

Understanding brain stem death

Information for families

Great Ormond Street Hospital
for Children NHS Foundation Trust

We realise this is an incredibly difficult time for you and your family, and hope that this leaflet gives you some basic information and helps to answer any questions you may have.

What is brain stem death?

Brain stem death is one of the two ways doctors can certify someone, either an adult or a child, as having died. The other is cardiorespiratory death, and is when breathing and circulation has stopped.

The brain stem is at the very bottom of the brain and controls many functions vital to life such as consciousness, awareness, breathing and the ability to regulate heart rate and blood pressure.

The brain stem can stop working for a number of reasons for example, when other areas of the brain are affected by trauma, bleeding, infections or tumours. Regardless of the cause the brain responds to injury by swelling and unlike other areas of the body there is little room for expansion inside the closed skull. Pressure then builds up and causes a

decrease in blood flow as well as damage to the tissues.

This pressure and swelling causes death by a process called 'coning' where the brain is forced through a small opening at the base of the skull where it meets the spinal cord. Medical treatment may help to limit the build up of pressure but it is not always possible to stop or reverse this.

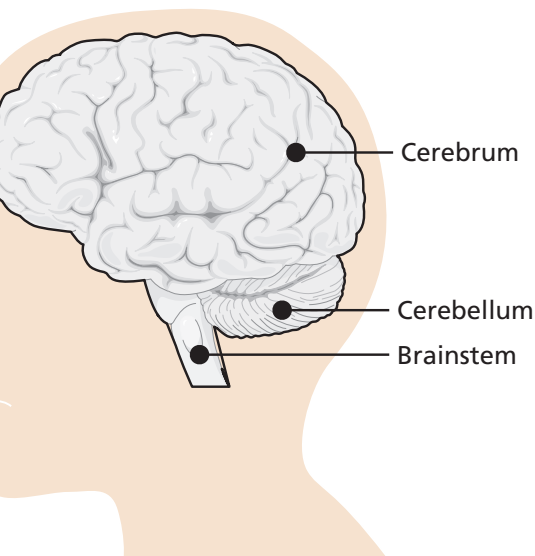
When the brain stem stops working, the brain cannot send messages to the body to control our unconscious functions, and equally cannot receive messages back from the body. If this is the case, then the person has no chance of recovery, the damage is irreversible and according to UK law, the person has died.



What tests are used to confirm brain stem death?

The tests used to determine brain stem death are carried out by two senior doctors at your child's bedside. One of these doctors will be from another team in the hospital so not involved in your child's care. This ensures independent checking of the results of these tests.

They follow a nationally agreed protocol and are conclusive. Before the tests are started, checks are made to make sure that any factors which might affect the tests such as medicines or an extremely low body temperature have been ruled out.



All the following criteria need to be met before brain stem death can be certified;

- **Your child's pupils – the small black parts in the centre of each eye - do not respond to a direct light being shone in their eyes**
- **Your child's natural eye movements are absent**
- **Your child does not show any cough or gag reflex – coughing or choking when the back of the throat is stimulated or the breathing tube is suctioned**
- **Your child does not respond to pain when pressure is applied to certain areas of the body**
- **Your child's eyes do not blink when the surface of eyeball is stroked with a piece of tissue or cotton wool**
- **Your child does not breathe when taken off the ventilator.**

During this time, it is necessary for the level of carbon dioxide in your child's blood to rise and exceed the level that always stimulates a breath. Blood tests will be taken from one of the lines in your child's artery to measure carbon dioxide in the blood before and after the disconnection. The doctors will also look for any signs of breathing during the time off the ventilator, which can be between 5 and 10 minutes.

These tests are repeated and witnessed by each senior doctor to confirm that the brain stem has stopped working.

Frequently Asked Questions

Who decides that it is time to test my child for brain stem death?

If the consultant caring for your child suspects that brain stem death has occurred, they will discuss it with you and they will confirm timing of the tests. This is dependent upon your child's injury or condition and their progress within the intensive care unit. It is a national standard to test anyone who may be brain stem dead.

Why do we have to wait for the tests to be carried out?

Sometimes we have to give medications to keep a child sedated while in Intensive Care. On rare occasions, these medicines can have an effect on your child's reactions to these tests and so we must make sure that the effects of the medicines cannot interfere with the tests.

It is also necessary to ensure your child's blood chemistry and other factors such as temperature are not affecting the assessment.

Am I allowed to stay with my child while these tests are being carried out?

Generally yes. Some parents want to stay with their child while the tests are being carried out, while others prefer to leave. Talk to the nurse or doctor caring for your child if you would like to stay. They will tell you whether this will be possible, and arrange for someone to stay with you during the process to explain fully what is happening.

Why does my child's heart continue to beat after brain stem death has been confirmed?

Your child's heart has an inbuilt mechanism for pumping as long as it has a supply of oxygen and blood - this does not need the brain to continue working. While the ventilator continues to blow air into your child's lungs, their heart continues to receive oxygenated blood and your child may also be given medicine to maintain their blood pressure. The heart will continue to beat for a period of time after brain death - this does not mean that your child is alive, or that there is any chance of recovery.

What about reflex movements of my child's arms and legs?

A reflex movement is an involuntary or automatic action. The nerve pathway for a reflex movement passes through the spinal cord, but not the brain, instructing the muscle to contract as a response to stimulation.

While these movements may be distressing it is important to realise they are not an indication that the brain is functioning.

Once the tests have shown my child has died, what happens next?

After the tests staff caring for your child will discuss with you what happens next and the timing of this. The legal time of death will be the time that the first tests were completed.

If you would like to discuss anything during this difficult time your child's nurse will be able to help, there are also other specialist nurses working in the ITU who are very experienced in end of life issues and can provide specialist support.

If you would like to talk to one of the hospital chaplains or your own religious adviser, please ask your nurse to contact them for you.

Notes

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