

A midwife's guide to pregnancy, birth, feeding and EDS

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Introduction

The Ehlers-Danlos syndromes (EDS) are heritable disorders of collagen. As collagen is a major component of connective tissue and present throughout the body, EDS can affect the skin, ligaments, muscle, blood vessels and organs. The most common types are the hypermobile, classical and vascular types, with hypermobile EDS (hEDS) being the most common. Many people with hEDS go undiagnosed for many years, suffering from pain and anxiety amongst a host of other issues. HEDS can also affect the autonomic nervous system leading to dysautonomia and autonomic dysfunction such as dysregulation of all the bodily involuntary functions: heart rate, blood pressure, temperature, breathing and balance.

Due to the hormonal changes taking place in pregnancy, many with EDS experience an increase in the number and severity of symptoms, and there are also some issues specific to pregnancy and birth that can present additional challenges. A knowledge of the possible issues facing those with EDS can help midwives, GPs and other healthcare workers to better support and manage their patients.

Minor disorders of pregnancy

Varicosities

The impaired collagen in EDS causes blood vessels to stretch and bulge leading to a greater incidence of varicosities. Pregnancy brings an increase in progesterone, further softening the smooth muscle of the blood vessels. Varicose veins, haemorrhoids and the vulval varicosities may all appear or worsen in the patient with EDS and simple self-help strategies should be suggested at the first appointment.

Varicose veins: Encourage your patient to maintain their usual exercise regime. Gentle walking and water exercise (swimming, hydrotherapy) can be particularly helpful and many physiotherapists offer hydrotherapy classes. Elevation of the legs, avoiding crossing at the ankles or knees, and passive leg exercises can all help to improve circulation. Support tights can help ease aching veins.

Haemorrhoids (piles): Both internal and external haemorrhoids can be eased by avoiding constipation. Maintaining a healthy diet with plenty of fibre (fruit, vegetables, grains) and fluids will aid regularity of bowels, as will gentle exercise. Pelvic floor exercises should be taught and your patient encouraged to do them regularly to help improve circulation. Iron tablets can increase the risk of constipation so consider alternatives if your patient is anaemic. There are a number of cooling gel products on the market and these may be worth suggesting to help soothe the perineum after birth. In some cases, self-help options are not enough and a prescription of effective creams or suppositories is necessary.

Vulval varicosities: These can be very painful. Pelvic floor exercises will improve circulation and propriety gel pads can relieve pain and swelling. Standing for long periods can make them worse and your patient may need to rest off her perineum to ease the fullness and aching. Ensure that the presence of vulval varicosities is recorded in your patient's maternity notes to alert her birth attenders.

Heartburn

This burning, acidic feeling in the oesophagus is caused by reflux. Many people with EDS have ongoing reflux and symptoms may worsen during pregnancy. Spicy foods, caffeine, alcohol, citrus foods and milk can all make symptoms more likely; whilst eating small regular meals, drinking water (to dilute the acid), avoiding late evening meals and lying on the left side at rest can all help improve symptoms. If symptoms persist, a prescription for antacids should be considered.

Oedema

A common symptom of pregnancy, the additional laxity of blood vessels in EDS may exacerbate symptoms. Monitor carefully and encourage your patient to keep her legs higher than her hips at rest and avoid crossing the ankles. Support tights and regular passive leg exercises will help to improve circulation and ease oedema. Women with EDS may experience an earlier onset and more severe symptoms of carpal tunnel syndrome causing tingling and numbness in the fingers and, sometimes, radiating pain up the forearm. A physio can provide splints and simple exercises to reduce discomfort and swelling.

Nausea & vomiting

A common feature in pregnancy and not easy to relieve, the woman with EDS may be more than usually sensitive to raised progesterone levels which can cause nausea, vomiting and vertigo. Most suggested treatments have not been shown in studies to be useful. However, it appears that maintaining a stable blood sugar may be helpful. Suggest that your patient eats little and often and stabilises her blood sugar by eating a sensible mix of both simple and complex carbohydrates. Avoiding any foods and fluids that trigger the nausea and, if middle ear symptoms are apparent, minimising sudden head movements and resting quietly at the worst times of day can bring some relief. Generally, nausea and vomiting pass at about the 16 week mark but, for those with progesterone-triggered middle ear symptoms, ongoing strategies may be needed throughout pregnancy. If symptoms are very severe, then medication and rehydration in hospital may become necessary.

