

South East Coast Neonatal Network

Too small too soon

Information for parents of babies born early around 23 to 24 weeks

You have been given this information because your doctors think that you may have your baby very soon. You and your family need to know what is likely to happen for your baby and the risks of any treatments.

A normal pregnancy lasts for 40 weeks. Babies born after only 23 or 24 weeks are so small and fragile that they often do not survive. Their lungs, heart and brain are not ready for them to live outside the womb without intensive medical treatment.

There is a chance that your baby will survive, but also a chance that treatment could cause suffering and harm. Treatment involves being in intensive care and on a breathing machine for weeks or months. It means having many procedures that could be painful or uncomfortable for your baby. Some babies need surgery on their heart, eyes or bowel. Babies can have problems in the early days and months or go on to have lifelong problems or permanent disability.

Parents have difficult decisions to make at this time and your views and values are very important.

Your doctors will talk with you about your situation in more detail.

Patient Information Booklet

What are the options?

For babies born at around 23 or 24 weeks doctors may provide **intensive treatment** or they may provide '**comfort care**' for the precious but short time your baby lives. What is right for your baby and your family is different in different situations.

In making these difficult decisions it may help to ask yourself:

- 'What is most likely to happen for my baby?'
- 'What is the worst thing that could happen for my baby?' 'What am I most afraid of?'

Your doctors will talk with you about your situation and try to understand what is important for you and your family. There is no right or wrong answer.

Intensive treatment

If you feel that intensive treatment is right for your baby, a breathing tube would be put into their nose or mouth. They would be taken to a Neonatal Intensive Care Unit. The chance of survival with intensive treatment is about 50:50.

Comfort care

If you feel that comfort care is right for your baby, they would be carefully dried and wrapped and (if you would like this) given to you to hold. They would have treatments that make their short time as comfortable as possible. Doctors would avoid treatments that cannot help them or might cause them pain or discomfort.

**It is important to talk with your doctors.
They will give you more information about your own situation.**

NOTES:

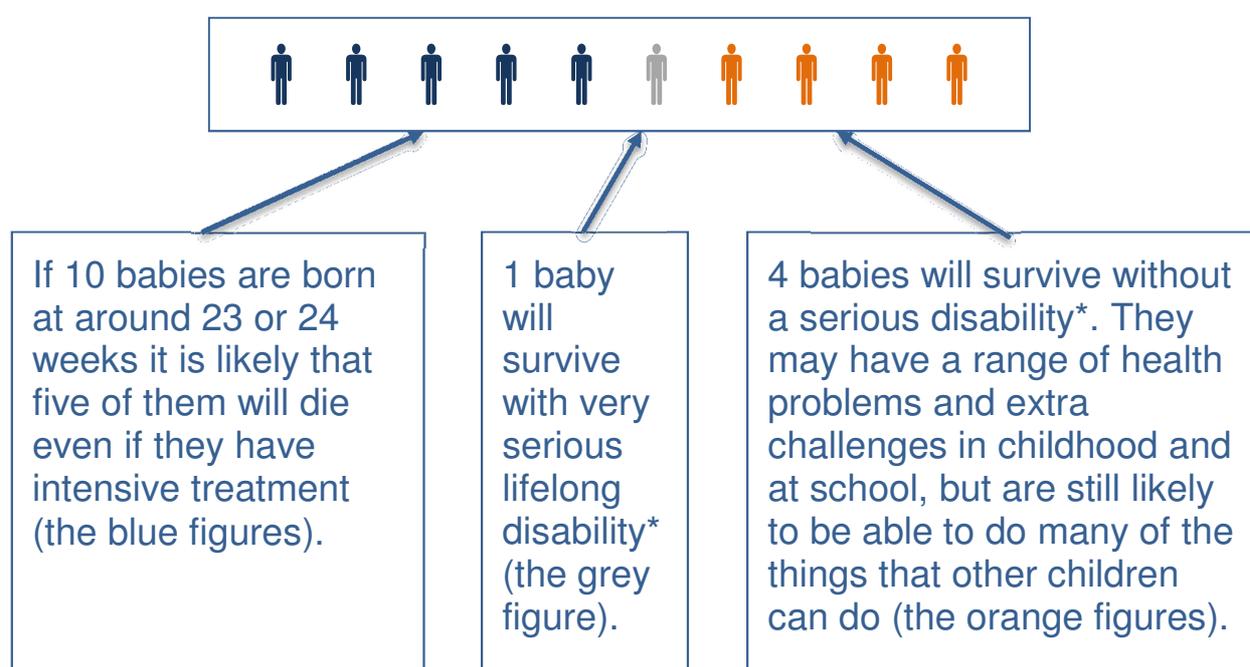
The big picture

In making your decisions, it can be helpful to look at the big picture.

