DebRA
Working for a life free of pain

Pregnancy and Childbirth in EB

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With grateful thanks to those people with EB who have shared their experiences of pregnancy and childbirth with the nursing team.

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A charity registered in England and Wales (1084958) and Scotland (SCO39654)

Who is this booklet intended for?

This booklet is directed primarily to those people with either dystrophic EB (DEB), or non-Herlitz Junctional EB (non-H JEB) who are either considering a pregnancy or are already pregnant. However some people with the more generalised forms of Simplex EB may also find the advice on skin management useful. Specific notes for health care professionals are available as a separate leaflet entitled ‘EB and Pregnancy- A guide for Health Care Professionals’. You can obtain this from the DebRA office. However some midwives and obstetricians may find this booklet useful. If at any time you want further clarification of any of the information contained in this booklet, please contact your EB Nurse Specialist (see useful contacts) who will be pleased to help.
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In no way is this booklet intended to be a substitute for professional obstetric advice given by your GP, Obstetrician and Midwife. It does however hope to complement this advice by giving information tailored to the needs of those with EB.

Introduction

All potential parents considering a pregnancy have both hopes and anxieties. For those with EB there may be many questions both about the health of any future children, and also for women anxieties about the effect of any pregnancy on their own health both during pregnancy and at delivery. The years of child rearing that follow should also not be overlooked. It is the aim of this booklet to answer some of the questions that arise, and the information given is based upon experience gained in working with parents who have EB. Additional information has been taken from articles written by teams caring for people with EB throughout the world.

Before becoming pregnant

Can I have a baby?

Many young adults with the severer forms of EB are unaware that it is a possibility for them to have children. We now know a number of women with both dystrophic and non-Herlitz Junctional EB who have given birth to healthy children (1) and who have gone on to raise them successfully. In addition we also know of men affected by both dystrophic and non-Herlitz JEB who have fathered children and have participated in childrearing.

Will my baby have EB?

In order to be able to give you information about the chances of your baby inheriting EB it is important that you have a firm diagnosis with clear information on the way your EB has been inherited. If you are unsure about this you should make an appointment to see your consultant in order to clarify this information or to have the necessary tests done. If you do not have a dermatologist you should ask your GP for a referral to St Thomas’s Hospital in

London, or Heartlands Hospital in the Midlands where there are consultants who are experts both in diagnosing and managing EB (See useful contacts)

You may also find it useful to read 'The Genetics of EB' by Professor Irwin MacLean. This is available from the Debra office (See useful contacts)
If you have recessively inherited dystrophic EB (RDEB)
There is usually no family history of EB in this situation, and both of your parents will be 'healthy carriers' of the genetic mistakes leading to RDEB
There is only a very remote possibility that your baby will inherit EB. One article on the subject refers to the risk as being 'negligible' (2) This is because we all inherit one gene for each of our characteristics e.g. hair colour, eye colour and skin structure from each of our parents. 'In a recessive condition both copies of the gene have to be defective in order for the person to have the disorder' (3). This means that although you can only pass down a gene for skin structure that is affected by EB, your partner would also have to pass down a gene carrying the mutation for EB in order for your baby to be affected. It is thought that the carrier rate for recessive dystrophic EB in the general population is about 1:350 (3) This gives an overall risk of 1:700 of your having a child with EB. In genetic terms this is thought to be a very minimal risk indeed. We do however appreciate that this is a very real concern for many prospective parents, given that for anyone to be affected by EB is the result of a very rare chance phenomenon.

If you have recessively inherited non-Herlitz Junctional EB
The situation is as described above for RDEB, however the carrier rates for JEB in the general population are thought to be 1:300 (estimate) therefore your chances of having a child affected by EB are 1:600 (approx)

However it must be noted that if your partner is a close relative e.g. a cousin, or has a family history of EB you should seek expert advice before embarking on a pregnancy as the risks of having a child with EB are greatly increased.

Can my partner be tested to see if he/she is a carrier?
Unfortunately the present state of the science does not allow for carrier testing in RDEB. This is because the genetic mutations responsible for causing RDEB are to be found on the gene encoding for a protein called collagen V11. Collagen V11 is a crucial component of anchoring fibrils, which hold the epidermis to the underlying dermis. The gene encoding for collagen V11 (carrying the genetic instructions) is one of the largest genes we know of and the mutations (or mistakes) that cause RDEB can be found in numerous sites on this gene. Therefore, although we will be able to find your mutation and tell you if your partner carries this or not, we will not be able to tell you that they do not carry another mutation that can also cause RDEB. To search the entire collagen V11 gene is a hugely difficult task and can be thought of as akin to 'looking for the proverbial needle in the haystack' without actually knowing what the needle looks like! However you may be comforted by the fact that we now have a number of children who have been born completely healthy where one parent has recessively inherited EB.
The situation is very similar in non-Herlitz Junctional EB and as a general rule carrier testing is not offered.