Headaches

Many people with EDS suffer from regular headaches. Hormonal changes and a raised metabolism can lead to an increase in the occurrence of headaches for all pregnant women and those with EDS may need additional support. Increasing fluids and taking simple pain medications such as paracetamol can help greatly. Sometimes headaches are caused by nasal congestion which is increased in pregnancy. Steam inhalations and sniffing oils such as eucalyptus in common remedies (Vicks and Olbas Oil) can be suggested as a simple self-help strategy. It is essential that your patient knows to seek urgent medical attention if her headache is accompanied by nausea, flashing lights or is not relieved within an hour of taking paracetamol.

Tinnitus

Many people with EDS suffer from tinnitus as a result of the instability of the bones in the middle ear. Extra circulating progesterone may exacerbate this condition. Use of white noise generators at night (it is possible to buy specialist pillows for this purpose) can aid more restful sleep but, if symptoms are severe, referral to an ENT specialist may be considered.

Sleep

This is often poor in people with EDS and they often find it difficult to experience regular deep sleep. Sleep can also be adversely affected by painful joints, tinnitus, palpitations and poor thermoregulation. Taking simple pain remedies before bedtime, using light bedding and a cool fan and keeping a regular bedtime may help to protect your patient's sleep.

Musculoskeletal problems

It is not uncommon for people with EDS to say that their pain symptoms started in their first pregnancy. It is possible that the increased laxity of pregnancy does not settle properly postnatally.

In any event, women with EDS need to be particularly careful to protect their joints throughout pregnancy and during the postnatal period. Early referral and ongoing regular appointments with a specialist physiotherapist can be invaluable in helping your patient to remain mobile and to reduce joint damage. Carefully monitored use of painkillers and timely appointments with other specialists such as podiatrists and occupational therapists can ensure that symptoms are reduced and managed. It is also important that your patient avoids excessive weight gain in order to avoid additional strain on vulnerable joints. Below are a few of the most common muscular-skeletal issues seen in pregnancy.

Pelvic Girdle Pain (PGP)

This used to be called symphysis pubis dysfunction. The increased laxity and instability of the pelvic joints causes pain all around the pelvis which can range from mild aching after sitting still to considerable disability requiring use of crutches or wheelchair. Some studies found that, whilst the general pregnant population has a 7% incidence of PGP, this is increased to 26% in the woman with EDS. Symptoms can begin earlier in the woman with EDS and it may take a lot longer for them to disappear after birth. Some women with EDS continue to suffer with PGP for many years after childbirth and considerable support may be needed. The following should be considered and discussed with your patient:

- Referral to a physiotherapist who can offer help and support with exercises, providing specialist pregnancy belts and suggesting simple lifestyle changes to minimise pelvic instability. It may be wise to refer early in pregnancy in order to reduce the likelihood or severity of PGP.
- When sitting and lying, legs should be kept parallel and hip-width apart. Avoid crossing the legs or sitting at awkward angles. N.B. Proprioception can be very poor in the patient

with EDS and so she may need help from a partner to remind her when she is adopting awkward positions.

- Standing on one leg for dressing should be avoided (sit on the bed or chair to put on socks).
- Legs should be kept comfortably together when moving in and out of the bath, bed and car or when turning over in bed.
- In bed or when resting, a pillow or two the whole length of the legs or using a propriety “pregnancy pillow”.
- A warm hot-water bottle or heat pad on the lower back can offer effective, drug-free pain relief. Remind your patient not to put it on her pregnant abdomen.
- A TENS machine can be used on the upper or lower back.
- Regular use of paracetamol under the supervision of the GP is currently considered a safe form of ongoing pain relief.
- Avoiding lifting heavy objects.
- Changing position regularly can reduce stiffness and aching.
- Maintaining their usual exercise routine. There seems to be particular benefit to those with EDS from hydrotherapy. N.B. Many women find that the naturally occurring endorphins and adrenaline of labour reduces their PGP pain significantly during the birth. However, it is essential that your patient’s maternity notes and birth plan detail her PGP symptoms as well as her EDS so that any birth attenders can protect her pelvic joints.

