

Welcome to SOFT UK!

You are receiving this to help with your support journey with SOFT UK. This pack will outline some of our support offerings in one easy to find place, helping to make an already complicated time, a little easier to navigate.

We understand that your journey will be evolving over time, and no matter what happens, or where this story may lead, we are here to support you at every stage, during and after your pregnancy.

Our Support Line

If you haven't been in contact with our support team already, then they are here to help. A diagnosis of Trisomy 13 or Trisomy 18 can feel isolating. Our primary mission at SOFT UK is to ensure families can access support when they need it.

The SOFT UK support line provides a safe, confidential place for anyone whose pregnancy or child is affected by Edwards' syndrome (also called Trisomy 18) or Patau's syndrome (also called Trisomy 13). Whether your experience is recent or happened long ago, we aim to support you for as long as you need us.

You can contact the support team via the following methods:

0300 102 7638
support@soft.org.uk

Who do we support?

- Parents who have a prenatal higher chance result or diagnosis of Edwards' syndrome or Patau's syndrome.
- Parents who are caring for a child with Edwards' syndrome or Patau's syndrome.
- Decision making during pregnancy.
- Bereaved parents.
- Parents who have / are planning to end a pregnancy.
- Other family members.
- Friends and colleagues.
- Healthcare professionals.
- Other professionals supporting families.

Who will be responding to your call or email

We have a small team of dedicated and trained Peer Support Volunteers to offer confidential, non-judgemental and compassionate support. They are all parents themselves who have had a similar experience to you.

What to expect when you contact the helpline

The SOFT UK Support Line offers support across the UK (England, Wales, Scotland and Northern Ireland) in the following ways:

- Information about Edwards' and Patau's syndrome.
- Caring for a child affected by Edwards' or Patau's syndrome.
- Bereavement support (coping with grief, anger, hopelessness, guilt, anxiety, facing the future).
- Practical information relating to decisions required during and after pregnancy. Our information is based on the 'lived experience' of other parents.
- Signposting to other services and sources of support that may be helpful.
- Coping with another pregnancy after the death of a baby.
- SOFT UK does not offer medical advice.

Opening times and confidentiality

The team are available to speak on the telephone or respond to emails from **Monday to Friday (not bank holidays)**. Your call will initially be responded to by an answerphone where callers can describe the support they need and leave their contact details. We aim to return your call within 24 hours during opening hours. Or you can email us at support@soft.org.uk if you prefer. We aim to respond to emails within 24 hours during opening hours.

Calls and emails are confidential. We will not share information outside of SOFT UK, except if there is an immediate risk of harm to you or someone else.

My Support Volunteer

Name:

Email:

Expectant Family Group Calls

We host an Expectant Families group call on Zoom once per month. This is a safe space to talk with others going through a similar journey as yourself, and gives a chance to ask questions. If you'd like details of the call, either let your support volunteer know, or feel free to email kate.hart@soft.org.uk who will gladly send an invite.

Facebook Support Groups

We host a number of support groups on Facebook, where families can share their experience, and ask questions that you may have throughout your journey.

The following groups can be accessed here:



[SOFT UK - Your Trisomy 13/18 Journey](#)



[SOFT UK - Support For Families Ending a Pregnancy](#)



[SOFT UK - Grandparents](#)



[SOFT UK - Bereaved Parents Support Group](#)



[SOFT UK - Support For Dads](#)

Family Stories

We have a number of family stories, told by those who have faced different aspects of a Trisomy diagnosis and experience. The stories range from all aspects, and will hopefully provide more insight in what you can expect to face, and some of the questions you may face throughout your own journey.

These stories are available in different formats, written and audio, and can be found below:

Podcast: <https://anchor.fm/softuk>

Written Stories: <https://www.soft.org.uk/family-stories>

Supporting Your Journey

Everyone's journey is unique, with no two cases of Trisomy being the same. Throughout your experience, you will encounter questions and situations that need different levels of support. Below are some of the different ways SOFT UK can support you.

Audio family stories available through all major podcast platforms, giving you more information about different types of experiences

Expectant Family group calls to introduce you to others on their own journey

Volunteer support phone line, giving you the opportunity to connect with one of our trained volunteers who will help you to navigate your own journey

Face to face event where you can connect with families and professionals

SOFT UK Support



Remembrance stars to honor the babies and children we have lost

Written family stories available on our website

Facebook groups catered to the more specific element of your journey

Grandparents group calls to support your extended family with their own questions

Family Link List, connecting you with families who have a similar experience

This page is for you to tear out and give to your healthcare team

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Working Together - Support for healthcare professionals

SOFT UK has over 30 years of lived experience of families receiving a higher chance screening result or diagnosis of trisomy 13 or 18; decision making in pregnancy; bereavement; ending a pregnancy and care for a surviving child affected by Edwards' or Patau's syndrome. We have a large community of families and expert healthcare professionals and work with a range of partner organisations, including the NHS in England, Scotland and Wales.

We understand that it's not just families who have questions or are seeking information regarding Trisomy 13 and Trisomy 18. As a medical professional we can offer you information and support and you are more than welcome to contact our team.

We can offer:

- Access to lived experience which may help with specific care and support for the families you are working with.
- Evidence-based research, publications and information resources.
- Professional advisers who are experts in the care and treatment of Trisomy 13 and 18. Our advisers work with us in developing information and resources.
- Free, bespoke training sessions delivered online and tailored to meet your particular needs.
- A wide range of peer support services you can refer parents and families into, including individual support via phone or email; virtual calls with other families; and free family events across the UK with the primary aim of connecting families.

If you wish to access any of the above or can't find what you are looking for on our website or you need further information, please contact us via the following methods:

Telephone helpline - 0300 102 7638

Email at contact@soft.org.uk

To arrange any training, please contact shaun.dowdall@soft.org.uk, our Operations Manager, who will be happy to discuss your specific needs.