Can pre-natal testing be offered to parents with one partner having a recessively inherited form of EB?
Pre-natal testing of the foetus is not offered in this situation. This is because the risks of having an affected child are so small. 1:700 for RDEB and 1: 600 (approx) for Non- Herlitz JEB. The other issue to consider is that even in the most skilled hands it is still possible to provoke a miscarriage when carrying out pre-natal testing. The chances of provoking the miscarriage of a perfectly healthy foetus outweigh the risks of having a child with EB. The rate of excess miscarriage (i.e. a rate above what would normally be expected) in chorionic villus sampling (taking a small piece of the early placenta) is about 3% (5) and therefore far exceeds the risk of having a child with EB. Most doctors therefore consider it is unethical to offer this procedure in this situation.

If you have dominantly inherited EB
This is the case in dominant dystrophic EB (DDEB) and EB Simplex (EBS)
In this situation you will normally be aware of a strong family history of EB with one of your parents having the condition. There is no carrier status in a dominant condition and the chances of your having a child with EB are 1:2 with each pregnancy. Very occasionally an individual will be born with DDEB where there is no family history and both parents are unaffected, this is known as a de-novo mutation i.e. you have developed a new dominant mutation all of your own. In this rare situation you will have again a 1:2 chance of passing DDEB to each of your children. On the whole dominantly inherited forms of EB are milder than the recessively inherited forms of the condition.

Can I have pre-natal testing if I have a dominantly inherited form of EB?
As mentioned above if you have a dominantly inherited form of EB your chances of passing EB to your children are 1:2 with each pregnancy. If you or your partner has Dowling Meara EB Simplex you will be offered pre-natal testing. This is because babies born with Dowling Meara EB Simplex can often be very severely affected at birth and in the early years. In other forms of dominantly inherited EB pre-natal diagnosis is not offered in the UK. This is because it is felt that the dominant forms of EB whilst troublesome and distressing for some people are in fact too mild to warrant pre-natal diagnosis and potential termination of any affected foetus. In addition one also has to consider the potential loss of a healthy foetus incurred following pre-natal testing. The rate of miscarriage attributed to pre-natal testing is thought to be about 3%.

What is pre-implantation diagnosis?
Pre-implantation diagnosis is being offered in some centres in order to detect an embryo affected by a genetic disorder. In order to carry out the test the mother's eggs are fertilised outside the body and one cell is taken from each developing embryo to ascertain which are affected. A small number of unaffected embryos are then placed in the mother's womb. In some centres this test is used in situations where a severe recessively inherited form of EB is a likely outcome of any pregnancy, and where the family have had a previously affected child. This test is particularly indicated for couples where termination of pregnancy will not, for whatever reason be countenanced. However this is not an 'easy' option as the technique is akin to IVF and as such it is not easy to establish a pregnancy.

It should be carefully noted that one form of EB cannot become another form, as the genetic mutations causing each form of EB are different. It is also usually the case that a

child affected with a dominant form of EB will be affected in a similar way to his or her affected parent.

If you receive your healthcare outside the UK you should contact your EB Centre for advice regarding pre-natal diagnosis as practises do vary from country to country.

Getting fit for pregnancy.

If you are a woman with EB who is considering having a child, you might like to consider getting your body in the best possible shape before becoming pregnant. There is a lot of general advice available regarding this including some GP's who offer pre-natal guidance. A midwife may run the latter service. If any concerns arise in this situation with regard to your EB please ask the GP or midwife to contact your dermatologist or your EB Nurse Specialist. In the context of EB you should ensure you have seen your healthcare team recently and had your blood checked, particularly for anaemia. It is also very important to check whether any of the medication you are taking will affect the baby. You may need to discontinue some medication and have substitutes for others. Additionally if you have a form of EB where eating can be problematic you might like to see a dietician to see how you can optimise your diet. If your hands are affected by your EB and you have contractures you might like to consider planning hand surgery before you become pregnant. This is because handling a new baby requires a certain amount of manual dexterity, and also because you may not wish to be admitted for hand surgery whilst your child is small. It will also be wise to speak to your EB team and your consultant before embarking on a pregnancy in order to consider whether there are any specific health issues you need to be aware of. If you are unable to speak to them before you become pregnant you should certainly speak to the EB team and your GP as soon as you are aware of a pregnancy.