Before term, measure and document how far your patient can move her legs apart without pain, request that vaginal examinations are done with her lying on her side with leg-parting reduced and to avoid the use of lithotomy poles if at all possible.

Back pain

This may occur with or without PGP. The strategies used to alleviate PGP are also relevant for non-PGP backache. In addition, advise your patient that extra care should be taken with posture. The natural lordosis of pregnancy should be corrected just enough to reduce over-stretching of the ligaments, so encourage your patient to gently tuck her coccyx under as she sits and walks and to “walk tall”. Her poor proprioception may cause her to over-adjust and your feedback may help her to correct her lordosis gently.

Suggest that your patient chooses her home and work furniture (especially chairs) carefully and ensures that her feet can rest comfortably on the floor. A small cushion in the lower back and legs raised on a comfy stool can ease the stress on aching back joints.

Wearing well-fitting shoes with a low heel and using her usual orthotics is important as may be a visit to the podiatrist to have her orthotics checked and, if necessary, adjusted. Many women discover that their feet get bigger in pregnancy and for the women with EDS this may be even

more noticeable. Shoes should, therefore, be well-fitted. Soft inserts can help to protect the soft, fragile EDS tissue from bruising and blisters.

Pacing of daily activities can reduce pain and exhaustion: this may mean asking for extra help with household tasks and sitting down for ironing, washing up etc.

Lifting should be avoided if possible but otherwise, knees should be bent, the back kept straight and the item to be lifted be brought in close before picking it up. Your patient should avoid twisting when lifting.

Most NHS physios run back care classes for pregnant women and your patient should have a referral as soon as possible after booking rather than waiting for problems to arise.

Pain management

The increased laxity in the EDS joints and tissues can lead to the initiation of or increase in pain that should not be ignored. Whilst back pain and PGP are probably the most obvious musculoskeletal problems, necks, knees, ankles and feet, as well as other joints can suffer too. Speak to your patient about her current pain medications so that it can be changed to be both safe in pregnancy as well as adequate to keep her comfortable. Most people with EDS have preferred coping strategies for their daily aches and pains and here are a few other suggestions:

- Massage
- Warm baths
- Heat packs (do not put these on the abdomen)
- Fidgeting
- Gentle, daily stretching without over-stretching
- TENS
- Hydrotherapy
- Pregnancy pilates
- Mindfulness meditation
- Distraction (music, reading, crafts, cooking etc)

Proprioception

EDS can cause poor proprioception which in turn can lead to stumbles, trips and falls. Your patient with EDS will already be very aware of their tendency to stumble and will need advice to take extra care on stairs and on uneven ground.

Heart palpitations

Many people with EDS are used to heart palpitations and ectopic beats. These may increase, or become apparent for the first time, in pregnancy. An ECG to eliminate anything of concern can

be offered. The palpitations should settle back to normal-for-her after the birth as hormone levels settle.

Breast changes

Most (but not all) women find that their breasts grow during pregnancy due to hormonal changes. The hyper-elastic skin in the woman with EDS means that extra support is important. A properly fitted bra should include wide shoulder straps and supportive material without seams over the sensitive nipple area. If your patient is used to, and prefers underwired bras, then she can be reassured that there is no evidence that they cause damage to the pregnant breasts. However, many women find that sports or yoga bras have the firm stretch and wide straps that give comfort and support.

There is no need to 'prepare' breast and nipples for breastfeeding. After birth, when the milk 'comes in' regular paracetamol and ibuprofen can reduce the pain of engorgement and wearing a very soft but supportive bra, even in bed, can provide comfort. Over-the-counter cold compresses can reduce the engorgement as can demand-feeding. N.B. Although many care-givers still recommend them, RCTs have shown that savoy cabbage leaves only work as long as they are cold and only work because they are cold – in other words, it is the cold rather than the cabbage that soothes the swollen breasts!

