Registered charity: 1071811 (England & Wales) SC053187 (Scotland)

Press Pack

The Ectopic Pregnancy Trust is a world-class charity based in the UK specialising in ectopic pregnancy. We exist to support anyone going through this traumatic time. We strive to raise awareness of the condition and to improve diagnosis and treatment by representing lived experiences from those who have suffered the condition to the medical profession and influential groups like the government and journalists.

What is an ectopic pregnancy?

An ectopic pregnancy is a pregnancy that implants outside the uterus. The most common site for this is in a Fallopian tube, which transports the embryo (egg) from the ovary to the uterus. As the pregnancy grows, it causes pain and bleeding and, if not treated quickly, will eventually rupture. This can cause internal haemorrhaging which can sometimes lead to death for the woman or pregnant person.

Key statistics

- Around 1 in 80 pregnancies are ectopic.

- Each year in the UK nearly 12,000 women have ectopic pregnancies diagnosed (Source: 2016 MBRRACE Confidential Enquiries into Maternal Deaths and Morbidity 2009–14). From anecdotal evidence and due to how statistics are recorded, this is thought to be an underestimation. It is believed the number of cases of ectopic pregnancy may number more than 30,000 per year in the UK alone.

- The MBRACCE-UK report 2024, “Saving Lives, Improving Mothers’ Care” shows that women are still dying from early pregnancy problems and ectopic pregnancy remains the most frequent cause of maternal death in early pregnancy. During the report’s two-year period, in the UK and Ireland, 12 women died from an early pregnancy-related cause. These were **all** due to ectopic pregnancy.

- Ectopic pregnancy deaths have risen again – from 5 reported in 2019, to 8 in the 2022 report, to now 12. This is an alarming trend and ectopic pregnancy deaths in this report is almost twice the rate in the previous report. [Note: 8 deaths in 2018-2020 (2022 report covers three years) to 12 deaths in 2021-22 (2024 report covers two years)]

- The report states that all 12 women who died from an ectopic pregnancy could have had better care. Improvements to care may have made a difference to the outcome for nine women (75%).

- The report highlights the need for women and clinicians to be aware of the symptoms of ectopic pregnancy and to “Think Ectopic”.

The Ectopic Pregnancy Trust was established in 1998, founded in memory of Sophie Winter by her parents. Sophie lost her life to a misdiagnosed ectopic pregnancy.

The Ectopic Pregnancy Trust believes that the deaths and trauma associated with ectopic pregnancy should be prevented. We seek to relieve the distress associated with the experience and provide ongoing support following diagnosis and beyond.

Our vision

The Ectopic Pregnancy Trust believes:

- no woman or person should die from an ectopic pregnancy;
- any woman or person capable of conceiving of childbearing age who is sexually active or undergoing fertility treatment (like IVF), who has ectopic pregnancy symptoms, should be considered to be pregnant until proven otherwise. to maximise the speed of diagnosis;
- anyone diagnosed with an ectopic pregnancy should receive as many treatment options as the stability of their medical condition allows; this includes expectant management, medical treatment with methotrexate, and surgical treatment;
- it should be universally recognised that early diagnosis enables treatment choice, preserves fertility and enables a person to feel a greater degree of control over their medical condition. This commonly reduces the emotional impact of the ectopic pregnancy;
- it should be universally recognised that the emotional effects of losing a baby far outweigh the physical condition even in the early stages of pregnancy; and
- anyone who has suffered an early pregnancy loss should have access to all of the information and support they need to aid their physical and emotional recovery.

Our aims

The Ectopic Pregnancy Trust’s strategic aims are:

- to ***provide information and support*** to all persons affected by ectopic pregnancy and other early pregnancy complications and the healthcare professionals who care for them;
- to ***advance education and to promote awareness*** of ectopic pregnancy and other early pregnancy complications among the medical profession and wider public; and
- to ***support research*** into ectopic pregnancy and other early pregnancy conditions.

To fulfil our aims, we work hard to:

disseminate **our patient information suite** to hospitals across the UK. A trusted resource, this includes posters on physical and emotional aspects of ectopic pregnancy as well as leaflets to be handed to anyone experiencing the condition. The suite contents signpost to our support services and was Highly Commended in the 2019 BMA Patient Information Awards.

> *'a wealth of information, support and hope to sufferers of ectopic pregnancy'*
>
> *– BMA Awards Reviewer*

BMA
Patient information awards
Highly commended

Trusted Information Creator
Patient Information Forum

- provide a **valuable resource through our website**. It includes sections on the definition of ectopic pregnancy, symptoms, diagnosis and treatment, physical and emotional recovery and trying to conceive again as well as information for partners. The NHS signposts to our resources.

- facilitate a **supportive online community** through our message-boards and Zoom groups.

- respond to thousands of queries via **email and our call-back service** helpline.

- **represent the patients' voice** as stakeholder for updating the NICE clinical guideline on Ectopic pregnancy and miscarriage: diagnosis and initial management.

- **collaborate closely with other charities and organisations to improve care** throughout the path to parenthood before, during and after pregnancy, and after losing a baby or pregnancy. This includes as part of the Pregnancy & Baby Charities Network, Baby Loss Awareness Alliance, and the All-Party Parliamentary Group (APPG) on Baby Loss.

- **work with healthcare professionals** to remind about the condition when assessing a person with symptoms and Think Ectopic. The campaign is endorsed by The Royal College of General Practitioners.

Working with newsrooms and journalists

Raising awareness about ectopic pregnancy through the media is essential. Awareness of symptoms among the general public leads to people seeking medical help earlier, facilitating rapid diagnosis, which may result in less invasive treatment options and even saving lives.

The Trust can assist newsrooms with information and stories on ectopic pregnancy, early pregnancy complications, and pregnancy and baby loss. The Trust can also put journalists in touch with people whose lives have been affected by ectopic pregnancy and pregnancy and baby loss and who can give first-hand accounts of the condition and its legacy, as well as being able to share some heart-warming stories of hope following ectopic pregnancy.

Further information

Website: www.ectopic.org.uk
(includes information on symptoms, diagnosis, treatment, and recovery)
Office line: 020 7096 1838
Email: press@ectopic.org.uk

Ambassadors: Charlotte Crosby, Michelle Gayle, Dame Laura Kenny DBE, OLY, Amanda Redman MBE, Susan Penhaligon

20 11 2024