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This edition is lovingly dedicated to our incredible community members living with Ehlers-Danlos Syndromes (EDS), hypermobility, chronic conditions, and rare diseases. We see you, whether you're smiling while embracing a body that thinks joints should be optional, managing a list of diagnoses longer than most people's shopping lists, and doing your best on days when "just existing" deserves a gold medal.

You are the experts of your own bodies, the quiet champions of everyday life, and the living proof that flexibility (literally and figuratively) is a way of life. Your strength, humour, and heart ignite the fire in us every day.

This one's for you - your courage, your creativity, and your amazing ability to keep going, even when life feels like a never-ending obstacle course made out of jelly.

*Thank you for being here.
You are deeply valued and fiercely loved.*

Understanding Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders

Ehlers-Danlos Syndromes (EDS) are a group of inherited conditions that affect the body's connective tissues - the essential material that supports skin, joints, blood vessels, and organs. When connective tissues don't function as they should, it can lead to symptoms like very flexible joints, stretchy or delicate skin, and a tendency to bruise easily or heal slowly after injuries.

Some people experience joint hypermobility without meeting the full criteria for EDS. This is known as Hypermobility Spectrum Disorder (HSD). While being flexible might seem like a positive thing, extreme flexibility can cause pain, joint instability, and increase the risk of injuries over time.

A helpful way to think about connective tissue is like the mortar between bricks - it keeps everything in place, holds the body together, and helps different parts stay connected while still moving independently.



How Common Are EDS and HSD?

The frequency of these conditions can vary widely depending on the type and how it is diagnosed:

Classical EDS (cEDS): This rare form is thought to affect about 1 in every 20,000 to 40,000 people.

Hypermobile EDS (hEDS): This type is harder to pin down because it is often underdiagnosed. Estimates suggest it could affect anywhere between 1 in 500 to 1 in 5,000 individuals.

Other rare forms: Types like vascular EDS and kyphoscoliotic EDS are extremely rare, affecting fewer than 1 in 100,000 people.

When it comes to **Hypermobility Spectrum Disorders (HSD)**, general joint hypermobility - without symptoms - is actually quite common and found in 10-20% of the general population.

However, when hypermobility leads to pain or other difficulties, it becomes less common and often needs specific support.

In practice, many people show signs of EDS or HSD without having a formal diagnosis, and the real numbers may be higher than research currently suggests.



EDS and Hypermobility Comes with Common Complex Challenges

Connective tissue conditions impact overall health in various ways, which can create additional and often complex challenges:

Chronic Pain: Widespread joint, muscle, and nerve pain due to instability, dislocations, and soft tissue strain.

Joint Instability and Dislocations: Joints may dislocate or partially dislocate (sublux) easily, even with small movements.

Muscle Weakness and Fatigue: Ongoing exhaustion from the extra effort required to stabilize unstable joints.

Frequent Injuries: Sprains, strains, bruising, and slow healing due to fragile connective tissue.

Autonomic Dysfunction (e.g., POTS – Postural Orthostatic Tachycardia Syndrome): Symptoms like dizziness, fainting, rapid heart rate, and temperature regulation issues.

Chronic Headaches or Migraines: Often related to neck instability, cranial cervical instability (CCI), or vascular issues.

Skin Fragility: Soft, stretchy skin that bruises and tears easily, sometimes leading to scarring.

Sleep Disturbances: Difficulty falling asleep or staying asleep due to pain, discomfort, or dysautonomia.

Proprioception Issues: Trouble sensing where body parts are in space, increasing injury risk.

Anxiety and Depression: Emotional struggles often related to chronic pain, medical trauma, or being misunderstood.

Respiratory Issues: Breathing problems related to connective tissue affecting the chest wall or airway.

Eye and Vision Problems: Dry eyes, lens instability, or other connective tissue-related eye issues.

Slow colon movement (Sluggish colon): The muscles of the colon can move more slowly, causing stools to travel too slowly and absorb too much water, leading to constipation.

Rectal prolapse: Sometimes, the rectum may slip out of place and push down through the anus, often because the muscles supporting it have weakened.

Anal fissures: These are small tears or sores near the anus, often caused by passing hard or large stools, which can make toileting painful.

Gastrointestinal issues: Common experiences of bloating, abdominal pain, vomiting, constipation and/or diarrhoea, reflux nausea, post-prandial fullness, dyspepsia, dysphagia, ARFID/ disordered eating.



How Can We Offer Better Support?

First and foremost, it's important to remember that self-injury, difficulty getting to the bathroom in time, or fears around eating are ***not behavioural problems***. They are signs someone may need extra understanding and support.

Ways to help might include:

Believe them: Trust what they say about their experience, pain, fatigue, or needs - even if it's invisible to you.

