



## St John's Institute of Dermatology

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# Epidermolysis bullosa (EB) – information for pregnancy and childbirth

**This leaflet provides a general guide to some of the key things you are likely to encounter and questions you may have during your pregnancy. It supplements the professional guidance your obstetrician and midwives will require when managing your care. If you have any questions or concerns, please speak to a clinician caring for you.**

The care and management you will need during pregnancy and childbirth will vary enormously depending on what type of EB you have and how it affects you.

Specialist advice and support, for you and for other healthcare professionals during your pregnancy, is available from EB specialist teams so make contact with your EB team if you are planning or have become pregnant.

### Inheritance

Whether you are likely to pass on your EB to your unborn child depends on the type of EB you have.

With dominantly inherited forms, there is usually a long family history of EB and there is a one in two (50%) chance of your child being affected with **each** pregnancy. Typically, EB Simplex (EBS) and Dominant Dystrophic EB (DDEB) fall into this category.

If you have a recessively inherited type of EB (RDEB or Junctional EB) the risk of your child being affected is relatively small. For you to be affected with EB, both your parents were **healthy** carriers of the recessive gene, but were unaffected themselves. You will pass on **one** of the recessive EB genes to your baby, but it will only be affected by EB if your partner is **also** a carrier of the same faulty gene. **The carrier rate** is thought to be about one person in 350 in the general population, so the risk to your baby is small.

If your partner is a close family relative (for example, a first cousin), or if your partner's family also has a history of EB, the risk is considerably greater. If this is the case, further discussion is recommended before you become pregnant

## Pre-natal testing

This is not routinely offered, but as advances are made in genetic screening, specialist centres may be able to offer this service.

Please talk to your EB nurse or doctor about the risk of your baby having EB, and options for pre-natal testing.

## Ante-natal diagnosis

Ante-natal testing is not routine but may be recommended to see if your baby has inherited EB.

This is most likely to be advised if you have EB simplex – generalised severe (formerly known as EBS Dowling Meara) or DDEB.

Whatever type of EB you have, please talk to your EB team about the risk of your baby having EB and the options that are available to you.

## Care during pregnancy

**Morning Sickness** can be a problem in early pregnancy for many women. In some types of EB fragility can extend internally. If this is a problem for you, frequent vomiting may cause blistering in your oesophagus. If you experience particular soreness after vomiting you should speak to your EB nurse for advice.

**Weight gain** is expected during pregnancy, but some women, particularly those with the more severe forms of EB, may be underweight and will need specialist dietary advice and support during pregnancy. A specialist EB dietitian is available at many EB centres.

**Ultrasound scans** are a routine part of ante-natal care. As long as you have intact skin over your abdomen there should be no problem with standard ultrasound scans. Just remind the person carrying out the scan to take care when wiping off the gel so that they don't rub too much.

If you have a more severe form of EB, scanning may be more difficult as the pressure required on your abdomen to see the foetus may cause blistering to your skin. If you are worried about having a scan, get in touch with your EB nurse who will be able to support you and offer advice to the person taking the scan.

**Urinalysis.** You will be asked to bring a urine sample to every maternity appointment. If you have any open wounds in the perineal area, the midwife may detect blood in your urine. There can also be pregnancy-linked reasons for the blood which should be investigated, but you should also tell your midwife that it may be related to your EB.

**Vaginal examinations** can be carried out, but you need to ask the midwife to be very careful, particularly if you have any perineal issues. Make sure the midwife uses well-lubricated gloves.

## Planning your delivery

The decision to have a normal vaginal delivery or caesarean section should depend on you and how your pregnancy has progressed, rather than on the type of EB you have. Your choice should be made after talking with your obstetrician, midwife and the EB team. Some women with relatively severe EB have had normal vaginal deliveries with few problems, however many women opt to have a planned caesarean section.

An EB pregnancy information and dressings pack can be provided by your EB nurse. This will include relevant professional guidelines for your obstetrician and midwife, contact details for your EB nurse and some useful dressings. You should keep this with your “labour bag” and make sure you share it with whoever is looking after you during your delivery.

