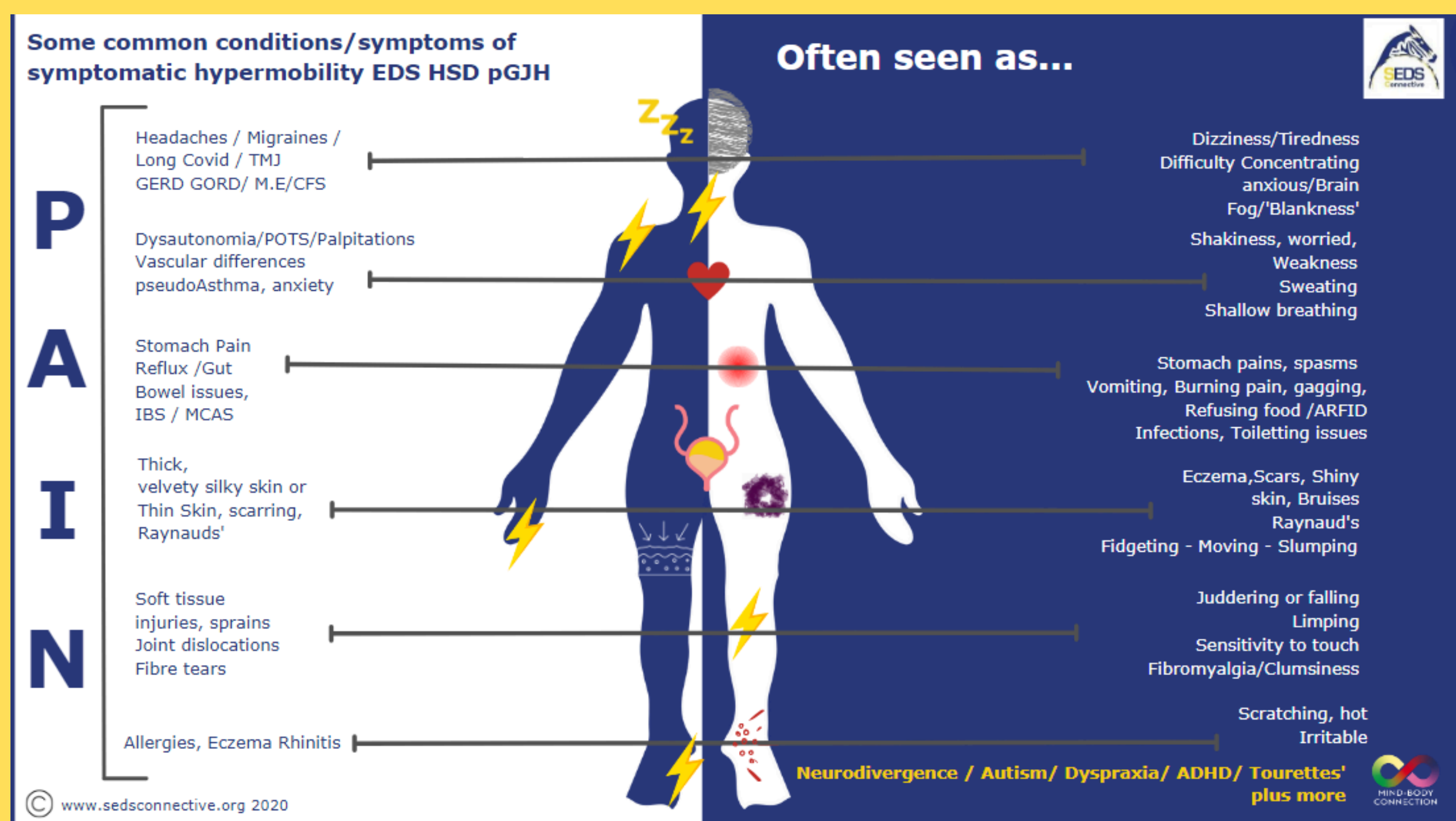
**1**  
point  
(per limb)