Listen without judgement: Sometimes just being heard makes a huge difference. Let them share without rushing to offer solutions.

Respect their limits: Understand that their abilities may vary day to day. What's possible one day may not be the next.

Offer practical help: What may seem like simple things, like carrying heavy items, helping with errands, or creating a more comfortable environment can be very meaningful.

Be flexible: Plans might need to change last minute. Show understanding and avoid making them feel guilty.

Celebrate the "small" wins: Living with EDS or any chronic condition can be exhausting. Celebrate moments of joy, no matter how seemingly small.

Educate yourself: This shows that you care. It can also help you advocate for them if needed.

Encourage rest and self-care: Support their need for rest, pacing, and gentle care of their bodies without making them feel "lazy" or "overly cautious".

Use affirming language: Avoid dismissive comments like "you don't look sick" or "everyone gets tired". Instead, acknowledge their experience.

Stay present: Chronic pain can be isolating. Knowing you're there - consistently and kindly - means more than you might realise.

Common Experiences that Can Make Co-Occurring Conditions Challenging and Supports that Can Help

For many in the Autistic community, co-occurring conditions can come with hidden hurdles. Some common experiences include:

Sensory overload: Things like the temperature of the water, the feel of soaps, strong scents from hygiene products, or harsh bathroom lighting can all create discomfort.

Feeling a loss of choice: When routines feel like something being forced upon someone rather than something they get to control, it can be upsetting.

Anxiety around body changes: Shifts in how the body looks or feels can be overwhelming, especially when they seem sudden or unpredictable.

Executive functioning struggles: Getting started with tasks or remembering the steps involved can feel daunting.

Social pressures and masking: Trying to meet external expectations around hygiene can be exhausting, sometimes leading to shutdowns or burnout.



These overlapping conditions can make life more complex, but the right supports can help, such as:

Remove the Pressure

When we lower the sense of obligation, it can transform into a moment of self-acceptance, self-care, and comfort rather than a chore. Some ways to do this include:

Bring in Playfulness: Turning routine activities into games or imaginative moments can make them more inviting. Maybe it's pretending and playing make-believe, or bringing a favourite stuffed animal.

Use Casual, Open Language: Instead of giving direct orders like "Go wash your hands," you might say, "The sink's free if you want to freshen up," or invite participation: "I'm going to wash my face, want to join?"

Let It Be Part of the Background: Sometimes it helps if the main goal isn't the main focus. For example, watching a favourite show or listening to music during chores can make it feel more relaxed.

Create Easy Opportunities: Setting up 'to do' stations - like a water bottle next to the bed - can make caring for oneself feel easier and natural.

Allow for Flexibility: Rather than sticking to rigid schedules, offer room for routines to happen when energy and timing feel right.



Create Sensory-Friendly Routines

Paying attention to sensory preferences can make a huge difference:

Temperature Choice: Letting someone adjust the temperature to their preference - whether it's water or air conditioning - can feel much more comfortable.

Texture Matters: Different textures suit different people. Experimenting with foams and gel products can help find the right fit. Textures also matter with foods. Chewy, slimy, wet or mixed-textured foods can be a turn off. Some foods just have the right 'mouth-feel'.

Soft, Comfortable Clothing: Scratchy clothes can add to discomfort. Soft, tagless garments can make transitions easier.

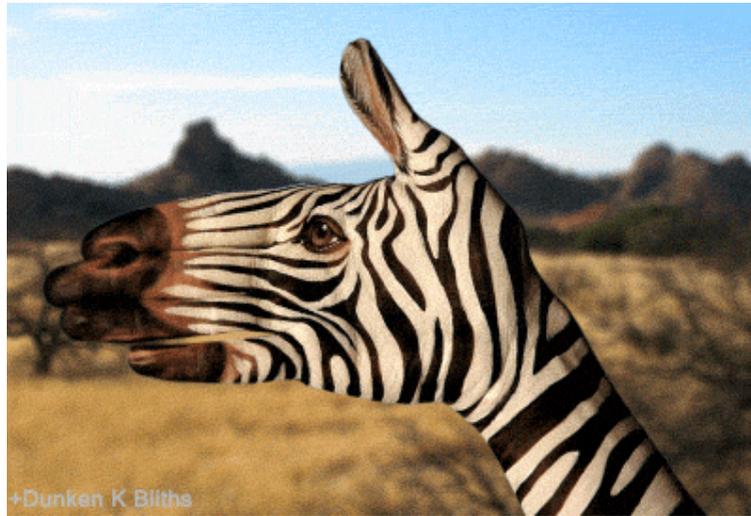
Noise Awareness: Electric toothbrushes, hair dryers, and the constant buzz of electronics can be overwhelming. Quieter options, headphones or using music to mask sounds can help.

