

Pregnancy and EDS

The information contained in this factsheet is shared with the best of our knowledge and should not replace medical advice from a health professional.

Pregnancy is a time of huge hormonal changes, many of which increase tissue laxity and so, whilst some pregnant women with EDS have an improvement in their usual symptoms and some notice no change, many do experience an earlier onset of common pregnancy symptoms, a more significant impact and a slower improvement than women in the general pregnant population. Here are some of the more common pregnancy symptoms. Happily there are many things that you can do to lessen them.

For most women with EDS, pregnancy is very manageable. The care pathway you follow should be the appropriate one for your own EDS subtype. It is important that you speak to your midwife as soon as you know you are pregnant to ensure you are put on the correct pathway. Whatever your EDS subtype, you should aim to maintain a good diet, optimal weight, a daily conditioning routine, and ensure that you are referred to the maternity physiotherapy team and any other specialist support professionals as soon as possible.

Heartburn

The oesophageal sphincter, which usually keeps stomach contents and acid down, softens in pregnancy and becomes less effective, allowing regurgitation. This can cause a burning sensation in the throat or chest and a sour taste in the mouth.

What to do:

- eat small but frequent meals
- avoid spicy foods
- eat sat at the table rather than on the sofa
- avoid drinking milk - this can increase stomach acid
- sip small amounts of water to dilute any stomach acid but do not drink too much as this can simply make eaten food sloppier and easier to regurgitate!
- lie on your left side in bed to keep stomach contents down

If symptoms persist or worsen, speak to your GP

Nausea and vomiting

Those with EDS are often more sensitive to hormonal fluctuations and so can experience an earlier and more profound onset of 'morning' sickness.

What to do:

- keep your blood sugar up and stable - eat regular small meals of complex carbohydrates, including overnight - keep some bread and butter, or similar, by your bed and snack on it every time you wake up. Likewise, keep sports drink or fruit juice by your bed and take sips through the night
- rest - tiredness can make symptoms worse
- avoid cooking and other smells
- avoid sudden head movements as this can trigger queasiness
- having food and drinks containing ginger may help but evidence is limited
- there is also some evidence supporting the use of acupressure bands which can be bought at most chemists

Most women find their symptoms are manageable but, if you cannot keep anything down, your urine becomes sparse and dark, you feel weak and dizzy, vomit blood, have tummy pain, a fever, or are losing weight, call 111 urgently for advice.

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Varicosities

The tissue-relaxing effect of pregnancy hormones can soften the smooth muscle walls of veins causing blood to pool and swellings (varicosities) to form. These varicosities most commonly affect the legs, the anus and the vulva.

Varicose veins

What to do:

- avoid crossing your legs, standing or sitting for long periods or gaining too much weight
- walk and generally stay active to help keep blood moving
- when resting, circle and move your feet backwards and forwards
- maternity support tights available from chemists can help to ease aching and swelling
- raising your legs on a pillow (or use books under the foot of your bed) overnight

Haemorrhoids or piles

These can be internal or external and the best way to both avoid and ease them is by preventing constipation.

What to do:

- increase fibre AND fluid in your diet - only increasing fibre can make stools more bulky which, in the elastic EDS bowel, can make matters worse
- keep conditioned and active
- whilst pelvic floor exercises can improve circulation, for those with an EDSy over-active pelvic floor, learning to relax as well as tense the muscles will keep your whole vulval area functioning well
- unless prescribed by a doctor, do NOT supplement your diet with iron tablets or liquid
- try a freezable gel pad. Cover the frozen pad in a thin cotton cloth before placing it next to the affected area for 20 minutes. After use, do not reapply for at least another 2 hours

Vulval varicosities

What to do:

- maintain pelvic floor health as described above
- cool the area using gel pads as for piles

NB. Pregnancy varicosities rarely rupture but your midwife needs to be told about them so she can make a note for your care team and advise you further.

Oedema

Although usually harmless, always tell your midwife if your fingers, ankles or face feel puffy as oedema or tissue fluid can be linked to pre eclampsia.

What to do:

- when sat or lying, elevate your legs higher than the level of your hips. Pillows placed under the mattress will ensure the legs are elevated overnight
- Use oiled hands, and avoiding any varicosities, gently but firmly massage your fingers and legs towards your heart.
- wear support tights to ease leg oedema
- circle your feet and hands whenever you have a spare moment

Nosebleeds

The delicate lining of the nose can become much more likely to bleed in pregnancy and so those with EDS may suffer more and/or longer nosebleeds.

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What to do:

- sit down and pinch the soft part of your nose for about 10-15 minutes without releasing
- lean your head slightly forwards to prevent blood going down your throat
- avoid blowing your nose for 24 hours after the bleeding stops

If bleeding doesn't stop, call 111.

Tinnitus

Ringings in the ears is an often overlooked challenge in EDS and the increased hyper-mobility of the inner ear structure caused by pregnancy hormones can make matters worse.

