

The test case

To have to terminate pregnancy because your unborn baby has a major abnormality is something you probably either fear deeply or believe could never happen to you.

Unfortunately, it happens to more than 2,000 couples in the UK every year. Yet GPs, midwives, early antenatal groups or obstetricians rarely discuss the possibility with expectant parents.

But should you ever be faced with such a choice, remember you are not on your own. There is plenty of professional help, and many voluntary befrienders who know from experience how you will be feeling, and who would be willing to offer support.

Thanks to the rapid advances in gene therapy, the Genetics Interest Group (an umbrella help organisation) sees hope for the future. It feels that one day, parents who find their unborn baby is seriously abnormal may continue a pregnancy they would otherwise have terminated, in the hope that treatment will become available for the baby's difficulty while she

is still young. Diagnostic tests are also being developed, and are performed increasingly early (see Tests section). This is in an effort to avoid the possibility of harrowing later terminations.

How do you find out?

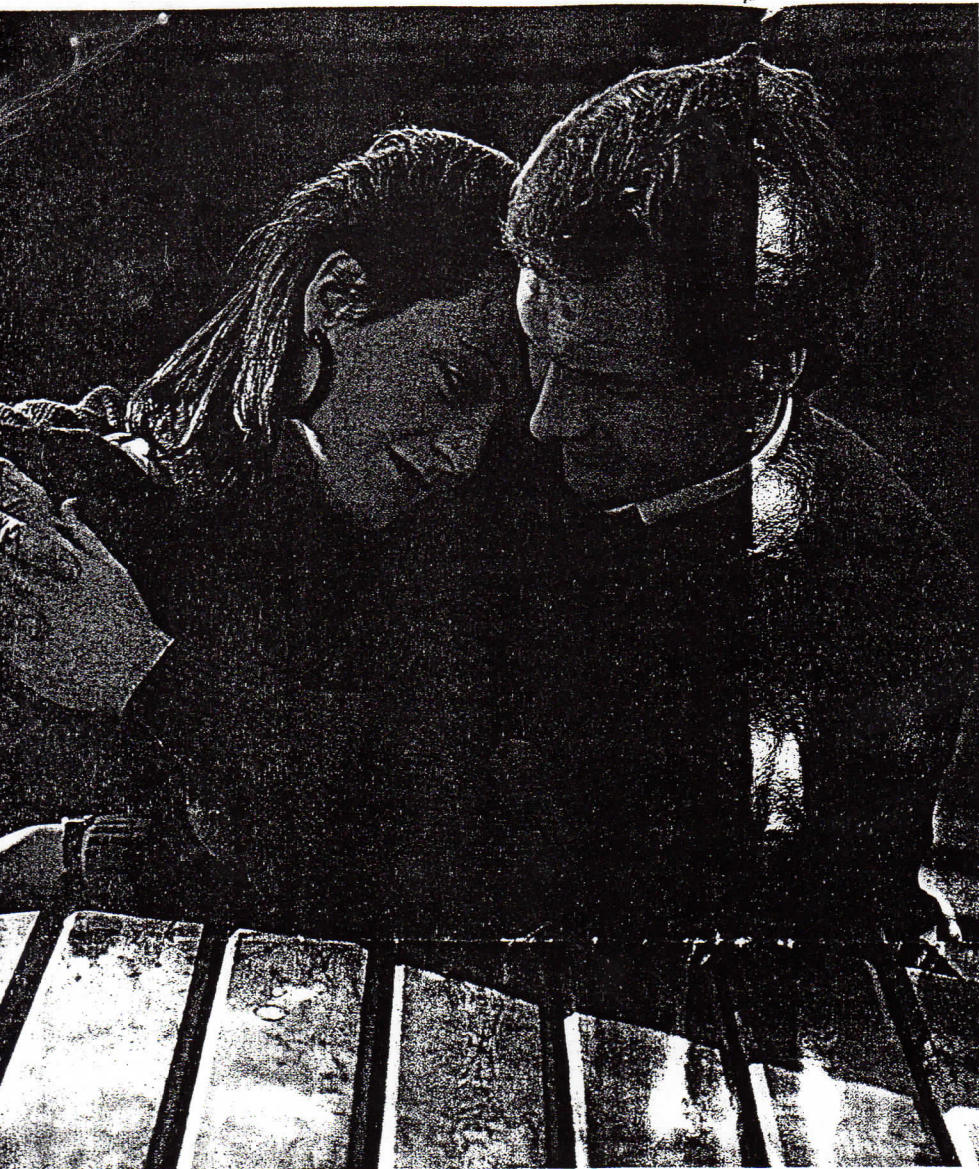
If routine antenatal tests detect a problem what happens next regrettably varies wildly from hospital to hospital. Some are caring, sensitive and professional—others less so.

