

THAMES VALLEY & WESSEX NEONATAL OPERATIONAL DELIVERY NETWORK

Too small too soon

**Information for parents of babies born early
around 22 to 24 weeks**

Patient Information Booklet

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 (specialist baby doctors and nurses) team will talk to you about this in detail as well as giving you this information 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).

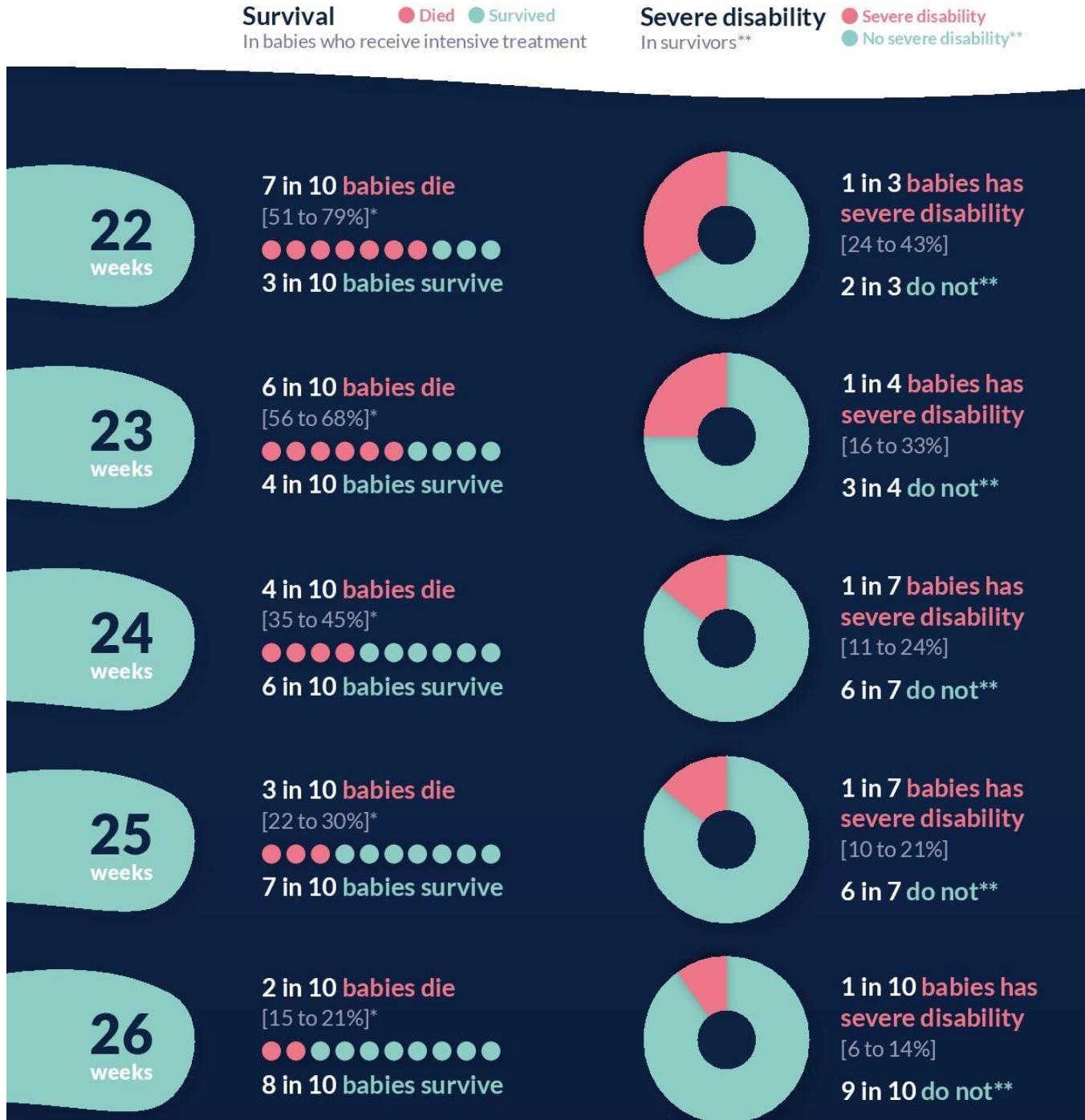
Babies born before 22 weeks are so small and fragile that they do not survive. Their lungs and other organs are not ready for them to live outside the womb. Such tiny babies may show signs of life for a short time after birth but even with the very best neonatal care they cannot survive for more than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

Babies born from 22 weeks sometimes are not strong enough to survive labour and either vaginal (normal) 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.

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 earlier (more prematurely) 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 difficulties with feeding) and eye problems. Developmental problems may include problems with movement, learning and behaviour that can range from mild to very severe; such problems are described 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 for babies born alive between 22 & 26 weeks' gestation[†]



The survival percentages are for babies who are born alive and receive active stabilisation.

[†]Some babies born this prematurely cannot survive labour and birth

* The lower and upper figures indicate how certain we are of the true survival rate.