**1**  
point



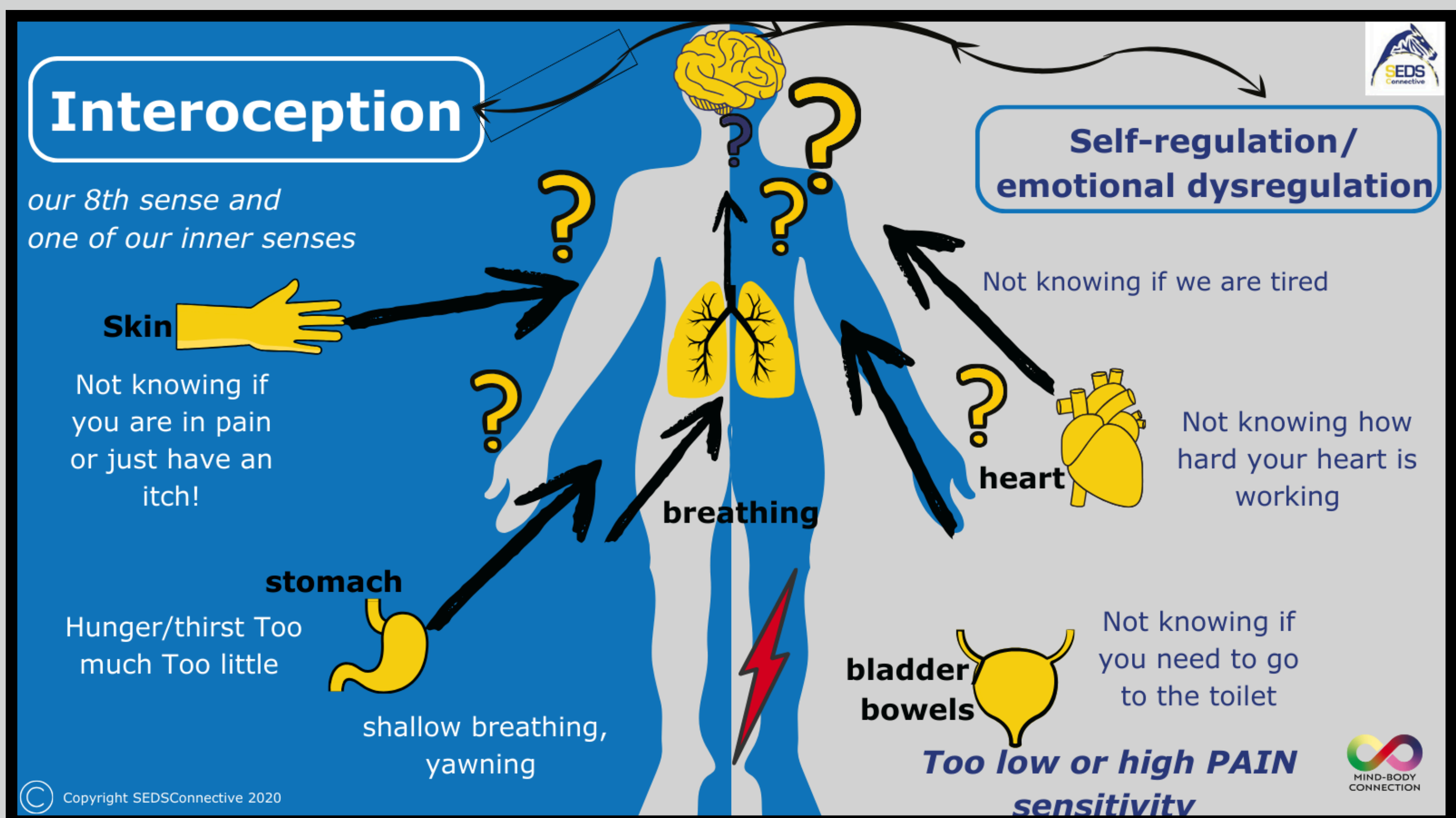
This makes those with the symptoms and conditions even more at risk of trauma, disbelief and are often told it's 'all in their head'. Diagnosis is usually undertaken by clinical assessment and family history including the Beighton Scale. Rarer types of EDS can be diagnosed with genetic testing.



EDS and HSD are multisystemic, heritable, connective tissue disorders involving the protein called 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. Nearly every part of the body can be affected symptomatically.

# Interoception

Many people with hypermobility particularly those with neurodivergence, have poor interoceptive awareness. This is one of our inner senses. It challenges one's sense of 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 12 can be genetically tested. They are a group of heritable connective-tissue disorders.