Advice on preparing for pregnancy can be obtained from
Your GP
A midwife
Your EB team
Family planning clinic
Advice is available on the Internet from
www.fpa.org.uk www.bupa.co.uk www.bbc.co.uk/parenting.

Planning on caring for your baby.

This is something that parents often do not think about until pregnancy actually occurs. However in the context of EB it may be worth giving this issue some attention before you embark on a pregnancy. Caring for a small baby is tiring and requires a lot of physical effort. This effort increases as the child grows. Alongside this are the difficulties presented by such tasks as nappy changing, making up bottles, anchoring car seats and opening folding pushchairs. If you can, it might be worth spending time with friends who have babies and children in order to closely observe the tasks required, and which ones if any are likely to present problems. Our experience to date is that most parents with the severer forms of EB, particularly where there is hand involvement, will need some help in caring for their

baby. This might be the other parent, your own family or help obtained via social services. It is also worth asking your EB Nurse Specialist if you can be put in touch with another parent who has your form of EB. Although the challenges presented are unlikely to discourage you if you are committed to having a child it is better to make the choice from a position of having a certain amount of knowledge of what lies ahead.

Becoming pregnant

Many adults who have one of the severer forms of EB are often concerned about their ability to have a normal sex life. With proper consideration this should not be a problem. For women it is important that you are properly aroused and time spent in foreplay will ensure the vagina is well lubricated before having sex – it’s also more fun! Women have also told us that they prefer to abandon the ‘missionary position’ of the man on top in favour of woman on top, thus they can control the situation. Vaginal lubrication may also help although you should check that this does not contain a spermicide if you are hoping to become pregnant. You should also be clear with your partner about what might cause problems for your skin. If you are not having periods regularly it is possible that you are not ovulating and therefore you will not become pregnant. In this situation you should discuss this problem with your health care team and maybe see a gynaecologist.
For men. We have spoken to a number of men with EB who have an active sex live with few problems. Like women you should be clear with your partner about what you can tolerate and what you can’t. On the whole blistering of the penis does not seem to be a problem; however using a condom (buy condoms with extra lubrication) will help if blistering does occur, until the blister heals. The condom is rolled on over an erect penis and as it is perfectly smooth and soft it will do no damage. Wait until the penis becomes flaccid before attempting to remove it. Your specialist medical team and the EB Nurse Specialists are always willing to discuss any problems that may occur as a result of a sexual relationship. If when you come to clinic you would like to talk to a member of staff in private in order to discuss intimate concerns, please don’t hesitate to ask.

Pregnancy for Women with EB

Iron deficiency anaemia

Is a common problem in pregnancy and of course in some forms of EB. If you have had time to plan your pregnancy you will be helped by ensuring you have had a blood test to check your haemoglobin and iron levels. If these are low corrective treatment can be prescribed. In most cases oral iron will be prescribed. An iron infusion may be used in the severe forms of EB. It may also be helpful to see the dietician to discuss dietary sources of iron. Blood will be taken regularly during your pregnancy, and this may be a problem for some women with EB due to poor venous access. If this is the case you may need to have blood taken by your EB team and the results sent to the obstetric team. However on the whole this has not been too much of a problem in the women we know, possibly because of the increased circulating blood volume of pregnancy that may make taking blood easier.