## Normal vaginal delivery

You have the best understanding of your EB and what you are able to tolerate. Your midwife’s priority will be to provide the best care for you and ensure the wellbeing of your baby, but they may have only very limited understanding of EB. Being well prepared before labour is very useful, but it would be best if your birth partner also has a clear understanding of how to manage delivery with EB, as they may need to speak up on your behalf during the labour.

If you have one of the more severe forms of EB, discussions and planning between your obstetrician, midwife and your EB nurse well before your delivery date would be very helpful. Your EB nurse will be able to help to coordinate this.

## Caesarean section

Following consultation with your obstetrician, midwife and your EB team, you may make the decision to have a caesarean section.

With most types of EB, managing a caesarean section will be very similar to any surgery and should be straightforward. Ideally the section will be planned, but it is always worth thinking ahead about what to do if you need an emergency procedure.

Surgical wounds in all types of EB generally heal well, and sutures (stitches) or clips can be used to close your wound in the same way as for women who don’t have EB.

If you have a more severe form of EB, your pregnancy and delivery will need to be much more closely monitored and supervised. As pregnancy in women with RDEB is rare, information about the best way to deliver your baby is limited. What is absolutely essential is thorough assessment, preparation and coordination of your care, and your EB team will support you throughout your pregnancy to make sure this happens.

## Feeding

Most women with more severe forms of EB choose to bottle feed because of the fragility of the nipple area. If you do choose to breast feed, your midwife will need to work closely with you to help your baby to latch on properly, and you should expect pain and blistering of the nipple. Some women find nipple shields to be helpful.

## The new baby with EB

If you suspect your baby has inherited EB, you should contact the paediatric EB team at either of the national centres for epidermolysis bullosa – Great Ormond Street Hospital, or Birmingham Children’s Hospital (details at the end of this leaflet).

Guidance about the care of a new baby with EB can be found at:  
[www.gosh.nhs.uk/healthprofessionals/clinical-guidelines/epidermolysis-bullosa](http://www.gosh.nhs.uk/healthprofessionals/clinical-guidelines/epidermolysis-bullosa)

## Useful sources of information

### DEBRA

The EB service at St Thomas' Hospital runs in collaboration with the charity DEBRA – the national charity supporting those directly affected by, and working with, EB.

**w:** [www.debra.org.uk](http://www.debra.org.uk) **t:** 01344 771961

### Useful guidelines for health care professionals

Surgical guidelines – useful in event of a Caesarean section (this links to a document that is currently under review, however the content has not changed since it was published).

[www.debra.org.cn/fileadmin/user\\_upload/medresearch/2016/surgical-procedures.pdf](http://www.debra.org.cn/fileadmin/user_upload/medresearch/2016/surgical-procedures.pdf)

Best Practice in care of patients with EB. This covers complex management of EB and includes lots of information about suitable dressings.

<https://www.debra.org.uk/downloads/community-support/woundcare-guidelines-2017.pdf>

### National centres for epidermolysis bullosa

Guy's and St Thomas' Hospital, **w:** [www.guysandstthomas.nhs.uk](http://www.guysandstthomas.nhs.uk)

Heartlands Hospital, **w:** [www.heartofengland.nhs.uk/heartlands-hospital/](http://www.heartofengland.nhs.uk/heartlands-hospital/) **t:** 0121 424 2000

Birmingham Children's Hospital, **w:** [www.bwc.nhs.uk](http://www.bwc.nhs.uk) **t:** 0121 333 8224

Great Ormond Street Hospital, **w:** [www.gosh.nhs.uk](http://www.gosh.nhs.uk) **t:** 020 7829 7808

### Contact us

If you have any questions, please contact us. Adult EB Clinical Nurse Specialist team (contact via EB administrator) **t:** 020 7188 0843, Monday to Friday, 8am to 6pm.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** [www.guysandstthomas.nhs.uk/leaflets](http://www.guysandstthomas.nhs.uk/leaflets)

### Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline. **t:** 020 7188 8748, Monday to Friday, 9am to 5pm

### Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS) **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**t:** 020 7188 3514 (complaints) **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

### Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch. **t:** 020 7188 8815 **e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

### NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day. **t:** 111



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