

Extreme Preterm Pathway (document 5)

Parent Information Leaflet

Who is this information for?

You have been given this information because your healthcare team think that you may have your baby extremely early (prematurely). You and your family need to know what is likely to happen, for you and your baby, if this occurs. The maternity team and neonatal team (the doctors and nurses who are experts at dealing with premature babies) will talk to you about this in detail as well as giving you this information leaflet and you will have the opportunity to ask any questions that you wish.

What does this mean?

A pregnancy usually lasts for about 40 weeks. How many weeks you are along in your pregnancy (gestation) is usually worked out from an ultrasound scan at around 12 weeks (your dating scan).

Babies born before 22 weeks are so small and fragile that they do not survive. Their lungs and other organs are not ready for them to live outside the womb. Such tiny babies may show signs of life for a short time after birth but even with the very best neonatal care, they cannot survive for more than a few minutes or hours.











Babies born from 22 weeks sometimes are not strong enough to survive labour and either vaginal (natural) or caesarean birth. If they are born alive, they may be able to survive if they receive intensive medical treatment. However, some extremely premature babies sadly die despite this treatment. The earlier the baby is born, the less likely it is that they will be able to survive (please see table below for survival rates).

Babies who are born extremely early are also at increased risk of problems with health and development as they grow up. These risks get higher the more prematurely (earlier) a baby is born and are especially common in those children born before 25 weeks of gestation. Health problems may include; breathing difficulties, gut problems (including issues with feeding) and eye problems. Developmental problems may include; problems with movement, learning and behaviour. These various health and developmental issues can range from mild to very severe. You can find a more detailed description of such problems on the following page.

The doctors and midwives will talk to you about what they expect for your baby. In some situations, there are difficult decisions to be made about how to care for your baby before and after birth. The right thing to do can be different for different families. That is why it is important that you are fully informed and feel able to let the doctors and midwives know your wishes for your baby.

'Outcome'

Below is a description of what we know about the small numbers of babies born extremely prematurely in the whole of the UK, and of those who survive how many are likely to have a 'severe disability' as they grow up.

Gestation:	Survival:	Severe Disability in Survivors:
22 weeks	3 in 10 babies survive 	1 in 3 babies has a severe disability 
23 weeks	4 in 10 babies survive 	1 in 4 babies has a severe disability 
24 weeks	6 in 10 babies survive 	1 in 7 babies has a severe disability 
25 weeks	7 in 10 babies survive 	1 in 7 babies has a severe disability 
26 weeks	8 in 10 babies survive 	1 in 10 babies has a severe disability 

The majority of babies grow up without severe disability. A proportion of these children without severe disability could develop other problems as they grow up which may mean, for example, that they need extra help in school or have some problems with walking or moving around. Some may have social and emotional problems. The likelihood that children have these problems is greatest the earlier they are born, and problems are most common in children born before 25 weeks of gestation.

Survival data from the Wales Neonatal Network is available in the network's annual report. These reports contain survival and outcome statistics for all babies born prematurely who were considered well enough following delivery to be admitted to a Welsh hospital. The annual reports are available by following this link: <http://www.walesneonatalnetwork.wales.nhs.uk/reports-publications> or, if using a search engine, search

for “Wales Neonatal Network Annual Report”. These reports are written primarily for medical professionals, so if you have any questions after reading an annual report, please speak to your care team.

What does ‘severe disability’ mean?

Disability can mean different things to different people and can cover a wide spectrum of problems. When talking about babies who have been born extremely prematurely, the term ‘severe disability’ includes problems such as:

- Not being able to walk or even get around independently (this includes conditions such as severe cerebral palsy)
- Being unable to talk, or see or hear properly
- Difficulties with swallowing or feeding safely
- Having multiple health problems with frequent visits to hospital
- Needing to attend separate school for children with special educational needs
- Being unable to care for themselves or live independently as they grow up

What does this mean for your baby?

The figures above are an average for all babies born extremely prematurely in the UK, but every baby and family are different. It is impossible to predict exactly what will happen for every child. The chances for your baby depend on a number of different things. As well as how early they are born, it also matters how much your baby weighs when it is born, whether it is a boy or girl, whether it is a multiple birth and also how well you and your baby are around the time of birth. The neonatal team will be able to go into further details about how this may affect your baby, either before or after the birth as needed. If they are admitted to neonatal intensive care, there can be further unpredictable medical problems during their admission that may affect your baby’s survival or ‘outcome’. Your neonatal team can speak with you further about this if you wish.

What can parents do?

What is right for your baby and your family is very individual to you. Your doctors will talk with you about your situation and seek to understand what is important for you and your family. They will support and guide you and involve you in making decisions about treatment for your baby. Thinking about your hopes, your wishes, and your fears about your baby can help the team to support you in the best way possible.

What may happen with my baby?

Stillbirth: Some babies who are born this early do not survive labour and delivery. If this happens, your baby will be given to you to hold for as long as you would like. You will have the opportunity to spend as much time with them as you would like and to make memories with them. Under UK law, only babies born after 24 completed weeks of gestation can be registered as stillborn. Bereavement support and facilities will be made available to you if you wish.

Neonatal Intensive Care (NICU): You and the team may decide that starting neonatal intensive care would be best for your baby. This will mean you will need some extra treatments before your baby is born. You will be given steroids (up to two injections 12 to 24 hours apart) to help the baby’s lungs and brain and magnesium (via a “drip” or injection) which also helps to protect your baby’s brain. You may need to be transferred to a specialist centre, ideally before you have your baby, but there may not be time to do this safely. The team will also talk to you about the treatment that will be given to your baby immediately after birth and what may happen next depending on how your baby reacts to this treatment. They will also discuss the importance and benefits of breastmilk for babies born this early. Despite your baby being born extremely

prematurely, your body will still be able to produce breastmilk, and the midwives and neonatal team will help support you to express breastmilk if you wish.