Skin
On the whole reports, both written (1) (2) and verbal present a mixed picture with the skin improving in some women and deteriorating slightly in others. Some women feel that pregnancy is beneficial to their skin. The appearance of the skin improves in most women and this may be because your skin retains more moisture in pregnancy, and the effect of the increased blood volume can make you look pinker than normal – the so-called pregnancy ‘bloom’ (6). You may find it helpful to wear loose fitting clothing made of natural fibres such as cotton or linen, as most women feel very warm in pregnancy particularly during the later months. The stretching of the skin of the abdomen has been thought to be particularly problematic for women with EB, however this has not proved to be the case. Using a rich, bland moisturiser is claimed by some to reduce the incidence of stretch marks and it certainly promotes comfort. For most women with one of the severer forms of EB being overweight at the start of a pregnancy will not be a factor. However in those with the less severe forms being overweight may contribute to increased blistering during pregnancy. This is because the laying down of fat in pregnancy, in preparation for breast-feeding may lead to the formation of skin folds where sweating, friction and consequent skin loss become a problem. This may be eased by the application of a thin layer of cornflour in the folds. This reduces friction. You can also obtain dressings such as Mepilex Lite or Mepilex Transfer (Molnycke) from your EB Nurse or GP. These are very fine foam dressings that are coated with silicone making them easy to remove from your skin and can be used as padding in areas at risk of friction damage. Breasts also become heavier in pregnancy and some soreness may occur underneath them. Again the cornflour and the dressings as above will help. If you are able to wear a bra, you should be fitted for one that will support your breasts well with minimal friction. Bras with wide straps such as sports bras may be helpful and many shops, including Marks and Spencer’s provide an expert fitting service. Later in the pregnancy you may need a maternity bra, this is particularly so if you plan to breast-feed.

Constipation
As we all know this is a particular problem in EB, and is one of the less glamorous side effects of pregnancy. This is due in part to the pregnancy hormones, which slow the passage of food through your digestive tract and in later pregnancy the pressure of the growing baby on your rectum. Oral iron medication can also add to these difficulties. You should aim to have this problem well controlled early in the pregnancy. You will benefit from seeing a dietician to discuss the use of fibre-rich foods and food supplements. Drinking plenty of water and juices will also help as will exercise, if your EB allows you to do any. Lactulose is safe for use in pregnancy. However many people with EB now take Movicol, which is to be taken with caution in pregnancy. You should discuss the use of Movicol with your EB team/Obstetrician.
Some women develop haemorrhoids (piles) during pregnancy as a result of constipation. This is particularly unwelcome in EB as they add discomfort to an area, which may already be painful. Additionally piles do bleed and can contribute to anaemia.

Medication
As you know some drugs can affect the developing baby. It is therefore important that you discuss with your healthcare team which drugs are safe for use in pregnancy.

Morning sickness.

Morning sickness can be a problem for many pregnant women in the first 3 months of the pregnancy and contrary to the name the nausea can last all day. Since the disaster with thalidomide in the 60's, drugs are generally not given to correct this problem. However due to the fragility of the oesophagus in some forms of EB the effect of vomiting can be to cause further damage to the throat. This is due both to the force of the vomiting and the stomach acid. If this is a problem you should discuss it with your midwife who will be able to suggest some simple remedies. Advice is also available from NHS Direct (7) on www.besttreatments.co.uk search on morning sickness. . Many women also find that strong odours will bring on nausea so if possible these are best avoided. Remedies include ginger, taking vitamin B-12 or wearing an acupressure wristband. A company called Mothers Bliss sells lollipops designed to reduce pregnancy-induced nausea, these are called 'Preggie Pops' and are available in ginger flavour. They also sell an audiotape called 'Morningwell', which the makers claim aids relaxation and therefore reduce nausea Both theses products can be obtained by calling 0208-925-6150 or over the Internet at www.mothersbliss.co.uk If the nausea and vomiting is severe you should seek medical advice.

Heartburn

Heartburn is the 'burning' feeling in the oesophagus caused by the reflux of powerful stomach acid up the oesophagus. This is a particular problem in some forms of EB, and as with vomiting can cause further oesophageal damage. This problem can be further exacerbated in pregnancy due to the effect of the hormone progesterone which relaxes the sphincter at the top of the stomach allowing food and stomach acids to leak back up the oesophagus. In addition, the growing baby pushes the stomach upwards. Simple measures such as sleeping on two pillows will help as well as avoiding eating close to bedtime. You should also avoid coffee, rich foods and citrus fruit or juice. Some people with EB will be taking anti-reflux medication and/or antacids – you should discuss the wisdom of continuing these with your healthcare team.

Dental care

There used to be an old saying 'have a baby and loose at tooth', and whilst this is not the case, you are more at risk of developing gum disease in pregnancy, which may lead in the long term to loss of teeth. The pregnancy hormones can cause the gums to swell and become more fragile, leading to bleeding. This is bad news for women with DEB and non-H JEB as they frequently have fragile mouths and gums. It might therefore be helpful to see either your own dentist or the EB Specialist Dentist in order to get your mouth in as good a state as possible. Once you are pregnant dental care is free and remains so for the first year of your child's life.