It is worth noting that women that feed lying down and freely for the first week appear to have fewer problems with feeding and supply.

Stretch marks

Stretch marks are caused by over-stretching of the dermal layer in the skin. People with EDS are more prone to stretch marks and pregnancy is a common cause. There is currently no proven preventative treatment and there is no way of getting rid of them once they appear. However, massaging the skin with a good oil such as grapeseed oil or jojoba oil is relaxing and may ease some of the itching associated with stretch marks. They fade in time.

Mental Health

It has been noted that people with EDS appear to be more prone to anxiety and depression. The reasons are probably multi-factorial. It is essential that mental health is monitored and, where appropriate, treated in pregnancy to reduce the likelihood of post-natal depression. The likelihood of both antenatal and postnatal depression are increased where there is a previous history of mental health illness and antenatal depression is a predicting factor in post-natal depression. If your patient is currently being treated for anxiety, depression or any other mental illness, she should see her GP early in pregnancy to discuss safe treatment options. SHE SHOULD NOT STOP TAKING HER MEDICATIONS without speaking to her doctor first. The vast majority of anti-depressants are safe in pregnancy, and ALL medications that are safe in pregnancy are safe to take during breastfeeding.

Your patient should be encouraged to self-monitor her mental and emotional health. Here are some suggestions for maintaining good mental health:

- Eat healthily and regularly
- Get out in the fresh air every day
- Take regular gentle exercise such as walking, swimming or pregnancy pilates
- Avoid alcohol
- Sit in a sunny spot or in bright daylight for half an hour every day
- Learn mindfulness meditation and consider downloading an app for pregnancy mindfulness
- Set a regular going to bed and getting up time

Labour

There are some risks and complications pertaining to labour and birth whose incidence is increased in the patient with EDS and about which it is important to be very aware. These should be detailed in the maternity notes and also in your patient's birth plan.

Pre-labour spontaneous rupture of membranes (SROM)

Due to the fragility of connective tissue, those with EDS are more prone to pre-labour SROM. They may well experience SROM pre-term. It is worth discussing this phenomenon with your patient and advising her about your local hospital guidelines. Many hospitals advise induction and antibiotics. The evidence for this is mixed and, if your patient is concerned, she can be offered a meeting with your local consultant midwife. There is some evidence that, because the membranes 'belong to' baby rather than mother, if a baby has EDS the likelihood of pre-labour rupture of membranes is increased.

Epidural

Although not fully understood, it is not uncommon for those with EDS to have a poor response to lignocaine. As this is the drug used in epidurals, you need to be aware if your patient has a poor response to lignocaine at the dentist or if she believes that she is, or may be, insensitive to it. A referral to the hospital anaesthetist antenatally for assessment should be offered so that management and other options can be discussed.

Anaesthesia

Due to the dysautonomia apparent in many people with EDS, general anaesthetics can cause a significant drop in blood pressure. This should be discussed with your patient and the hospital anaesthetist should be made aware that your patient has EDS.

Precipitate birth

Although the latent phase of labour may well last as long as that of an unaffected woman, women with EDS are more prone to a precipitate active labour. This can be intense and frightening for the woman and alarming for the unprepared birth attender. Women describe the distress at being disbelieved when they progress very rapidly in their first labour. It is essential that your patient understands that she should transfer to her chosen place of birth as soon as labour establishes and that her maternity notes and birth plan alert the birth attenders to this possibility. She should also know how to call for an ambulance if she is unable to transfer to hospital. If there are no other concerns at booking, it might be worth discussing home birth or birthing at a nearby birth centre rather than at a distant general hospital.

Second stage may also progress very quickly: see below for details about tissue damage and malposition.

Malposition of baby

Due to the extra-lax ligaments and joints within the EDS abdomen and pelvis, babies of women with EDS may come through the pelvis and deliver asynclitic, persistent occipito-posterior or even occipito-transverse. Whereas unaffected women may struggle to birth their babies in unusual positions, women with EDS may have no problem pushing their baby out 'facing the wrong way'! Caregivers need to be alerted so that they do not feel the need to use forceps or ventouse too quickly if they discover the baby in an 'unfavourable' position. The author happily birthed her first son with the head facing persistent occipito-transverse.

