

Decision Making

Please note: *The information provided in this section has been sourced from the ARC website and was not created by Ellie's Gift. ARC has been instrumental in supporting the development of Ellie's Gift and their contribution has been significant to the content within our specific TFMR area. ARC were also involved in the focus groups that helped inform and shape the content that has been developed to support families experiencing TFMR.*

When you are told your baby has or might have a genetic condition or anomaly you may feel very alone. You may think that no one can possibly understand how you feel. When you are given the news that your baby has an anomaly, you lose the healthy baby of your dreams and sometimes your belief in yourself.

At first, it is likely that you will have a mixture of very confusing emotions. There will be grief at the loss of the healthy baby you had hoped for, as well as sadness for the baby you are carrying. In this state of emotional turmoil the decision about the future of the pregnancy can feel almost impossible. With some conditions, there is lots of information available; with others, very little is known. You may have to ask to speak to a geneticist or paediatrician to get some of the answers you want and/or contact a specific condition organisation.

Only you can decide what is best for you and your family. The responsibility of this can feel very challenging. You may find you go back and forth from one decision to another. This can feel really difficult but is part of the decision-making process. Eventually you will know which route forward feels right for you; or as some parents have described it, you will know which way seems the 'least worst option' in the circumstances.

ARC offers practical advice, independent information and individualised support to parents whose baby is diagnosed with any condition or anomaly. If you contact us on our helpline, we can:

- help you to make sense of what you've been told and to find out more if necessary.
- listen to you and acknowledge the difficulties of your situation
- support you in coming to a decision that feels right for you and your family.

Please don't hesitate to contact the ARC helpline as we have many years' experience in providing independent non-directive support to parents in distressing circumstances.

ARC - Call our helpline

Want to talk? We're here as often as you need us. Our helpline is answered by trained staff.

020 7713 7486

Monday to Friday: 10.00am – 5.30pm

Or text: **07908 683004**

Tuesday and Thursday: 8 – 10pm – email
info@arc-uk.org to arrange an evening call.

Disclaimer

The information contained within this resource was correct and accurate at the time of production, based on the original sources available in **2026**.

Information, guidance, services, contact details and external resources may change over time. Ellie's Gift CIC cannot guarantee that information remains current or that external services, organisations or websites continue to operate as described.

Please check the original source or relevant organisation directly for the most up-to-date information.