Symptoms include bruised, thin skin OR soft & thick velvety skin, pain, brain fog, 'anxiety' heart palpitations, extreme fatigue, gastrointestinal tract issues and allergies, as well as neurodivergences such as Autism, ADHD, Dyspraxia, Tourettes and maybe more.

The most common type of EDS (c.90%) is hEDS. It's diagnosed on clinical assessment and family history. 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, more bendy and stretches easily. It does not necessarily mean hyperflexible - in fact sometimes it appears to be the opposite. It can result in stiff muscles, and muscle spasms at the most inconvenient times!

# How can symptomatic Hypermobility affect my sex life?

If you or your partner(s) have a form of SH 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 hypermobility are around:

Fatigue

Chronic Pain

Joint Dislocation or Subluxation

UTIs and Interstitial Cystitis

Bruising

IBS

Vaginal Tearing

Sensory Issues

Anxiety

Heart BP





# 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, 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. 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(s), 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 partner(s) 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.

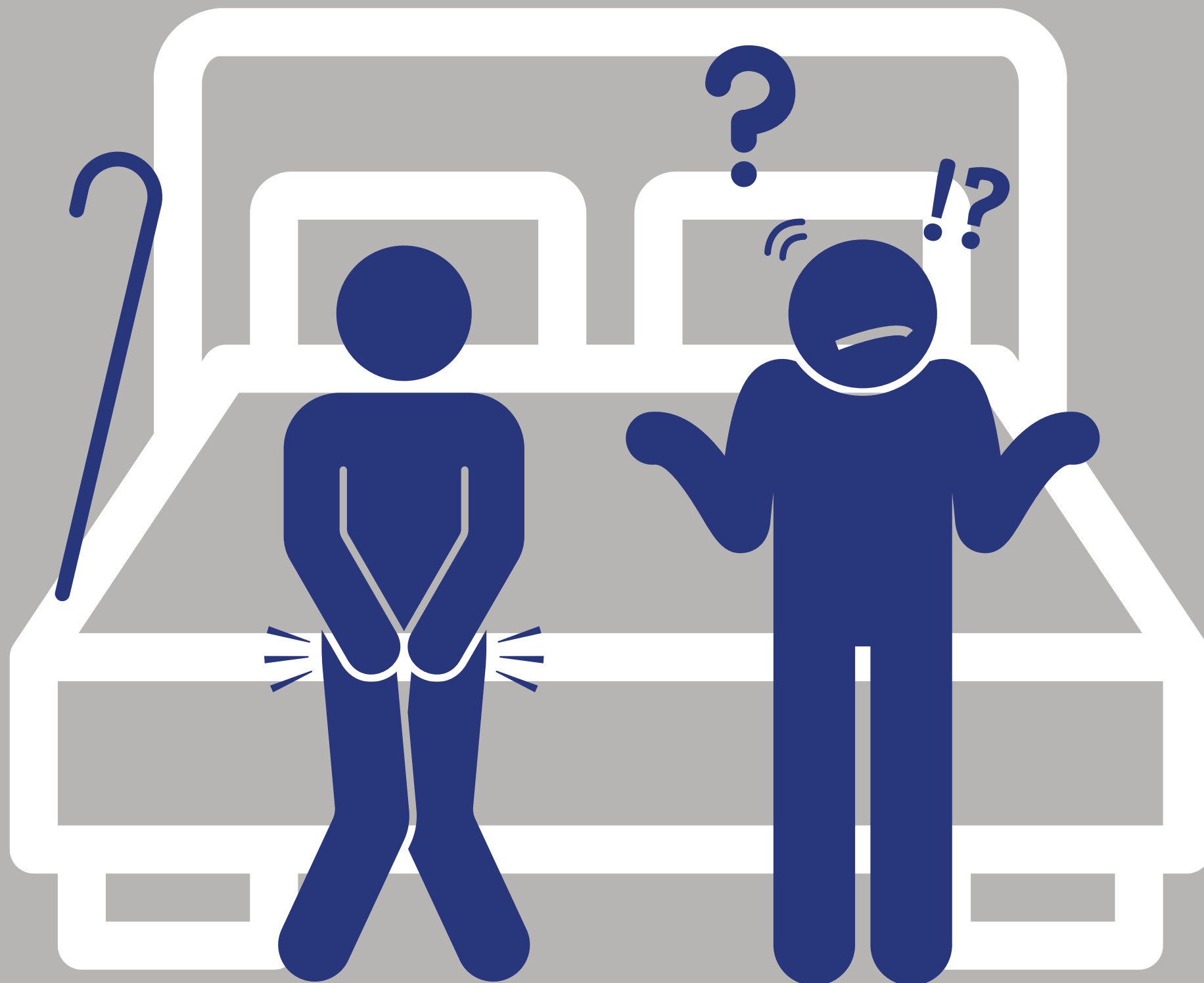
# Harsh Reality!