Bleeding

Because of the fragility of the cell membranes, women with EDS can be more prone to bleeding after birth. Usually this is just 'more than usual' but it may amount to post-partum haemorrhage. Your patient and her birth attenders should be adequately alerted to this increased possibility so that they can monitor carefully and make provision for extra care during the third stage of labour. Careful discussion about management of third stage should take place and, if your patient would prefer a 'natural' third stage, it may be sensible to have Syntometrine already drawn up so that it can be given more quickly if heavy blood loss occurs.

Perineal tears

Women with EDS have fragile skin that is more prone to tearing and may take longer to heal. Extra care should be taken during birth to prevent damage. In addition, it is worth discussing the following:

- **Perineal massage:** The evidence in favour of perineal massage is mixed. However, women report being better prepared emotionally for the sensations of the head being born when they have massaged regularly antenatally. Suggest that your patient uses a simple massage oil and is very gentle as the EDS tissues are more prone to bruising.
- **Second stage:** Allowing the baby to descend a little more gently through the pelvic tissues and encouraging your patient to wait until her natural urge is strong will allow a gentler stretching of fragile tissues.

- **Lignocaine:** If you know or suspect that your patient is or may be insensitive to lignocaine let your caregiver know BEFORE suturing starts. Extra lignocaine can be used both in and on the delicate tissues to reduce the sensation of suturing.
- **Sutures:** The EDS skin can take longer to heal and dissolvable stitches such as Vicryl Rapide may dissolve before healing is complete. Request in your patient's maternity notes and in her birth plan that silk sutures be used for perineal repair. Although rarely used in maternity units now, these sutures are soft and comfortable and can be left in until healing is complete. It may be necessary to locate these antenatally and ask that they are kept with your patient's hospital maternity notes so that they are quickly available after the birth.
- **Keeping sutures clean:** Daily bathing or showering without using soaps and creams on the perineum can reduce the risk of infection. There is no evidence to support the use of essential oils such as tea tree but a propriety cold gel pad in your patient's pants may soothe and reduce bruising and swelling.
- **Pelvic floor exercises:** Women with EDS are more prone to vaginal and rectal prolapse. The regular practice of these simple exercises can help vaginal tissues return to normal after birth and reduce the likelihood of urinary and faecal incontinence long-term.
- **Post-natal pain relief:** Use simple pain medication such as paracetamol and ibuprofen to reduce pain and inflammation.

Wounds

As discussed above, the EDS tissues need extra care if torn or cut. Ensure that your hospital obstetric team is aware of your patient's EDS so that, in the event of a caesarian section they can adapt their suturing accordingly.

Use of codeine post C/S can cause constipation which can be more of a problem in a woman with EDS who may well have pre-existing gastrointestinal issues. She will need advice on how to adjust her diet and fluid intake accordingly.

Although many care-givers advise women to feed a baby underarm ('rugby ball' method) following a C/S, this can be tricky and impractical as well as unnecessary. See below for suggestions on feeding and baby care.

Your patient will need to know that her wound may take a little longer to heal and how to support it when she coughs, laughs and sneezes. The hospital physio should be alerted to your patient's extra challenges.

Baby care

It is easy when focussing on caring for a new baby for the patient with EDS to forget about protecting their own body and joints. Encourage her to think about her home environment before the birth and make simple adjustments to make life easier, more comfortable and safer.

Changing nappies

Everything should be close to hand before starting so that there is no need to twist and reach. Suggest that your patient use a changing table at a comfortable height or show her how to change her baby on a bowl on her lap. If her proprioception is poor, she may well feel safer sat down with her baby securely held on her lap.