Joanie Dimavicius, director of the support group Support for Termination After Foetal Abnormality (SAFTA) says, 'We had to give evidence recently to the House of Commons on *all* aspects of maternity services. One of the things we discovered was that too many centres are saying to pregnant women, "If you don't hear from us in four weeks, everything is all right". Its not always all right. Results do get lost, go astray—that's why they should always be chased up as the lost ones might include yours. What's more, hospitals inform women about their results in very different ways. Some might just tell you to pop in and see your

New techniques have been developed to detect foetal abnormalities. But what do they involve and what are the moral implications? Nikki Bradford finds out.

obstetrician at 4pm next Tuesday. Others will actually give you the news straight away, over the phone and out of the blue when you are at home on your own.'

Yet some, like Luton District Hospital, have specially trained bereavement midwives available for when the couple get the results of say, an amniocentesis, from their consultant. She'll make contact with them the next day, ensure they fully understand all the options, explain all the facts in a gentle, non-directive way and help them come to a decision which is right for both of them and their family. Genetic counsellors, who are only available in some specialised units, ►



would only get involved after a termination. They would help the couple assess their risk of having another baby with a similar genetic defect, and work out what they would like to do about future pregnancies.

'Such counselling is very hard for the medical profession. Parents who've just been told their baby has a serious abnormality go into shock at the news,' says SAFTA. 'They may hear perhaps the first few sentences only, explains Joanie, 'because they are already grieving, both for the loss of the normal baby they had hoped for, and for the potential loss of the abnormal baby they now know they have instead. They may feel anger, guilt, or total denial. And as we are now so used to doctors helping us and telling us what to do, it is natural to ask, "Tell me what to do, doctor. What's best?" Doctors should not give their own opinions—though some still do, unasked. The decision is not theirs to make, it's yours. And you may need all

the support, understanding and help going to find the best way for you, your family and your partner—as well as for the baby you are carrying.'

Your choice

Parents are often made to feel as if the only choice is abortion. This is simply not true. There are several options open to you. Depending on what is wrong with your baby, the severity of the problem, your family circumstances and what you feel instinctively and emotionally you can:

- Go ahead with your pregnancy, have your baby and look after her yourself for as long as she is with you.
- Have the baby, but apply to have her adopted at birth.
- Have a termination as soon as possible.
- Wait a few more days—or even weeks—both to come to terms with the situation a little more, and, as some mothers have explained it, to give the baby as much validity as possible.

This time period depends very much on *when* you had the results of your tests. Chorionic villus sampling (CVS), can give you the news by about nine to 12 weeks which means that at this point, if you wished, there is still time to have an abortion under general anaesthetic. This is a less traumatic option than the later one of early artificial labour to expel the foetus.

After about 14-15 weeks most doctors will not perform an abortion under general anaesthetic and by suction. This is because it would damage the cervix and compromise the success of future pregnancies.

The difference in termination methods

A termination using suction to remove the contents of your womb, under general anaesthetic, means you do not feel any pain at the time. It is a quick procedure, but one that means you go to sleep pregnant and wake up 'empty' as SAFTA puts it, 'with only memories of the baby'.

A termination by inducing labour with either prostaglandin pessaries or

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a drip is likely to take a long time (six to 24 hours) and be particularly painful. This is because of the induction process, and because your body is physically unready to give up the foetus. The usual forms of pain relief (gas and air, pethidine, usually an epidural and possibly sedation) available at any birth would be available to you. Many women who have opted for termination due to foetal abnormality have chosen to go into labour as, for them, it made the baby more real.

Going to term

If you decide to go ahead and have your baby, there are many questions you might first want to ask your obstetrician, a paediatrician or genetic counsellor (to whom your doctor can refer you). These could be:

- How severe is the abnormality likely to be? ▶

- How will it affect the baby's comfort and well-being, both in and out of the womb?
- Will the baby suffer any discomfort or pain as a result of her condition?
- How long will she live after the birth?
- What special care will she need at home? Would I be able to take her home or would she need to remain in hospital?