As a person with SH, you might at some point 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(s) 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 / extreme tiredness is a big issue for pretty much every person with SH and associated conditions like dysautonomia (issues with our autonomic nervous system) and those experiencing non-restorative sleep.

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 tiring.

Many of us also have issues around sleep, dysautonomia, sleep apnea 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).



## Skin / Tearing and Bruising

People with SH can have thin, velvety skin that is very nice to touch and which may or may not bruise easily. Others might have very delicate skin with a higher risk of bruising and damage.

Vaginal tearing is something 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(s).



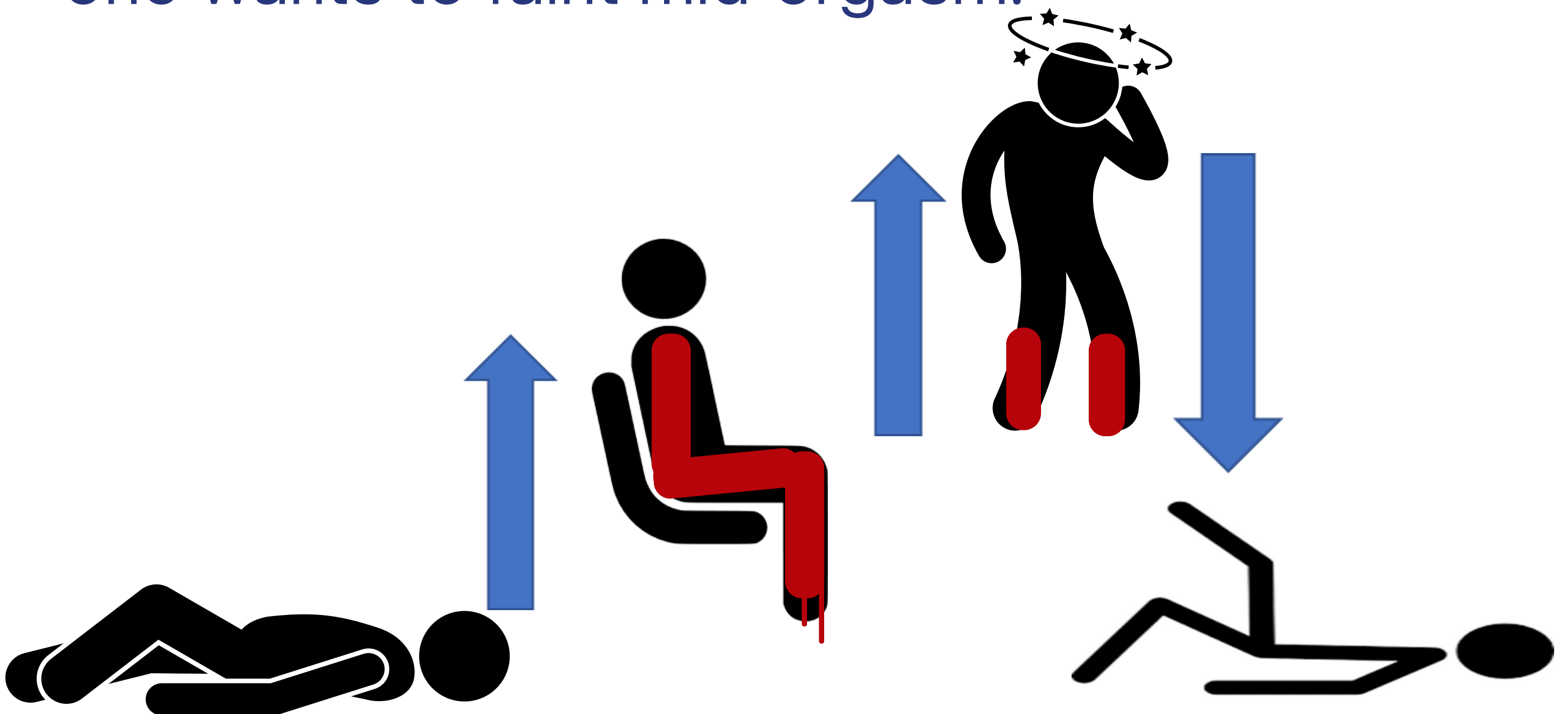
# Dysautonomia

Dysautonomia is a dysfunction of the autonomic nervous system.

POTS is subtype of 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 hayfever, rhinitis to multi-systemic Mast Cell Activation Syndrome (MCAS) or even full blown anaphylaxis.

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

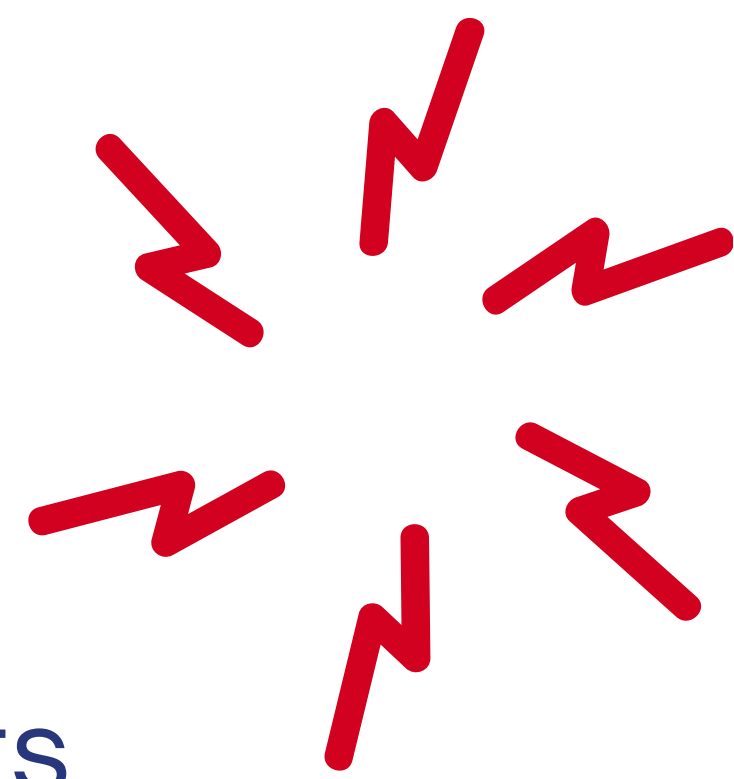


Allergies can be non IgE-mediated, where something in the body/environment triggers a reaction, such as stress, a room perfume scent or the detergent used on the sheets causing rashes or wheals

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(s) in advance. Be sure to have a pain signal to let them know if you are uncomfortable. Moans and 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, but those wishing to engage in BDSM, do so with lots of communication, education, and harm reduction strategies which take into account the individual's access needs. Bonus - the leather catsuit might reduce POTS symptoms, similar to compression-ware!

## Bladder Issues

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

Although people with vaginas are more likely to suffer, people with penises can also experience UTI infections. People with vaginas are more likely to suffer with UTI's due to the shorter length of the urethra and closer proximity to the anus, though 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. 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.

## Bladder Issues

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.

Also, hormonal change can be a big trigger for UTI's and IC, so puberty, menopause, Hormone Replacement Therapy, pregnancy, abortion, and transition-related hormone therapy are all strong indicators of UTI's.

# Pelvic Floor

Weak pelvic floor muscles can often cause issues with orgasms but you can use tools like pelvic floor trainers — these ensure 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 games similar to angry birds!

