

Ending a pregnancy for medical reasons (TFMR)

TFMR/TOPFA definition

'Termination for Medical Reasons' or TFMR also referred to as TOPFA Termination of Pregnancy for Fetal Anomaly are ways in which we refer to the medical interventions that result in a pregnancy being ended due to medical reasons.

TFMR can be a frightening and isolating experience and many parents who have been in touch with us have questioned whether bereavement support is available to them because of the particular circumstances of their loss. Please know that our support is here for you.

Receiving an antenatal diagnosis

Receiving the news of a medical problem relating to your pregnancy will probably be unexpected and may leave you in a state of shock. You may also experience feelings of sadness, guilt, and grief when coming to a decision about how to proceed.

If your baby was diagnosed with a medical problem that meant their health condition would have serious implications and threat for you and your baby's life, or that they may have poor prospects, a short life or not survive after birth, you will have had to decide whether to continue the pregnancy or not. This is an immensely difficult decision for many parents and one that no-one should make alone.

This chapter is aimed at helping you through your loss and to support you as you journey through the emotions this can bring. If you have not yet decided what to do after a diagnosis, you may prefer to research your options through <https://www.arc-uk.org/> Antenatal Results and Choices (ARC) | Support for Parents and Professionals (arc-uk.org)

Screening tests and diagnostic tests

The health of you and your baby can be checked during your pregnancy using screening tests and diagnostic tests. It can be helpful to understand the difference between the two types of tests.

- Screening tests are used to detect if a condition has a high probability of being present.
- Diagnostic tests will detect if the condition is actually present.

Making a decision

Ending a pregnancy for medical reasons is a complex and challenging situation. This may evoke many difficult feelings for you including grief, loneliness and guilt. It may also be difficult to know who to discuss this with and you may fear judgement from the people close to you, as well as the pressure of limited time to consider and react. Sands is here to support you along with other organisations such as ARC.

You may need to wait for test results that confirm which condition is affecting your baby or how it has impacted their health so far. You may also feel under pressure from other factors affecting you throughout your pregnancy, or you may simply feel that you need a resolution at what can be an immensely distressing time. The factors influencing your decision will be unique to you and your baby, and whatever they may be they are valid, as are your concerns and worries. For some parents external opinions can often influence their emotions and they are left navigating intrusive thoughts and feelings such as guilt and shame. We are here to listen and help you talk about the difficult emotions that can sometimes be a part of a traumatic response to TFMR for so many parents experiencing this

type of loss. At Sands we acknowledge that your baby is much loved and that making a decision to terminate for medical reasons is sometimes the only way that feels compassionate and appropriate for you, your baby and family.



Navigating Emotions

There is no right or wrong way to feel about your own personal TFMR journey. For some rationalising the decision of compassionately ending a pregnancy for medical reasons will be straightforward: understanding that their baby's quality of life and prospects would be poor allows them to make a decision of TFMR with little doubt. For others, deciding what to do after a diagnosis may not be so clear, and navigating this decision may come with mixed feelings and emotions. Your experience of TFMR is personal to you: sometimes grief may present as sadness, guilt and isolation, at other times

parents may feel angry or unable to accept their decision to terminate for medical reasons. You may possibly find that you feel all of these emotions at different times, as moving between emotions can be a common response to grief and loss. Parents we speak to often mention how isolated they have felt after experiencing TFMR, often minimising their own feelings of grief and sadness. Please know our helpline and other support channels are here for you to explore your experience of loss and how your grief impacts you.

Bereavement Support

More and more parents are experiencing baby loss through TFMR due to the advancement in diagnostic tests and scans, and our community and bereavement support service understand how difficult this is. Our helpline and other support channels are available for you to talk through how you have experienced TFMR and to explore how this has left you feeling.

The differing circumstances of baby loss through TFMR can often leave parents questioning what options are available to them when making funeral arrangements and saying goodbye to their baby. Please read through our bereavement support book and think about ways you would like to honour your baby. The memory making and saying goodbye sections of the book may be helpful to reflect on how you would like to create memories of your baby and also saying goodbye.

How or if you are able to hold and spend time with your baby may also be affected by what gestation your baby is. If you are unable to meet your baby, it doesn't mean you can't create memories. Our community can provide support and comfort to you when you are thinking of alternative ways to remember your baby. This can be such an important part of the grieving process and may provide you with an opportunity and space to grieve your baby and remember them.

If you are given the chance to meet your baby, it is very normal to feel anxious about how your baby may look when they are born. Talking about this with your midwife or nurse to understand what to expect or the bereavement support services team at Sands about how you feel can be helpful.

Relationships and Grief

Here at Sands we understand that loss can impact us all in different ways due to the individual ways we all grieve. Many parents we speak to describe how the loss of a baby can create challenges within a relationship due to the different way each partner grieves. Parents can sometimes have different thoughts and feelings around the decision to TFMR. Yours and their feelings and thoughts may change as you navigate the loss of your baby too.