****** Up to a quarter of children without severe disability may nonetheless have milder forms of disability such as learning difficulty, mild cerebral palsy or behavioural problems.

'Outcome'

These pictures are based on what we know about the small number of babies born extremely prematurely in the UK. They show how many babies survive out of every 10 babies born alive this early, and of those who do survive, how many are likely to have a 'severe disability' when they grow up.

The majority of babies grow up without severe disability. A proportion of these children will develop other problems as they grow up which may mean, for example, that they need extra help in school or have problems with walking or moving around. Some may have social and emotional problems. The frequency with which children have these problems is greatest the earlier they are born, and problems are most common in children born at 22 to 24 weeks of gestation.

The chance for your baby depends 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.

What does 'severe disability' mean?

Disability can mean different things to different people. 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?

We don't know exactly the future for your baby. Every baby is different and it is important to talk with your doctors and midwife. They will give you specific information about your own and your baby's condition.

Problems for premature babies

We find that babies born this early have some problems. Knowing more about these problems may help you work out which option is right for your baby.

Some problems affect the baby mostly while they are very small, while other problems affect the baby later in life if they survive.

Babies might have none of these problems several of these problems, or all of them.

Problems in the NICU

Lung problems

Babies born this early are often very sick after birth because their lungs are small and immature. At only 22 to 24 weeks the lung sacs that are important for breathing are only just starting to develop. Some babies cannot get enough oxygen because of this. Other babies develop scarring or damage to their lungs. The machines that help babies to breathe can lead to stretching or tearing of their fragile lung sacs. Babies who develop scarring of their lungs can improve with time, but may need extra oxygen and help with their breathing for several months.

Heart problems

Babies may have problems with low blood pressure after birth, and poor supply of blood to their body. They often need strong medicines to support their blood pressure. They may have problems with a blood vessel next to the heart (the 'duct'). The duct normally closes after birth, but in premature babies may stay open. Most babies born this early receive medicines to try to help the duct to close. Some need to have heart surgery to close the duct.

Brain problems

Babies may develop brain damage due to problems with the supply of oxygen and blood. Some babies develop bleeding in the middle of their brain. This is called 'intraventricular haemorrhage' or IVH. It can be picked up on ultrasound of the baby's brain. Mild forms of IVH may not be a big problem, but more severe bleeding increases the chance that the baby will have serious learning or movement problems when they are older if they survive. Babies can also develop damage to the brain from lack of oxygen. This is hard to see at first on ultrasound, but may show up later as cysts or 'holes'.

Eye problems

The back of the eye is still growing and developing for babies born very early. As a result of being born so soon, being sick, and needing extra oxygen, some babies develop a problem where the blood vessels at the back of their eyes grow too fast (called retinopathy). This can affect the baby's vision later.

Infections of blood or bowel

Babies born this early have problems because their immune system is not very strong. They are sensitive to infection. Infection can enter the bloodstream or it can affect organs such as the bowel. Serious infections can be life threatening. Infections of the bowel may mean that the baby needs surgery to remove part of their bowel.

Problems later in life

Most parents want to know whether their baby will have long-term health problems or disabilities if they survive, and how bad these would be.

There are different types of problems that can affect babies who are born very early.

Problems with movement

Damage to the baby's brain from being born so early can lead to the baby having problems with their movement later in life. This can mean that their muscles are stiff or hard to control (called cerebral palsy). Cerebral palsy varies. It can sometimes be quite mild. For example, the child might have trouble moving one hand or one leg, but have no trouble moving other parts of their body. Children with mild cerebral palsy are usually able to do most things like other children and go to a regular school. Or, cerebral palsy can be much more severe. Some children have problems affecting all of the muscles in their body. They may not be able to walk. They may need others to help them with most or all of their everyday needs.

Problems with learning

A baby's brain is still growing and developing in the last months of pregnancy. For the premature baby this has to occur outside the womb when they may be very sick. Children who have been born this early may be slower with their learning and development than children who were born on time. Many will need some extra help with their school work. Problems with attention and behaviour are also more common. Learning problems can be mild, or they can be much more severe affecting the child's ability to communicate, care for themselves and later on, live independently.

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.

Neonatal Intensive Care: 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 to help the baby's lungs and brain and magnesium 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.

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](#).

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 the conversation 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. Their eyes may not be able to open yet. The baby's colour is often purple or blue to start with.

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.

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 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 to make the best decision for your baby and for your family.

This space is for the health care team who are discussing this with you to write extra details about your baby or babies.

You may want to use this space to write down some questions to discuss with the team.

Many families find it useful to have follow-up discussions, so please ask to speak to the neonatal and maternity team again at any point.

Useful contact details:

Bliss - Premature and sick baby charity

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

SSNAP

Support for the Sick Newborn and Parent (Oxford charity)

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

Telephone: 01865 221359

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 1643332

Email helpline@sands.org.uk

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