

Transcript

Prenatal diagnosis and surrogacy podcast

Jane Fisher:

My name is Jane Fisher. I am Chief Executive of the UK charity Antenatal Results and Choices, or ARC for short. We provide unbiased information and support to women and couples who are going through antenatal screening and dealing with its consequences. On our national helpline a lot of the work we do involves supporting expectant parents when tests tell them that their baby is not developing as expected. It's this experience I'm going to draw on in this podcast in relation to the context of surrogacy.

Surrogacy even gets a mention in the Bible, but its modern form dates back to the mid-80s. And interestingly this coincides with when foetal medicine was formally established as a medical discipline. This means the trajectory of modern surrogacy is run very much in parallel with the last 35 years of significant developments in prenatal screening and diagnosis. Now, in most developed countries, pregnant women will be offered ultrasound scans and other tests to check the development of their baby in the womb. In all of the UK, apart from Northern Ireland, currently, women will be offered standardised screening for Down syndrome, Edwards syndrome and Patau's syndrome, as well a number of structural conditions.

Intended parents who go through surrogacy support organisations will most often draw up agreements with a surrogate that are likely to mention screening tests in pregnancy and the possibility of a prenatal diagnosis being made. There may be a discussion about potential lines in the sand perhaps regarding scenarios where the news from a scan or genetic test might lead to difficult decisions about terminating the pregnancy. But, unless any of the parties have personal experience, the likelihood is that this isn't a situation that anyone having these conversations will expect to be in. In some cases the embryo may have been screened and the intended parents will be confident that the surrogate they've chosen is fit and healthy. In other circumstances, expectant parents rarely give much thought to the possibility of a difficult outcome.

When the pregnancy is much wanted, expectant parents are full of anticipation of a healthy baby. They'll begin to conceptualise this potential new addition to their family as soon as the pregnancy's confirmed. I've never, in my almost two decades of working with ARC, heard women or couples even in the earlier stages of pregnancy talk about dividing cells or a developing embryo or perhaps talk about the visualisation of the foetal pole, no; instead expectant parents build their hopes and dreams around this conceptualised fully-formed healthy baby. All pregnant women will be given comprehensive pre-test information about antenatal screening tests and encouraged to make an informed choice about them.

Women in England are given a 42-page booklet to read before discussing their options with a midwife; however, we know that few women actually read the booklet assiduously and the pressure on appointment time with midwives means that the screening

discussion will usually be no more than a few minutes. The reality is that most women and partners who opt for screening do so expecting to be reassured. I'd argue that for many women in the first trimester, with that intense mix of emotions and the hormonal and physical changes that are going on, it's actually psychologically impossible to really imagine being told their baby's not developing as expected.

Parents may know that ultrasound scans are designed to detect anomalies, but the excitement of meeting their baby on screen will dominate. Scans for intended parents in the case of surrogacy can have an extra potency, as they're not carrying the baby and here is their intended child on the screen. What all this means is that when the sonographer has to break the news that they've noticed something of concern, or a midwife calls to say that a screening result shows an increased chance of a chromosomal condition, the shock and emotional impact is significant. Suddenly parents are confronted with the possibility of a different outcome to the one they'd envisaged. Now, they may face decisions about further tests to gather more information and may be confronted with considering whether to continue with the pregnancy or not.

So what about antenatal screening and its consequences in the particular context of surrogacy? On the one hand, it's unlikely the intended parents' hopes and dreams of a healthy baby are really any different to those in a non-surrogacy situation. They'll have chosen a surrogate who's undertaken to play her part in maximising their chances of a successful outcome. They may have done everything possible with their fertility specialists, including perhaps preimplantation embryo testing to help fulfil their dream; however, there is absolutely no way to guarantee a healthy baby. Every pregnant woman faces the possibility, albeit small, of being told the baby may have or has a genetic or structural condition.

The difference in the context of surrogacy is that the woman who's carrying the baby will not be ultimately parenting the child; it's the intended parents who have to consider the implications for the child and their family's future. When a chromosomal or genetic condition is suspected the intended parents will first need to decide whether they wish to have a diagnosis. This can only be achieved by having an invasive procedure such as amniocentesis which carries a small, 0.5%, but always significant chance of miscarriage. The surrogate of course will have to give consent to undergo this procedure. So it might be useful if this has been a scenario discussed before it actually occurs.

So let's imagine a prenatal diagnosis is made and the medical team mention the option of termination of pregnancy. If the condition is fatal, intended parents may feel termination is the least worst option, as the outcome cannot be a living baby; some though may wish to continue the pregnancy and have the opportunity to see and hold their baby when nature's taken its course. While a surrogate may want to do this for the intended parents, she may also weigh up whether she's prepared to proceed to term in these circumstances, when this represents the greater risk to her own physical health than terminating the pregnancy.

What about the prenatal diagnosis of a condition where the baby is likely to live but there'll be a level of disability. Let's take the example of a diagnosis from scans of spina bifida. The expectant parents we hear from at ARC are usually anxious in this situation to obtain all the specialist information possible about the consequences of the diagnosis for their perspective child. They'll consider what it might mean for the quality of life for their child. Well of course this is always very subjective and laden with uncertainty. They'll also think carefully about their capacity to cope in terms of their practical and

psychological resources. It's very likely that intended parents will do the same, but they have an added challenge.

Most healthcare teams are used to directing information about the prognosis for the baby to the woman carrying the baby. In this case the intended parents are the ones who need to know what it might mean for their future. In a small number of cases of spina bifida there may be mention of in-utero surgical interventions, with the aim of improving the prospects for the child after birth; however, it has to be said that such surgery is highly specialised and certainly not without health risks to the woman. This may of course go beyond the boundaries of a surrogate's altruism. In serious cases of spina bifida, termination will almost always be offered.

While the pre-pregnancy conversations that were had about this possibility may be a useful starting point, the emotionally charged reality may change decisions made when this is no longer an abstract prospect. There is no agreement, no legal contract that can be evoked to force a woman to terminate a pregnancy against her will. The ultimate decision on termination will rest with the surrogate. In most cases one would hope the close relationship forged between the surrogate and intended parents will mean they will find a way through these harrowing situations. But when this is not the case, the help of an expert impartial third party, most likely a skilled counsellor or therapist, may be helpful in helping them work out a way forward and then deal with the consequences.

Thankfully prenatal diagnosis of significant issues will affect only a small proportion of pregnancies; however, surrogates are not immune. It's a sensitive and ethically charged area and not something people like to imagine or really talk about. It can be particularly difficult to grapple with the what-ifs and the potential prospect of a pregnancy not going to plan when such great lengths are gone to, to achieve the desired outcome. But when the what-ifs become a reality, the decisions made will be life changing. And it's important we don't shy away from the extra complication that's introduced in the context of surrogacy. Whatever the opinions of the intended parents, these will never trump the bodily autonomy of the woman they've chosen to be their surrogate. And her ability to emotionally detach from the pregnancy may be severely tested by any prenatal diagnosis.

Surrogacy is not an easy route to parenthood. Because of the challenges and because prenatal diagnosis is not common, there may be a tendency to give it little consideration in the pre-pregnancy discussion phase. Difficult and uncomfortable though it may be, open and honest discussion about different prenatal scenarios, along with the ability to call on an expert, impartial third party if need be, are likely to be of benefit to those intended parents and surrogates who do find they're faced with the unexpected.