

Support for antenatal screening

Katy MacWard, from Antenatal Results and Choices, discusses the charity's work to support parents throughout antenatal screening and diagnosis.

Antenatal Results and Choices (ARC) is the UK's only national organisation to provide impartial information and support to parents at all stages of antenatal screening and diagnosis. In the UK, all expectant parents are made aware of the antenatal screening programme. In England and Wales, over 20 000 women will then be told that their baby may not be developing as expected (Public Health England, 2021; NHS England, 2023), causing a great deal of anxiety and uncertainty in the short and longer term.

ARC offers parents an expert helpline, resources, a private forum, peer support volunteers and in-person meetings, as well as materials for extended family, friends and employers. The charity has no investment in parents' ultimate decision, and does not offer medical advice, but has a thorough overview of current standards of care and where to signpost. The aim is to listen impartially and aid individuals in gathering all the information they need to proceed in a way that is right for their values and specific circumstances during and after a pregnancy.

'The support I received was outstanding...I would have really struggled without it. Even recently, I have been in touch about a new pregnancy. I would advise anyone who has received bad news during a pregnancy to make contact, as the support they will receive will be a lifeline during a dark and difficult time'. ARC parent survey 2023

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Antenatal Results and Choices supports healthcare professionals in caring for families who receive unexpected news during antenatal screening, through regular training and events

Just as crucially, the charity also supports healthcare professionals caring for these families. ARC delivers online and face-to-face 'sensitive communications' training, monthly 'case cafes', workshops, resources and events, such as regular conferences, around the UK to all medical professionals working in this challenging field.

Last year, ARC celebrated its 35th anniversary, a chance to reflect on their achievements, consider their impact and plan their future strategy. The charity's key focus for 2024–2026 is to widen their demographic impact through partnerships, to ensure ARC better engages with the needs of under-represented parents across the UK.

How ARC started

ARC was founded in 1988 by a group of bereaved parents and healthcare professionals who recognised that the practical and emotional needs of families ending a pregnancy after a prenatal diagnosis were not being met. Initially called 'Support after Termination for Fetal Abnormality', the founders worked hard to raise awareness and improve care in this sensitive area.

By the 1990s, as well as supporting those who had experienced termination for medical reasons, the charity was taking more calls from parents who had been told their baby was not developing as expected, and who were wondering whether to have amniocentesis or wanting to

discuss ultrasound findings. To reflect this widening remit, ARC was born in 1998.

However, ARC is still the only organisation in the UK to provide specialised bereavement support around termination for medical reasons. Thankfully, there is now more societal and media openness about pregnancy and baby loss. Every October, baby loss awareness week sees more people sharing their stories. The government recently announced that bereaved parents can apply for a certificate in memory of their loss before 24 weeks (Department of Health and Social Care, 2024), and social media, TV and films have led to increased awareness of miscarriage and stillbirth. However, in the experience of those who work at ARC, few families are happy to talk publicly about their termination for medical reasons. In fact, termination for medical reasons is more common than stillbirth, with over 5000 women and their families affected every year (Office for Health Improvement and Disparities and Department of Health and Social Care, 2024). ARC's beneficiaries testify to the fact that there is still significant stigma around a pregnancy termination, as a termination for medical reasons involves parents making an active decision that results in the loss.

The shock of a prenatal diagnosis

For most parents, scans during pregnancy are a positive experience. But for a significant minority, what happens in that darkened room changes everything.

'Nobody can prepare for the ice-cold shock of the sonographer turning around and saying, "there's something I'm not happy with and I am going to refer you to a specialist"'. Parent testimony, 2022

If the finding is significant, parents will be given their 'options'. In other words, they will be confronted with the agony of deciding whether or not to proceed with what is often a much-wanted pregnancy. This is when ARC's helpline provides a safe space because, as is often heard from parents, deciding whether to continue

with a pregnancy or not will be one of the most difficult experiences an individual will ever live through.

The decision to end a pregnancy after a prenatal diagnosis is never made lightly. In making what they know is a life-changing choice, parents consider factors based on their individual circumstances, family situation and the medical facts about their baby's outlook. They can often feel alone at this time and the responsibility of the decision can weigh heavily.

'The lady then said she had seen a heart defect...All of a sudden, carrying my baby now felt terrifying. It didn't matter what I did now, nothing would take this away from me'. Parent testimony

ARC hears regularly from bereaved parents grappling with the complicated grief that can follow termination. Their sustained support includes a private forum where parents can share experiences and coping strategies

If their baby's condition is survivable, parents sometimes worry that others may judge them for not proceeding. At ARC, they will find a safe, non-judgemental space. The charity also recognises that these distressing times touch the wider family, friends and colleagues. ARC is there for everyone affected.