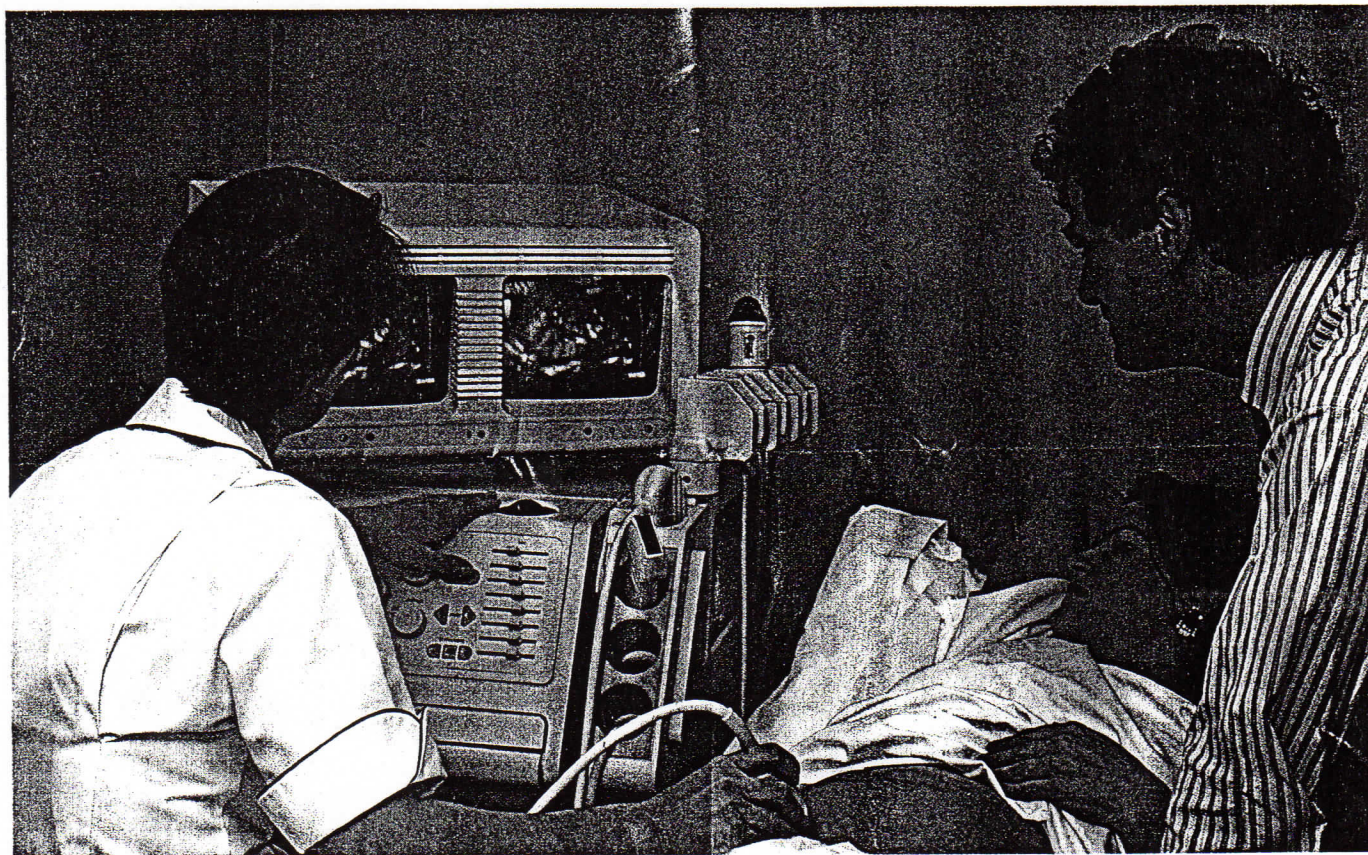
The answers vary. Some babies are profoundly affected and may live only a few hours or even minutes. Others may, with good care, live for many years.

Remember, there are many people

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proper funeral if you wished it, and *all* foetuses have the right to a cremation (if it's necessary) with dignity. Not, as has often happened, to be ignominiously disposed of in clinical hospital waste. Again, ensure the hospital is aware of your wishes.

You can also have gentle moments if you ask the hospital staff. Perhaps you would like a photograph to either take with you or return to see later or the baby's notes, with her tiny handprint or footprint on them. You could keep letters and cards from friends, or press flowers you were sent at the time (though some parents



to whom you can talk at this stage. Apart from your partner, friends, family, GP, midwife, health visitor and obstetrician, there are organisations like SAFTA.

Afterwards

If you decide to have a surgical abortion or an early induced labour you may feel anxious about what will happen when your baby is either removed on the operating table, or delivered. Talk to the staff at the hospital about your fears and wishes.

After a surgical termination you will not see the foetus. Some parents find this makes their grieving even harder because they have no tangible focus for their feelings. It's worth asking if there is an ultrasound scan photo available

in case you want to see it later.

After an induced labour, however, your baby would be small but fully formed. Many women feel it important to deliver the baby with dignity. Let the staff know how you feel about this beforehand. It can help to see, and even hold, the baby yourself. You and your partner could also spend some time together alone with her. This allows you a focus for your distress, confirms the diagnosis of abnormality and may help put to rest any fears about what your baby looked like.