The booking visit

This is the first visit to the antenatal team who will care for you during your pregnancy. It may be helpful to have information regarding your EB with you. This should include this booklet and any additional information your dermatologist or EB Nurse Specialist feels is helpful to provide. Please contact them for guidance. This also applies to men with EB whose partners are pregnant. A lot of anxiety can be caused when health professionals are not aware of the facts about EB, and it is seldom the case that health professionals will have seen EB before. This is particularly so with regard to information about genetic risks and it is helpful to all concerned to have clear information from the beginning.

Antenatal care

It is a good idea to inform your obstetric team from the beginning about your skin fragility and things that are likely to cause you problems. In the context of antenatal care this may include;

1. Taking of blood pressure – you may need padding between the blood pressure cuff and your skin in order that this very important test is carried out.
2. Abdominal palpation in order to assess the growth of the baby is carried out routinely at many of your antenatal visits. Ask the midwife or obstetrician to be very gentle to avoid blistering your abdomen.
3. Ultrasound in pregnancy should not cause a problem provided the probe is well lubricated and the scan is carried out gently.
4. Vaginal examinations are carried out in pregnancy and during labour. You should alert the person doing it to your need for extra care and ask them to lubricate their gloves very well. Blistering of the groin and perineal area may be a problem particularly in women with the Inversa* form of DEB. In the context of obstetric care you should warn the health-care professional of this problem and ask them to be extremely careful.
5. Taking of blood – this should be done with care and a gentle pair of hands may be preferable to the use of a tourniquet. Spirit swabs are sometimes used prior to the taking of blood, if this is the case ask the phlebotomist to swab the skin with care. Elastoplasts are often applied after blood taking so warn the phlebotomist beforehand that you cannot use plasters.
6. Urinanalysis is performed routinely during ant-natal care. If you have fragility of the genital region occasional false positives for blood may occur. The obstetric team should be made aware that this is a possibility. Occasionally people with EB do have some fragility of the urinary tract with consequent bleeding. If this is a problem for you please mention it to your obstetric team. These issues will also be mentioned in any letter your EB Consultant sends to your obstetrician.
7. If you suffer with wound infections, particularly in the genital region if you are planning a normal delivery, or in the abdominal region if you are having a caesarean section you should ask for wound swabs to be taken and an appropriate antibiotic given. Topical treatments may also be helpful. If you have wound infections of your hands it is important to clear these up before your baby arrives to ensure they are not exposed to any unnecessary risks.

* The Inversa form of DEB the body extremities i.e. limbs tend to be unaffected, whist areas such as the groin and the lining of the oesophagus can be particularly badly affected

If at any stage you are concerned about information being given with regard to your EB please do contact your EB team for clarification.

Planning your delivery

You and your obstetric team will decide the method of delivery of your baby with input from the EB team. You should be reassured that women with EB have delivered babies successfully by vaginal delivery (1,2) as well as caesarean section. If you feel anxious

about a vaginal delivery because of the fragility of the vagina or vulval area you should discuss this with your obstetrician. Our experience to date has been that women are usually given a choice, unless obstetric reasons dictate a particular method of delivery. All the women that we have worked with who have had a caesarean section have healed well, or if not this has been for reasons other than their EB.
You should have an information pack (including this booklet) regarding your condition to give to the obstetric team and the EB Nurse Specialists are very happy to visit the hospital where you will be having your baby to discuss your special needs. Along with the information pack, you should also have a supply of suitable dressings to be applied if you have a caesarean section. Even if you have planned a normal delivery you should have suitable dressings in case of an emergency caesarean section. The dressings we commonly supply are;

- Mepitel
- Mepilex
- Mepilex Lite
- Mepilex Transfer.

All these dressings are made by Molnycke and are coated with silicone to aid ease of removal. All can be obtained on prescription from your GP.

- Mepitel and Mepiform can be cut into thin strips and used to anchor intravenous cannula. If you use Mepitel a soft bandage will also be required. Mepitac, a silicone coated tape can also be used.
- Mepiform or Mepitac can be used to secure the epidural catheter (if you have one), but Mepiform should be cut into thin strips and removed with care by rolling it back on itself rather than lifting it at a 90-degree angle to the skin. Children with EB use Mepiform frequently, however some adults feel it is too sticky and we have had one case of it adhering. You are therefore advised to try a small piece cut into a thin strip on a less fragile area before using it to anchor IV's, epidurals etc.