For babies born at 23 or 24 weeks the chance of survival if they receive intensive treatment is about 50:50.

If the baby survives they may have one or more of the problems described in these pages. The problems might be serious or mild. They might be just while they are young, or they may be lifelong. About 1 in 4 or 1 in 5 children who survive have very serious problems affecting their movement (cerebral palsy) or learning or both that mean they will need lifelong help and support for everyday activities.

The diagram below shows this big picture.



**See later pages for more on disability*

We don't know what will happen for your child. We don't know if they will be one of the babies who survive, whether they will have a serious disability, or whether they will die. The chances for your baby may be better than these figures or they may be worse. Your doctor can give you some idea.

NOTES:

How your baby might look

Babies born this early often weigh as little as half a kilogram (1 small packet of sugar). Their skin is shiny, and thin, and covered with fine hair. Sometimes babies can be quite bruised from birth. Their eyes may not be able to open

The birth

Some babies who are born this early die during labour or delivery. The stress of the birth is too much for them. If this happens your baby would be carefully dried and wrapped and (if you would like this) given to you to hold.

If your baby is born alive there are two main options:

1. Intensive treatment

If you feel intensive treatment is right for your baby, doctors and nurses from the neonatal unit will be there for the birth.

They will quickly take your baby to an area in the delivery room or operating suite where they can be cared for by the newborn team.

Your baby would be specially wrapped to keep them warm. They would have an oxygen mask put on their face to help their breathing and inflate their lungs. They may have a breathing tube put in their nose or mouth. Once this is done the doctors can give the baby some medicine to help their lungs work better. For most babies, helping them breathe is enough to make them stable.

Occasionally if a baby's heartbeat stays very slow doctors may massage their chest (CPR) or give them medicines.

If possible you will have a chance to see and touch your baby before they are taken to the Neonatal Intensive Care Unit (NICU). If there is no NICU in your hospital a specialised transport team would take your baby to a large hospital where they can be cared for.

In the NICU

In the NICU your baby would be connected to life support with a breathing machine. They would be connected to wires measuring their oxygen, heartbeat and blood pressure. They would have a feeding tube in their nose. They may need two tubes in their blood vessels to give medicines and take blood samples. To start with these tubes are often put in the baby's belly button, but they might be in their hands or feet. The baby would be given medicine if they appear to be uncomfortable or in pain.

The first few days

The first few days after birth can be very difficult for babies born this early. They may not respond to treatment and may die in the delivery room or in the NICU. The baby may make it through this time but develop a serious complication due to being born so early.

Providing intensive treatment or comfort care

Doctors always think carefully about whether intensive treatment will help the patient or do more harm than good. If your baby has intensive treatment but is not responding, or develops a serious problem (e.g. bleeding in the brain) doctors will talk to you about whether intensive treatment is still the right thing to do, or it is time to move to comfort care.

2. Comfort care

When the outlook for a baby is very poor, some families ask doctors to provide comfort care for their baby at birth. They do not want to put their baby through intensive medical treatments that might not work, or that might cause the baby to suffer. Although it is extremely difficult to accept that a baby is not going to survive, for some families a decision to let their baby go peacefully is right for their baby.

About comfort care

Comfort care is special care provided for babies whose time is precious but short. It means providing treatments for the baby to make their short time as comfortable as possible. Doctors and nurses would avoid treatments that cannot help the baby and might cause them pain or discomfort.

If you felt that this was the right choice for your baby, doctors and midwives who specialise in the care of women and babies would be present at the birth to look after you and your baby.

The baby would be dried and wrapped and (if you would like this) given to you to hold. The baby may breathe and have a heartbeat. Their breathing may be fast or slow. They may have pauses (breaks) in their breathing, and may take deep infrequent breaths (gasps). This is part of the dying process and does not mean your baby is in pain. The baby's colour is often purple or blue because of low oxygen levels.

How long might my baby live?

It is hard to know how long you would have with your baby. Some babies die before they are born. Other babies receiving comfort care live for a short time. On average, babies born between 23 and 24 weeks who receive comfort care live for about one hour, but it might be shorter or longer for your baby. Babies do not usually appear to be uncomfortable or in pain. However, if they do there are treatments that can help them feel more comfortable.

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 23 or 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. About 2 in 3 babies develop this problem (called bronchopulmonary dysplasia - BPD).

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'. About 2 or 3 out of every 10 babies born this early develop a significant early brain problem.

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. About 3 in 10 babies born this early have serious problems with retinopathy and need laser treatment to one or both of their eyes.

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. Serious bowel infections affect about 1 in 10 babies.

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.

About 2 in 10 children who have been born this early, and who survive, have cerebral palsy. Half of these children (1 in 10) have one of the more serious forms of cerebral palsy.