If you and the team decide that intensive care is best for your baby, you should be offered the opportunity to be shown around the neonatal unit (if there is time for this) as it may help to see the neonatal unit and meet the people that work there before your baby is born. You can also talk to staff about expressing breast milk, as this makes such a big difference for premature babies.

Comfort Care: You and the team may decide that it will be best to provide comfort care to your baby, either because there is an extremely high risk that your baby will not survive or he/she is likely to suffer from life-long disability even with the very best treatment. Comfort care is also known as palliative care and is special care for babies whose time is precious but short. It means providing treatments that will make their time as comfortable as possible. We will help you to be part of this care if you would like. Holding your baby close to you and talking to your baby may be very comforting.

More information about comfort care or 'palliative care' for babies is available from Together for Short Lives (further details are at the bottom of this leaflet). Please feel free to ask your healthcare team further questions about comfort care if you wish.

What if my baby doesn't come now?

If your baby does not come in the next few days, their chances may improve. Ideally, they will stay in the womb for as long as possible (depending on the health of you and your baby).

If that happens, there may be different options for you and your baby around the time of birth. That will depend on when your baby comes and on other things that affect the baby's chances of responding to treatment. If this is the case, your healthcare team will continue to speak with you about what has changed and what different options may be available depending on when your baby is likely to be born, and you will be able to discuss and revise your agreed plans accordingly.

What might my baby look like?

Babies born this early can weigh less than half a kilogram (1 small packet of sugar) and can look quite different to how we imagine a newborn baby. Their skin is shiny and thin and covered with fine hair. Sometimes babies can be quite bruised from the birth. If the baby has died before being born, they will usually be still. Occasionally, where babies have died very close to being born, they may make brief reflex movements that disappear very quickly.

If your baby is born alive, they may take a breath and make a small cry, or they may not breathe and be quiet. Their eyes may not be able to open yet. The baby's colour is often purple or blue to start with.

Can I see my baby?

Yes. If your baby has been stillborn you can hold and cuddle them for as long as you and your partner wish, and you will have all the time you need to make memories with your baby. We will respect and support all parents' wishes around this difficult time.

If your baby is being admitted to neonatal intensive care, then there may be a delay as the neonatal team are caring for your baby immediately after delivery and are ensuring they are able to safely move your baby to intensive care. Before they are taken to neonatal intensive care, you may have the opportunity to briefly

see and touch your baby and to take photos if you wish, depending on how well they are following birth. Unfortunately, because of some of the medical equipment your baby may need to help keep them well following birth, you may not be able to hold them just yet. Once you have recovered from the birth, you and your partner will be able to visit them on the neonatal unit as much as you wish.

Transfer to a different hospital

When you have decided with the obstetric and neonatal care teams that starting neonatal intensive care would be best for your baby, research shows that for babies born before 27 weeks of gestation it is best, whenever possible, to be born in a specialist maternity unit with a specialist Neonatal Intensive Care Unit (sometimes called a 'Level 3 NICU'). If a baby born before 27 weeks of gestation is born in a maternity unit (or at home) where there is not a specialist NICU, then we know that the baby will generally do better if moved to a specialist NICU after birth.

If your hospital does not have a specialist NICU, this may mean that you will be offered transfer to one of these centres before your baby is born. We understand that this can be a very anxious time and that you may be moved quite some distance from home. It can be very difficult to predict which mothers will deliver early and so some mothers may be moved to another hospital and their baby not born early.

It may also be the case that you are considered too unwell or too far on in labour to be safely moved to another hospital before your baby is born. When it is not possible to transfer you before the baby has been born, your baby may be transferred by a specialist Neonatal Transport Team after the birth. Your own health needs may mean you will be unable to travel immediately with your baby, but your local maternity team will do everything they can to move you to the same unit as your baby as soon as it is safe to do so. If your baby does need to be transferred to another hospital after delivery, the specialist neonatal transfer team will come and speak with you, and you will be able to see your baby before the transfer in most circumstances.

We appreciate that moving to another hospital can be distressing for you and your family, especially if you are separated from your baby for a while. We will talk to you about this in more detail if it is decided that this is the best option for your family.

What if I have more questions?

This information has been provided to you as part of the conversation that your healthcare team will have with you about your baby. If you have any other questions do make sure you ask your doctors, midwives and nurses to answer them, so you have all the information you need about your situation and the options available to you. Your healthcare team want to work with you make the best decision for your baby and for your family.

If after your discussion with your healthcare team you or your family have further questions, please feel free to request a follow-up discussion. Many families find this helpful. You may find it beneficial to write down your questions before the discussion to ensure all of your questions are answered.

Further sources of information and support:



Bliss - Premature and sick baby charity

<http://www.bliss.org.uk/>

Phone: 020 7378 1122

E mail: ask@bliss.org.uk



Together for Short Lives - Charity for babies and children with life-limiting conditions

<https://www.togetherforshortlives.org.uk/>

Helpline: 0808 8088 100



Sands - Stillbirth and neonatal death charity

<https://www.uk-sands.org/>

Helpline: 0808 1643 332

Email: helpline@sands.org.uk



Tommy's - fund research into miscarriage, stillbirth and premature birth, and provide pregnancy health information to parents.

<https://www.tommys.org>

Helpline: 0800 0147 800

Email: midwife@tommys.org

Adapted from British Association of Perinatal Medicine (BAPM) Perinatal Management of Extreme Preterm Birth before 27 weeks of gestation - A Framework for Practice. October 2019.