The use of all these dressings can be discussed with your EB Nurse Specialist.

Normal delivery

If you and your obstetric team have decided that you will have a normal delivery there are a few issues with regard to your EB that should be borne in mind.

- Any vaginal or abdominal examinations should be performed with care.
- No adherent products should be used, as there are adequate substitutes.
- If you use Entonox you may need to apply lubrication to your lips (e.g. Vaseline) to stop the mouthpiece causing damage to your lips.
- Most hospitals allow you to labour and deliver on an ordinary bed, which for a limited number of hours should not cause a problem. However the delivery couch, if used can often be quite hard and you may have to ask for it to be padded.
- If you need an infusion to 'speed up' labour ask for Mepitel or Mepiform to be used to secure it in place (See above)

- In an effort to help you when you are ‘pushing’ your baby out people will sometimes hold your legs – if this is the case you should ask them to use padding between their hands and you. This is particularly so if you are sweaty (as many women in labour are) and if they have gloved hands.
- The midwife may offer to rub your back – this can be very soothing but you may need to apply cornflour or use a massage oil to stop friction damage.
- Occasionally women are catheterised prior to delivery if they have difficulty emptying their bladders (this may delay the descent of your baby’s head), again staff should be warned to carry this out with great care, particularly if you have had any blistering or signs of fragility in the urinary tract. If they need to tape the catheter in place a thin strip of Mepiform or a bandage should be used rather than tape.
- Many women sustain a slight tear or have an episiotomy to prevent an extensive perineal tear whilst delivering their babies head. There is no particular reason you should have an episiotomy just because you have EB, as ‘tears’ do heal well (8). We have had women with EB who have sustained a perineal tear, which has healed well. However this is a decision that will be made by your midwife, in consultation with you as she observes your perineum during delivery.

Caesarean Section

Usually a caesarean section will have been planned in advance allowing for staff to be briefed about your special needs. However occasionally the obstetric team will decide that for your and your baby’s welfare an emergency caesarean section is needed. This can be quite alarming, particularly if you have EB. However try not to panic and show staff the briefing notes regarding the care of women with EB during childbirth. Staff should have been prepared for this possibility in the antenatal period.

Your EB Nurse should supply you with dressings that can be used over your caesarean section wound. These are normally

- Mepilex
- Mepilex Transfer
- Mepilex Lite
- Mepitel with a secondary dressing
- All these dressings are made by Molnycke and are available on prescription from your GP. It is advisable to have a selection of these dressings in order that the midwife can select the most appropriate one for you.

PLEASE SEE SECTION AT BACK OF BOOKLET ‘INFORMATION FOR HEALTH PROFESSIONALS’ FOR FURTHER DETAILS.

Post- Natal Care

Breast or bottle?

Many women with EB will assume it is not a possibility to breast-feed, and indeed for some women the extreme fragility of their skin will not easily allow for them to make this choice. However we do know some women who have breast-fed despite their EB. This may be for just the first few days when the baby gets the first milk or colostrum which is rich in

antibodies, or may go on for many months. However no woman with EB should feel the pressure to breast-feed, as you are the one who is best able to judge whether this is something that might be a possibility for you. If you do elect to try and breast feed ask one of the midwives to ensure the baby is 'latched onto' the breast correctly. This is of vital importance to all breast feeders, but is crucial in the case of the women with EB in order to prevent soreness. The most important thing is to ensure the baby does not take just the nipple in to his/her mouth – they should also have some of the areola, which has tougher skin. This correct positioning also helps the milk to flow. If you do develop sore nipples you might be helped by using a nipple shield and your midwife will guide you on this. One woman with EB has told us that it is possible to feed 'through the pain' and come out the other side a successful breast feeder, however this takes an enormous amount of dedication and is not achievable for all women with EB.

Most women who do elect to breast-feed will need a supportive bra, which can be padded with Mepilex Lite or Mepilex Transfer to reduce friction. Women who breast-feed usually use breast pads to absorb any excess milk. These tend to be made of materials that may adhere to any open areas on your nipples. You might therefore like to use Mepilex Lite or Mepilex Transfer as substitute breast-pads.

Bottle-feeding

If you elect to bottle feed you must not feel guilty. Breast-feeding is not easily achieved if you do not have EB, and is frankly impossible for some women with EB. The considerations in EB, for an affected mother or father are ensuring you can hold the bottle comfortably and can undo the top with ease. We have had one woman who used her chin and chest as an additional help for her hand when holding the bottle. You might also like to buy a steam sterilizer rather than a Milton sterilizer, as you may find Milton will sting any open wounds you might have on your hands.