Mild Scents and Flavours: Scent-free soaps and milder toothpastes can reduce sensory overload, and so can mild-flavoured foods. Remember, our

tongues have powerful receptors.

Gentle Lighting: Bathrooms with bright, clinical lighting can feel harsh. Using softer lighting like fairy lights or a salt lamp can create a calmer environment.

Kind Touch: Some people are sensitive to how things feel against their skin. Using soft brushes or gently patting dry with towels can be more comfortable than rubbing.



Connect to Personal Interests and Passions

Linking personal interests to routines can bring in motivation and enjoyment:

For science enthusiasts: Turning routines into science inquiries. Learning how or pretending "do" science can be exciting.

For music lovers: Creating a custom playlist can turn routines into a mini concert or disco.

For fashion fans: Framing self-care as an extension of personal style and creativity can make it feel empowering.



Building Trust and Positive Associations

Respect the Learning Process: Everyone has their own pace when it comes to developing comfort.

Adapt to Energy levels and Capacity: Some days might require different approaches based on how much energy someone has.

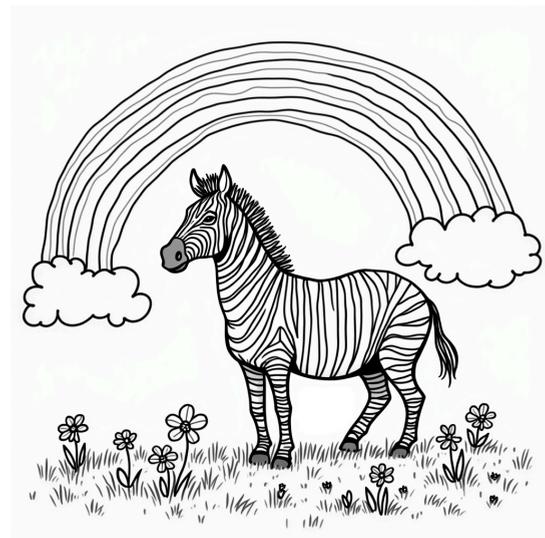
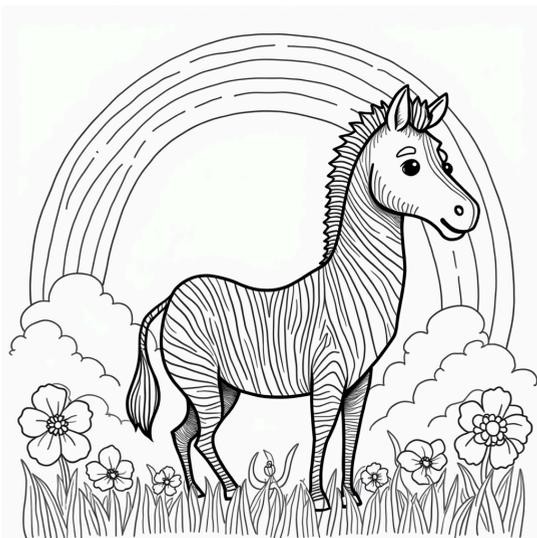
Nurture Positive Connections: Supporting routines with encouragement, humour, and kindness helps build a lifelong positive relationships with self.

Advocating for Rare Diseases with Our Zebra Colouring Pages

Zebras are the symbol of rare diseases, reminding us that while each Zebra's stripes are unique, together they can create something beautiful and strong, just like the rare disease community.

Many people in the Autistic Community also live with co-occurring conditions and are part of the rare disease community. Research shows that Autistic individuals are more likely than the general population to have genetic, metabolic, or neurological differences, some of which are classified as rare diseases.

Recognising this overlap helps us advocate for better understanding, early diagnosis, and inclusive supports for those whose experiences span both communities.



We have created two printable colouring pages you can enjoy at home.

Whether you're colouring for fun, for mindfulness, or to acknowledge the rare disease community, we invite you to get creative with your stripes.

*Click on the images to open in Canva for your printable version.

Celebrating All Ways of Communicating

We know that communicating is at the heart of connection, and every way of communicating is valid.

Let's remember to celebrate the diverse ways people share their thoughts, feelings, and needs. Whether it's through speech, sign language, written forms, AAC devices, non-speaking - even when communication needs change or vary - your communication is important, and it deserves to be respected.

Every voice, in whatever form it takes, deserves space to be heard, honoured, and welcomed. Because communication is connection. And connection is community.

All of your communication needs are valid



Even when your needs change or vary

Share Your Community News with GRANN!

We'd love your input!

Do you have something to share with the GRANN community? We're always looking for contributions for our newsletter! Whether it's an upcoming event, a personal story, resources, or important updates, we'd love to include it.

Email GRANN your suggestions or anything you would like to share or hit us up on [Messenger](#) - we can't wait to hear from you!

Let's keep our community informed and connected!



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