



Open prenatal repair for open neural tube defects in the fetus

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This procedure is for repairing an open neural tube defect in a baby before it is born (fetus). This procedure can be used but only when mothers and babies have regular checks to see how well it has worked. This is because of safety concerns for the mother and baby.

An open neural tube defect happens while the baby is developing in the womb. Part of the spinal column does not form properly, leaving a gap that allows the spinal cord and nerves to develop outside the body. This may result in the baby being born with spina bifida and can cause lifelong disability. Up to 26 weeks of pregnancy, open fetal surgery can be done, through the mother's abdomen and womb, to close the gap in the baby's spine. The baby continues to grow and develop until birth. The aim is to prevent further damage to the brain, spinal cord and nerves.

The <u>NHS website</u> may be a good place to find out more. <u>NICE's information on interventional procedures guidance</u> has more about what a procedure is and how we assess them.

Is this procedure right for me?

If you've been offered this procedure, your healthcare professionals should discuss with you what is involved, and explain the research study, and tell you about the risks and benefits. They should talk with you about your options, and listen carefully to your views and concerns. Your family can be involved too, if you wish. All of this should happen before you agree (consent) to have the procedure and to be in the study. You should also be told how to find more information about the procedure. Read more about making decisions about your care.

Some questions to think about

- What does the procedure involve?
- What are the possible benefits? How likely am I to get them?
- What are the risks or side effects? How likely are they?
- What happens if the procedure doesn't work or something goes wrong?
- What happens if I don't want the procedure? Are there other treatments available?

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