Sanitary towels

You will need to use sanitary towels in the post-natal period and on the whole we have found 'Always' towels to be the most suitable for women with EB. You may find the towels designed for use at night are more absorbent and therefore more suitable for use in this period.

Help at Home

For all parents with a new baby the first few weeks at home are both exciting and exhausting. You may need additional help to care for your baby, other than that that can be provided by your partner or family. If you feel that this might be the case please discuss your needs with your EB Nurse Specialist or one of the DebRA Social Care Team. A suitable package of assistance can usually be organised via Social Services and this should be done, if possible in the antenatal period as it can take some time to agree funding and find suitable carers to assist you. If you have any anxieties about this your EB Nurse Specialist can put you in touch with other families who have used this service.

Equipment

The market is awash with baby equipment, some of which is essential and some of which is expensive and entirely unnecessary. As many of the pushchairs, car seats etc are difficult to manipulate even if you have full hand function you will be well advised to visit a large store such as John Lewis or one of the bigger branches of Mothercare to try out equipment

before you buy. Your EB Nurse Specialist will be able to put you in touch with other families who have faced these difficulties and who may be able to advise you. However as the market for baby equipment is so huge and constantly being updated it is difficult to advise on specific pieces of equipment. The other variable is of course that all people with EB are different with different capabilities. However one piece of general advice given to all potential parents is to make your buying rather minimalist until you work out exactly what it is you will need and use. Your midwife, health visitor or ante-natal class teacher will be able to advise you on what is absolutely necessary before your baby is born.

All that remains now is to wish you the very best of luck and much happiness with your new baby.

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A charity registered in England and Wales (1084958) and Scotland (SCO39654)

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Jackie Hitchen – Senior EB Nurse Specialist (North)
Telephone 0121-705-7373 E-mail
Pauline Graham-King – EB Nurse Specialist
Telephone 0191-564-0563 E Mail

South (Of Birmingham)
Liz Pillay – Senior EB Nurse Specialist (South)
Telephone 0208-810-1265 E Mail liz.pillay@debra.org.uk
Jennie Hon – EB Nurse Specialist Telephone 01489-557486.
E-mail jennie.hon@debra.org.uk

EB Nurse Specialists at Great Ormond St Hospital (Paediatric Team)
Telephone 0207-829-7808
Jacqueline Denyer –Senior EB Nurse Specialist
E Mail Jackie.denyer@dial.pipex.com
Leslie Foster – EB Nurse Specialist E Mail fostel@gosh.nhs.uk
Sally Turner – EB Nurse Specialist E Mail turnes@gosh.nhs.uk

EB Nurse Specialists (Birmingham and North)
Telephone 0121-333-8224/5 E Mail eb.team@bch.nhs.uk
Ruth Ward – Senior EB Nurse Specialist
Natalie Hadley – EB Nurse Specialist
Dawn James – EB Nurse Specialist

EB Nurse Specialist (Scotland)
Telephone 0141-6462124
Evelyn Gilday – Paediatric Nurse Specialist

Hospitals having specialist EB Teams

St Thomas's Hospital (Adults)
Lambeth Palace Rd
London SE1 7EH
Telephone 0207-188-7188

Consultants
Professor John McGrath Telephone 0207-188-6409
Dr Jemma Mellerio Telephone 0207-188-6399
Specialist EB Registrar Bleep 0582 (Via switchboard as above)

Heartlands Hospital (Adults)
Lode Lane
Solihull B91 2JL
Telephone 0121 424 2000
Consultant Dr Adrian Heagerty Telephone 0121 424 4563

Edinburgh Royal Infirmary (Adults)
Lauriston Place
Edinburgh EH3 9YW
Telephone 0131 536 1000/2456
Consultant Dr Helen Horn

Great Ormond Street Hospital (Children)
Great Ormond Street
London WC1N 3JH
Telephone 0207-829-7808
Consultants
Dr Jemma Mellerio Telephone 0207-829-7808
Dr Anna Martinez Telephone 0207-829-7808

Birmingham Children's Hospital
Diana, Princess of Wales Children's Hospital
Steelhouse Lane
Birmingham B4 6NH
Telephone 0121 333 9999
Consultant Dr Celia Moss Telephone 0121 333 8228