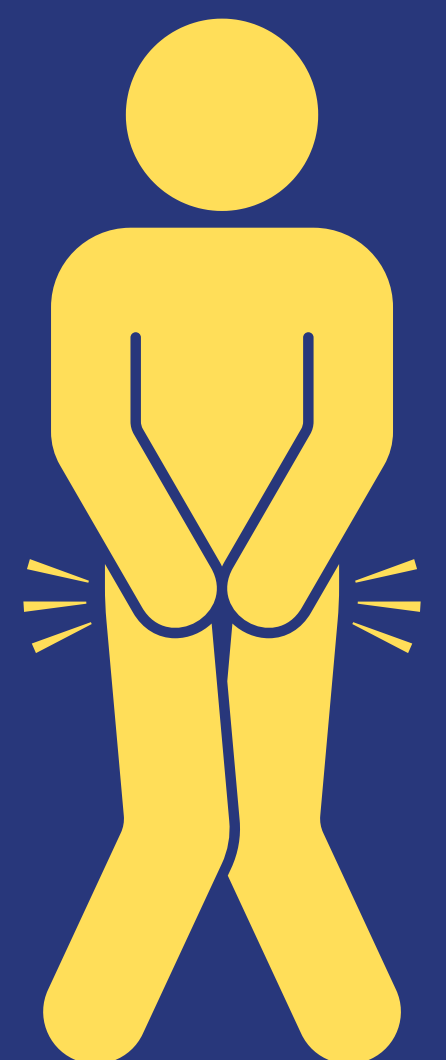
-Perifit Smart Kegel Exerciser

-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

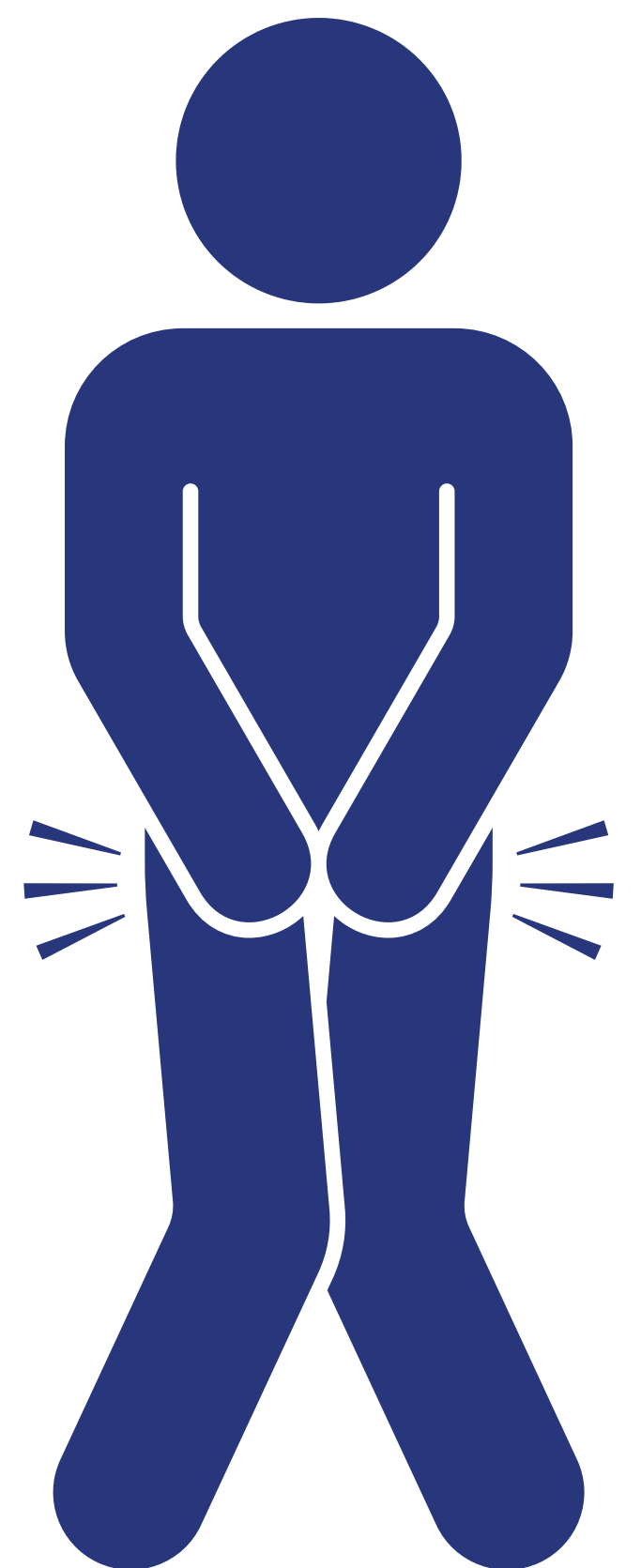
Interstitial Cystitis (IC) differs from Urinary Tract Infections in that it is not caused by a bacteria, but rather is due to a chronic condition which causes bladder pressure and severe bladder and pelvic pain.