A baby born before 28 weeks (seven months) is not recorded as a 'birth'. However, the hospital chaplain would still be happy to hold a remembrance service or perform a blessing. Your baby would also have the right to a

prefer not to have these as it reminds them of the traditional congratulations surrounding a birth).

Coming to terms

Some couples find they want to talk about what happened. Others withdraw and become isolated because they feel no one understands what they went through and would be embarrassed to discuss it even if they did. Couples may feel quite far apart, just when they need to feel closest. And a man can feel especially lonely if his wife or girlfriend seems to be getting most of the support available from family and friends. The help associations (see box) would also be able to help you if you wished to talk at this point.

If you do ever lose a baby in this way, you won't forget them. Some couples find it helpful to name their baby, hold a memorial service, even plant a rose or willow tree in their child's memory. Some may call that introspective, morbid even. But if it feels right for you, take no notice. The way you decide to remember your baby or deal with your grief can give you comfort now, and always, whether or not you have more babies in the future. ■

HELP

SAFTA 071-439 6124.

The Genetics Interest Group

Umbrella group for families affected by genetic disorders (0865) 744002.

The In Touch Trust

Similar organisation (061) 905 2440.

The Down's Syndrome

Association 081-682 4001.

AMNIOCENTESIS

When: usually at 16 to 18 weeks, and sometimes again at around 20 weeks.

Why: to detect chromosomal abnormalities like Down's Syndrome—and also to confirm any neural tube defects like spina bifida which have been indicated as a possibility by other tests such as the AFP (see below).

How: a fine needle, guided by ultrasound imaging, takes some fluid from the amniotic sac, via the mother's abdomen.

The cells it contains are then cultured and examined in a laboratory.

Takes: usually three to four weeks.

Note: Some research programmes worldwide are doing it at ten to 12 weeks. Miscarriage rate is approximately one per cent. It is routinely offered to mothers over 35, or 37 depending on the area health authority, because the likelihood of Down's and other abnormalities increase's as you get older.

CHORIONIC VILLUS SAMPLING (CVS)

When: nine to 12 weeks.

Why: an earlier way to check for the same things as amniocentesis.

How: tiny strands of the pre-placenta (chorion) are removed either with a fine needle guided by ultrasound via the abdominal wall, or a fine tube via the cervix.

Takes: only hours in some centres, within a day or two at others—since they check the tissue itself, rather than a culture grown from it.

Note: There is a higher miscarriage rate than amniocentesis (two to three per cent) but this is actually equal to the 'background' miscarriage rate for pregnancies at this stage anyway. There have been some controversial reports, not

confirmed either way, of birth deformities following CVS.

ALPHA FETO PROTEIN (the AFP test)

When: at around 16 weeks.

Why: to check for abnormal levels (either too high or too low) of foetal protein in the mother's bloodstream. Too low may suggest a chromosomal abnormality like Down's. Too high may mean several things:

- **twins or triplets** – being more pregnant than everyone thought (this is why a scan always needs to be done *first*—to check for multiple pregnancy and dates).
- **bleeding during pregnancy** an increased likelihood (only) of a neural tube defect like Spina Bifida.

A 'positive' result, which one in 20 mothers has, means you need *either* a very expert detailed scan, a CVS—which can be done till late in pregnancy – or an amniocentesis.

How: a blood sample is taken.

Takes: up to a week.

THE DOUBLE/TRIPLE TEST

When: around 16 weeks.

Why: can be a way of screening non invasively for Down's Syndrome, ie looking for an increased possibility of problems *not* definitely confirming there is one. May be used for younger women who, due to their age, are not usually eligible for amniocentesis.

The overall incidence of Down's babies is one per 1,000 (lower when you are younger, higher when you get into your late 30s and early 40s). As more babies tend to be born to younger women who don't routinely have amniocentesis, more younger women actually have Down's babies though it's seen as a problem affecting older women's pregnancies. Dr David Liu of Nottingham City Hospital says that a positive result means between a one in 250 to one in 350 chance of a Down's baby.

How: blood test from the mother.

Usually checks for two substances, Human Chorionic Gonadotrophin and Alpha Feto Protein. Some centres check for an oestrogen called Oestrodial too.

Note: The debate is growing on whether all women should be offered this screening test. Some experts feel it would lead to more (costly) amniocentesis procedures. Others believe that both money and emotional distress could be saved by the increased detection of Down's...

Thanks to Dr David Liu, senior lecturer at Nottingham City Hospital, Dr Jason Gardosi, senior lecturer and head of the Perinatal Testing Unit at Nottingham University Hospital and to the Society for Help After Termination for Foetal Abnormality.