This can sometimes result in relationships feeling fraught. Some parents find comfort in talking about their baby and their experience whereas others may find they are distancing themselves away from those around them and they may avoid thinking about their loss as a way to manage their grief.

You may feel anger towards yourself and others after experiencing the loss of a baby. With TFMR, feelings can also be affected by the decision process taken to end the pregnancy; it can take time for you and those around you to adjust. There is no right or wrong way to grieve, though it can be helpful to reflect on ways that help you to communicate your wants and needs to each other as you process your grief, finding channels of support that feel comfortable to you when you need it most. Sands are here to support everyone impacted by the loss of a baby.

Siblings

As you navigate the loss of your baby you may find that you are supporting others in your family, and if you have other children supporting your baby's siblings. This can be a difficult task to undertake when your own grief may be very painful and consuming.

Sands' children's activity books are a helpful way to encourage children to process their own grief and the loss of a baby, recognising that children understand and deal with loss in different ways at different stages of their own life. They can also enable you to develop age-appropriate ways of remembering your baby together. This can be helpful when building a connection and continued bond for the whole family.

Family and Friends

Our support book has a section for family and friends that can also be helpful. Family members and friends often want to help bereaved parents but are unsure of the best way to do so. Our support is here for them too. Speaking to someone impartial and confidential can be useful for anyone who is affected by loss. Our helpline provides that safe space for you and your family and friends to speak to someone honestly and frankly about any difficulties they are feeling.

Sharing your Story

Telling others what has happened can be one of the hardest things to do after your baby dies. This can be made even harder if your baby has died as a result of a TFMR, which may leave you feeling judged or that you feel you have to explain your situation to others at a time when you are vulnerable and in distress. Some people feel remorseful about having to bring sad news to their family and friends. Others may worry about their news adding to existing problems or being a burden.

It is also important to remember that your own emotions, wellbeing and thoughts are valid, and that you understand your situation and what is best for you and your baby. Others may form and share opinions based on their own values and experiences, but this does not mean that their opinions are correct and they may not fully understand your personal experience. In those situations it can be helpful to think about your own boundaries and needs and how you can protect yourself from unwanted opinions.

Pregnancy loss through TFMR may activate intense, confusing and painful feelings for you. It can be helpful to think ahead about how you want to tell others about your loss. This may include finding a sentence to explain what's happened which you are comfortable using in situations when you may feel vulnerable. It can be especially important to think about how much or how little to share if you feel your situation may not be fully understood by other people. You may not want to be drawn into conversations about your loss that could be difficult especially if others question your position or options.

Social media and the press can sometimes present unkind and minimising attitudes towards families who have suffered this type of loss, so prioritising your own wellbeing by choosing who and what you connect with is a vital part of helping yourself through this.

Cultural and religious considerations

Ending a pregnancy for medical reasons is a difficult and traumatic experience for most parents. It can be particularly complicated if it seems to go against cultural or religious beliefs you are connected to.

Every culture and the individuals within them have their own beliefs around baby loss and what it means to families, how that loss is understood by your community, and what you as parents need to

feel supported. No two experiences of loss are the same, so it is important to voice your own feelings and ask for what you need. With grief, our identity and our relationships with ourselves and others can often be challenged. It can be helpful to talk this through with someone impartial and unconnected to your life.

If you have a religious faith, you may find that you question it in challenging situations like that of ending a pregnancy. You may wonder why this is happening to you, rebel or feel dissatisfied with your life in ways that go against the beliefs you held up to this point. It can be helpful to remember that the feelings you are experiencing are valid and that many faith leaders have expertise in baby loss and can guide you through this time, supporting you through these feelings and helping you to find your own way of relating to your faith after what has happened. Accessing support in this way can also be helpful if you are able to use it to navigate and acknowledge your loss through a connection with your beliefs. Whether you have a religious faith or not, it is important to have opportunities to grieve in a way that is helpful to you.

Accessing Support

Sands is here to support you and your family after a termination of pregnancy for medical reasons for as long as you need us. There is no judgement made about anyone who has ended a pregnancy. Our support channels, volunteer support groups and online spaces welcome parents who want to share their experiences irrespective of the reasons for their baby's death.

With the rise and improvement of medical intervention, diagnostics and testing, more and more families have found themselves in the painful position of accepting TFMR as a part of their pregnancy journey. While you may find that many families you talk to have suffered a stillbirth, neonatal death or other type of loss, there are

also many families affected by TFMR in the Sands community. Connecting with others can show you that you have far more in common than you expected aside from the nature of your loss.

We can support you as you journey through the grief you may experience after losing your baby. Here at Sands, we have many options for you to choose from and these may feel more helpful at different times in your journey. Our support options include our Helpline, peer support such as our local group meetings, Sands United Football teams, online support groups, online community and Facebook group. You can use any or all these options, whatever works best for you.