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 bladder pain will be further exacerbated with any infections.

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.

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



## Sensory Issues

People with sensory issues might find that touch sensitivity is heightened or they can feel uncomfortable. Some people prefer a firmer touch, whilst others prefer a soft touch. Also misophonia can be an issue, with sex noises triggering sensory issues.



To others...these sensations can be “spooky” and “creepy” (sensory triggering) = so be sure to talk to your partner(s) about your likes and dislikes (sensory triggers).

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 and why we founded ourselves as a user-led charity- that there are strong connections between neurodivergence and hypermobility. In particular Autism, ADHD, Tourette's Syndrome and Dyspraxia probably dyslexia and dyscalculia.

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(s) (and indeed for overall harmony in intimate relationships).

Below are some things to think about but these will not apply to everyone, so make sure you have a frank discussion with your partner(s) 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 (triggering of sensory symptoms). They might like to do the same things everytime. Bed linen texture, lighting levels and/or smells in the room can be personalised as otherwise the autistic person can get distracted or even potentially definitely a mood killer!

## **ADHD/ AuDHD**

People with ADHD may hyperfocus on one topic and sometimes it may be sexual and that might cause a problem or distress to themselves or their partner. They also might become easily distracted during sex, and their minds can quickly wander elsewhere to think about other things, so keep things fun, zippy and interesting!



## **Tourette's**

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(s) during sex, be sure to discuss these in advance.

## **Dyspraxia**

A history of clumsiness, proprioception hypermobility issues and poor motor control may impact a dyspraxic person's confidence, so let your dyspraxic partner(s) 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 the foremost leading charity for neurodivergence symptomatic hypermobility actively supporting Ehlers-Danlos Syndromes (EDS) and Hypermobility Spectrum Disorder (HSD) or symptomatic hypermobility (SH) and associated conditions like chronic fatigue, IBS and fibromyalgia. Many members are multiply ND (Autism, ADHD, Tourette's, Dyspraxia, Dyslexia, Dyscalculia). We do support all ages and diversities. You do not need a diagnosis to join us and we support carers and families.

We were founded in 2018 in Sussex, UK but now are global charity. We advocate in education, health, social care, transport accessibility and work/business. We are a multi-award support winning charity our Founder and Chair, Jane Green, was awarded an MBE in the first King's New Year Honours List in 2023. We have won awards for our advocacy during Covid and later on in different areas.

We are run by volunteers, the majority of whom all have a form of Symptomatic hypermobility (SH) and neurodivergence(s).

# About Us

This toolkit was coproduced led by  
**SEDSConnective members.**

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**Contributions by :**

**Dr H Howitt PhD**

**G Earl**

Find us on

[www.sedsconnective.org](http://www.sedsconnective.org)



**Do you have  
a  
combination  
of  
these  
symptoms/  
conditions?**

- Skin: soft /thick velvety does not bruise OR thin, fragile & bruises
- PAIN: (fibromyalgia, arthritis, dislocations, subluxations, sprains and strains, hypermobility, double jointed)
- Extreme Fatigue: M.E / CFS/ LongCovid
- Neurodivergent (Autistic, ADHD, Dyspraxic, Tourette's dyslexic +)
- Clumsiness
- Dizziness/Fainting/racing heart
- Bowel/Bladder issues IBS
- Stomach pains, vomiting
- Headaches/Migraines/Brain Fog
- Anxiety/insomnia
- Allergies MCAS OI POTS + much more

**Are you  
disbelieved?**

SEDSConnective - JOIN US - [www.sedsconnective.org](http://www.sedsconnective.org)

We are the leading userled neurodivergent and symptomatic hypermobility (EDS HSD) charity. You do NOT need a diagnosis to join us!



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



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



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