ARC's services for parents

No parent can ever be fully prepared for the news that their baby is not developing as expected. But ARC's helpline team have the capacity to 'be' with parents experiencing acute distress, which can help contain them. The charity complements and extends the care parents receive from their healthcare team.

ARC's national helpline is run by a small professional helpline team

based in London. They receive calls, emails, live chat requests and texts from parents around the UK. There are also coordinators based in Scotland, Northern Ireland and Wales, who also organise country-specific meetings and events, as well as running professional training.

ARC's team handles over 6000 contacts a year by phone, email, SMS and live chat. These contacts include parents dealing with unexpected test results or difficult news from ultrasound scans, couples struggling with an uncertain prognosis or facing the decision about the future of their wanted pregnancy and bereaved parents wanting support in the aftermath of their decision making:

'I was so terrified that if I chose to terminate, that my whole life would have a black cloud over it...I was reassured that this was very unlikely and [that] most people went on to live a happy life, albeit they would be changed forever'. ARC parent survey 2023

ARC hears regularly from bereaved parents grappling with the complicated grief that can follow termination. Their sustained support includes a private forum where parents can share experiences and coping strategies, face-to-face meetings for bereaved parents and UK-wide peer support volunteers. These bereaved parents are trained to offer telephone support. ARC also provides emotional support to those who continue the pregnancy. Long-term, these parents are often referred to those organisations better placed to offer appropriate help around specific conditions.

ARC's services for professionals

It has always been important to ARC to maintain a close, collaborative relationship with professionals in the field. ARC runs a well-established training programme in communication skills, delivering difficult news and supporting parent decision making. ARC's confidential helpline is also open to professionals, as the charity recognises that this is a challenging area of practice.

In 2022–2023, ARC (2023) trained over 1000 professionals across the UK,

and reached a further 3000 via talks and stands at 10 national conferences. Every year, ARC also runs its own highly regarded conference; in 2024, this is titled 'diagnosis and decisions: optimal care through antenatal testing and its consequences'. Taking place in London on 4 October, eminent speakers include Dame Professor Lyn Chitty, Professor Jan Deprest and Professor Kypros Nicolaides. The conference is a great opportunity for professionals (from midwives to geneticists, sonographers to consultants) to hear from world-renowned experts, explore the parent perspective and network with peers.

ARC is also fortunate enough to be involved with decision makers such as the NHS Fetal Anomaly Programme (NHS England, 2023) and the NHS Fetal Maternal and Child Health Group's UK Screening Committee (UK National Screening Committee, 2024). This means ARC is able to feed back what they hear from parents and professionals to help improve standards of care. Additionally, ARC collaborates in research to make sure they keep up to date with the latest developments, maintain working relationships with expert clinicians and academics and, most importantly, ensure that research is of real benefit to expectant parents and families.

ARC's impact and future strategy

ARC operates in a complex, ethically charged area of healthcare, which makes it difficult to quantify their impact. However, when the service is audited and users

(parents and professionals) are surveyed, a consistent message received is that they all value ARC's independence and resources.

'I valued the information on the website immensely in the early days and now find the face-to-face meetings a useful place to help me process my experience... Other peoples' stories [help] me feel less alone and [to] contextualise what happened'. ARC parent survey 2023

In the 2023 surveys, 94% of parents said that their expectations were 'exceeded' or 'met' by ARC's services, and 99% of professionals said they would recommend ARC to their colleagues. By considering survey feedback and engaging sensitively with ethnically- and regionally-diverse organisations, the charity can plan how better to serve these communities.

In 2022, ARC also welcomed its first Coordinator in Northern Ireland. This appointment was a key initiative in providing equitable ARC services across the UK, in response to feedback from parents and professionals. The role allows ARC to provide education and support tailored to Northern Ireland's specific cultural, legal and healthcare sector needs.

'ARC helps to break down the stigma that exists around [termination for medical reasons] in Northern Ireland. The availability of this specialised support is invaluable support to us'. Childbirth and loss midwife at Belfast Health and Social Care Trust

Looking ahead, as fast-paced developments in antenatal screening and diagnosis continue, ARC is working to further extend their reach across the four countries. ARC wants to ensure that all parents facing unexpected or difficult news from ultrasound scans and genetic tests know ARC is here for them and can support their healthcare professionals to provide the individualised care they need. **BJM**

To find out more about ARC and our 2024 conference, visit www.arc-uk.org. You can also follow us on Twitter and Instagram (@ARCantenatal) and sign up to our professional newsletter by emailing info@arc-uk.org

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