What to do:

- avoid 'checking-in' to see if your tinnitus is better or worse - vigilance can trigger or exacerbate an episode
- speak to your GP about any current medications you are taking - some can trigger tinnitus and your GP may be able to change your meds for less ear-affecting ones
- avoid noisy environments and, when you can't, consider using noise-cancelling ear buds
- use CBT to help limit any hyper-vigilance behaviours you might have developed
- ensure you get enough rest

If your tinnitus is interfering with your ability to concentrate or sleep, ask your GP for an audiology referral and consider specialist hearing aids.

Headache and migraine

There are over 150 known causes of headache and migraine and those with EDS tend to suffer more. Many women find their headache experience changes in pregnancy - sometimes for the better.

What to do:

- ask your GP to review any headache medication you are already taking
- keep up a good fluid intake
- ask your midwife or GP for a referral to the maternity physiotherapist to explore the cause and correct treatment plan for your headaches

Musculo-skeletal problems

The already overworked EDS musculoskeletal system can struggle more than usual during pregnancy due to the increased tissue laxity. As soon as you know you are pregnant, ask for a referral to the maternity physiotherapy team for an ongoing plan of care and support. Alongside pregnancy physio support, maintaining a healthy weight and staying conditioned through exercise, here are a few extra tips for supporting aching and painful joints and muscles.

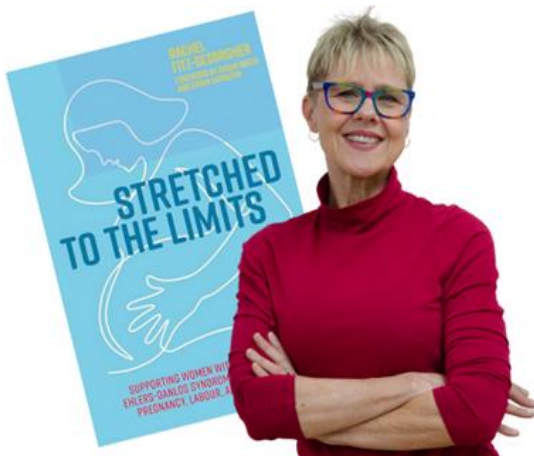
What to do:

- take simple but regular pain relief such as paracetamol
- use heat - sit on or against a heat pad so that it radiates up through the sacrum. Be careful NOT to use heat against your tummy as heat close to the baby can aggravate them
- whether you are sitting, standing, lying or walking around, aim to keep your legs parallel and hip-width apart at all times. Do not cross your ankles or legs and try to sit and stand straight rather than twisted
- at night or when lying down to rest, use one pillow from your pubic bone to your knees and another from your knees to your ankles to keep your legs parallel and hip-width apart
- use walking poles when out and about to stabilise your hips

- whilst pregnancy support belts (belly belts) can help some women, those with EDS sometimes find they squish the pelvic joints causing more pain, so speak to your physio for appropriate advice before buying a belly belt

Prolapse

There are many different types of prolapse. The risk of prolapse following vaginal birth in a woman with hEDS is not statistically any greater than in a non-affected woman UNLESS she has an episiotomy. Episiotomy is associated with an increased risk of future prolapse. As for treatment, the best advice for any mum antenatally and then again postnatally would be to get a 'Mummy MOT' with a specialist women's Physio.



Rachel Fitz-Desorgher has hEDS and is a retired specialist midwife; infant feeding and parenting consultant; media writer, expert presenter and writer for the Baby Show and author 'Your Baby Skin To Skin' and 'Stretched To The Limits: supporting women with hEDS through pregnancy, labour and postnatally'. She has four sons, four grandchildren and lives with her husband and dog in Berkshire.

Her EDS Facebook group can be found at

<https://www.facebook.com/groups/stretched.to.the.limits>

hypermobile Ehlers Danlos Syndrome (hEDS) and Hypermobility Spectrum Disorders (HSD)

Hypermobile Ehlers-Danlos Syndrome (hEDS) is the most common subtype of EDS

Treatment for hEDS is the same as for Hypermobility Spectrum disorders (HSD)

hEDS/HSD are Multi-systemic conditions affecting connective tissues throughout the body with common symptoms including easy bruising and increased risk of joint dislocation

Affects 1 in 20 pregnancies

Listen to the pregnant person, they know their body best

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

Parents and staff making decisions together *yes!*

Things to discuss together that might happen because of my hEDS/HSD:

- Premature birth
- Unsuccessful anaesthesia
- Pelvic organ prolapse through the vagina
- Unusually increased joint laxity (with or without dislocation)
- Complications with wound healing
- Unusually lax womb
- Potential bleeding
- Baby less likely to be in optimal position close to birth
- Unusually fast labour and/or birth

Things to know about me and my hEDS/HSD:

Things that are unique to me:

Things you can do to support me:

Things that might make symptoms worse for me:

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www.hEDStogether.com

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