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. Most learning problems in children who were born very early are of a mild or moderate degree. About 1 in 10 children who survives has a severe learning disability.

Disability

'Disability' usually means a problem that affects someone's ability to do everyday things. There is a wide range of disabilities and they may affect one or many parts of a person's life. They might be mild or very severe.

Sometimes parents find the possibility that their child might have a disability scary or distressing.

It is important to know that with support people with disabilities are often able to do most things just as well (or better) than people without disabilities. Most people with disabilities report being generally happy with their life. How much a person is affected by their disability can depend a lot on how much support they can get.

When we talk about serious lifelong disabilities in these pages, we are referring to movement problems (cerebral palsy) that mean a child is not likely to ever be able to walk. We are also referring to learning problems that mean a child has major problems caring for themselves, communicating and getting around.

Children with a severe learning disability may be able to have basic conversations, or they may have very limited or no ability to communicate. They may be able to learn some everyday tasks (getting dressed, toileting, feeding), or may be fully dependent on others. They may be able to live in supported accommodation when they are adults, or may need full-time care. Some children have both severe movement and severe learning problems.

Caring for a child with a serious lifelong disability can have a huge impact on families.

It is important to know that most parents of children who were born prematurely adapt to the challenges of caring for the child, whether or not the child has a disability.

However, if the child does end up with a serious lifelong disability, some parents may come to wonder whether it was right to choose the intensive treatment option.

Intensive treatment or comfort care – how to make the decision?

How should you decide between intensive treatment and comfort care? Every situation is different, and there is no right or wrong answer.

Here are two questions that might help you decide.

1. What is most likely to happen for my baby?

Talk with your doctor about what is likely for your baby. If it is most likely that treatment will not work and your baby dies, or that they survive with very serious disability, this may lead you to think that **comfort care** is the right choice for your baby.

If it is most likely that your baby survives without serious disability, this may lead you to feel that **intensive treatment** is the right choice for your baby.

2. What is the worst thing that could happen for my baby? What am I most afraid of?

For some families, the worst thing that could happen is that their baby dies. For them **intensive treatment** is the right choice as this gives the baby the best chance of surviving.

For other families, the worst thing that could happen is that the baby has to go through intensive treatment and then survives with a serious disability. They worry about the effect on the child and on the rest of their family. For those families **comfort care** may be the right choice. This option has the lowest chance of the baby surviving with a serious disability.

But this question may not be helpful. For other families both of those outcomes are feared.

Trial of treatment

If you are torn between these two options, an alternative is to have a **trial of treatment**. Some families will ask doctors to **try** intensive treatment, but to change treatment to comfort care if the baby doesn't respond or if the baby develops a serious problem like a major bleed in the brain.

The advantage of a trial of treatment is that it gives the baby a chance of surviving, and may allow treatment to be stopped if it looks like the baby is at risk of serious long-term disability.

But the disadvantage is that it increases the risk that the baby will go through intensive care but not benefit because they die. There is also no guarantee with a trial of treatment. Doctors rely on an ultrasound scan of the baby's brain to pick up bleeding. But the ultrasound doesn't always pick up brain damage, and some very premature babies can have a normal scan and later develop serious cerebral palsy or learning problems.

The other problem with a trial of treatment is that once treatment has started and the baby is in intensive care some families (and some doctors) find stopping treatment emotionally much harder to accept. They may find that they would be OK with a decision not to start intensive treatment, but that it is very hard to stop and let go. If you thought that you would feel this way, then a trial of treatment may not be the right choice for you and your baby.

What if I can't decide?

If you don't know what would be best for your family and for your baby you may find it helpful to talk to other members of your family. If there is time you could speak to different medical specialists about your situation, e.g. obstetricians and paediatricians. You may find it helpful to spend some time thinking about the things that you have been told, and the information in these pages. You could write out some questions and speak to the newborn specialists again if you would like more information about any of the things described here.

If you still aren't sure what is right for your baby, doctors may be able to provide a recommendation for you. However, since this is about your baby and your family what is right for someone else may not be the right thing for you.

If you can't make a decision between intensive care and comfort care, doctors will usually provide a trial of treatment for the baby. Some of the advantages and disadvantages of treatment trials are described above.

What if my baby doesn't come now?

If your baby does not come in the next day or two their chances will hopefully improve. Ideally, they will stay in the womb for as long as possible.

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. You can talk to your doctor about those options when the time comes.

NOTES:

For more information

You can talk to your doctor, midwife or nurse any time you have questions. These services may also be able to help:

BLISS

Premature baby charity

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

Telephone: 0500 618140

SANDS

Stillbirth and neonatal death charity

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

Telephone 020 7436 5881

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