Bathing

Leaning over the side of a bath to use a baby-bath is not good for the back so consider teaching your patient how to bath her baby in a clean sink. As with changing nappies, everything should be ready and close to hand before starting. If your patient struggles to hold things securely, suggest she buy a bathing seat to lie baby on in a large sink or baby bath. If she must use a baby-bath then suggest one that sits across the bath so that bending is minimised, or put it on the kitchen work surface to make filling and emptying easier. If there is another adult in the house at bath-time, suggest that she takes the baby into the bath with her. This is a favourite with many mothers and enables them to feed baby at the same time as getting both mother and baby washed during some skin-to-skin time!

Feeding

Most UK midwives teach a way of holding and feeding a baby that is difficult, uncomfortable and unsustainable for women with EDS. Using a position that requires holding for long periods of time with hands and raised elbows can lead to pain and nerve entrapment and should be avoided. The simplest positions are the comfiest for both mother and baby and it is worth seeking out a specialist infant feeding midwife with a knowledge of EDS to speak to your patient before baby is born so that she knows what to do from the very first feed. It is worth reminding your patient that her baby has evolved to have all the necessary rooting, latching and suckling reflexes, and that trying to help too much can just interfere with these. Using a simple cuddle hold ('Madonna Hold') with baby on the opposite thigh to the feeding breast, well under the breast and looking up at mother allows baby to lead the way. Your patient should be encouraged to let her arms hang in their natural place rather than to hold them up, and to bring baby in very close making it easier for baby to follow the natural reflex to reach up and take the breast. She should not be advised to 'look for the big mouth' as this will prevent baby feeling the breast which is the trigger for the rooting and latching reflex. Your patient can be encouraged to take advantage of the extra long arms enjoyed by many of those with EDS and hold baby on her forearm rather than her hand. This will prevent wrist pain and carpal tunnel syndrome. She should be shown how to hold her baby hands-free if wrist or hand pain is an issue for her.

There is no need to use a special chair, sitting position or cushion – a position that is comfy for your patient – sitting, lying or standing depending on where she is at the time – is best, and then she should feel free to change position when she gets fidgety or uncomfortable after a while.

As long as she keeps baby close to her as she moves, she can shift around as much as she needs!

Your patient can be reassured that the majority of pain medications are safe when nursing but she should ask a lactation specialist if she is unsure.

Carrying

The majority of babies need to spend much more time in arms than new mothers expect and, during the first 12 weeks, don't settle out of arms very much at all. Your patient needs reassurance that this is completely normal and is an in-built protective mechanism to keep her baby safe. However, this can cause pain in women with EDS and so it is worth discussing, before birth, how your patient might carry her baby for long periods of time.

Slings

Using a sling, worn close against the body can help to balance the weight evenly without putting string on the back and arms. Whilst there are many 'close carriers' on the market they can be expensive and a very cheap and simple 'ring sling' from a regular shawl can be used instead. Friends and family can be encouraged to share the load of keeping baby in arms when unsettled to allow your patient with EDS to rest her joints.

Prams, pushchairs and car seats

A lot of pushchairs, prams and car seats are heavy, cumbersome and not designed for those with EDS. Suggest that your patient buys minimally and wisely. She should consider the weight of the items and how easy they are to fold down and put in the car. She should think about where larger items can be stored when not in use so that they are easy to access and do not require lifting.

Prams and pushchairs often have adjustable handle height and these should be set correctly by your patient so that bending is minimised and she should consider getting one that allows her baby to face her and to be up high to minimise bending to get her/him in and out. Your patient should ensure that she can easily manage the clasps and locks and that getting them in and out of the car is safe and comfy.

Car seats should be as light and easy to use as possible and, if possible, your patient should test before buying. Keeping the car seat on a table or work surface will minimise bending when getting baby in and out, and from lifting from too low down.

It may be that your patient with EDS has to make a careful balance and compromise between weight and ease of handling and folding.

In Conclusion

There is no doubt that the patient with EDS can present with, and develop, many and varied challenges during pregnancy, birth and parenting. Some of these are exacerbations of issues that unaffected women face, and some are particular to those with EDS.

Thoughtful discussions and careful care-planning, as well as timely referral to other members of the healthcare team, can help to minimise the complications and distress that your patient will face and, hopefully, to reduce the possibility of long-term sequelae.

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