pregnant **pause**

As many as one in one hundred pregnancies is ectopic. Mismanaged, it can be life-threatening. **Jill Glenn** talks to Laurie Irvine, founder and Chief Excutive of locally-based national charity the Ectopic Pregnancy Foundation, plus hears about one mother's ectopic experience, and meets her beautiful baby daughter.

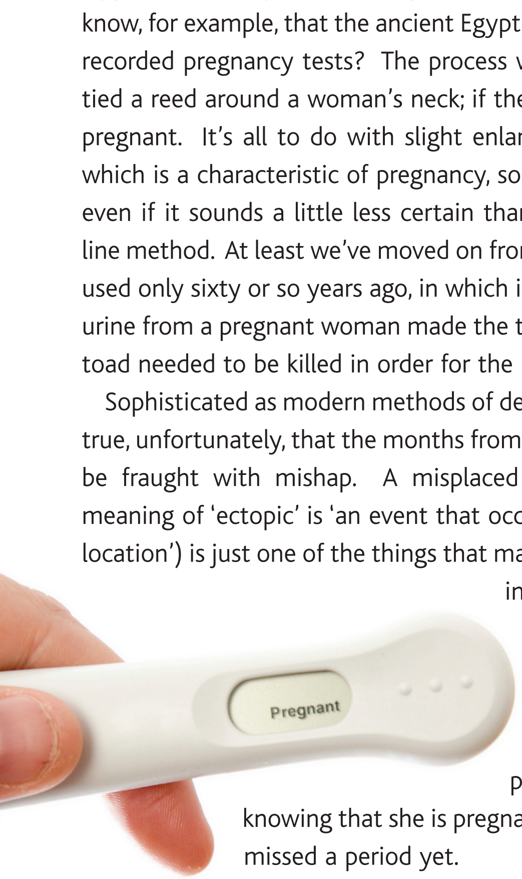
Ectopic pregnancy occurs when the fertilised egg implants outside the cavity of the womb, usually in the fallopian tube. As the pregnancy grows, the fallopian tube stretches and causes pain and discomfort. If not identified and treated quickly enough, the tube can burst… causing internal bleeding, which can lead to collapse and even death. It's a dramatic, devastating experience for any patient.

You'd expect – or I'd expect – that most of the medical interest in the diagnosis and management of ectopic pregnancies would come from women. Some sort of sisterly solidarity. It seems I'm wrong – at least if the gender bias of the Ectopic Pregnancy Foundation is to be believed. The Foundation's Trustees are all male, as is its faculty. Several, including Laurie Irvine himself, trained at Charing Cross Hospital Medical School – a loose connection that Laurie values highly – although their subsequent experiences have been many and varied. All give their time to the Foundation (based at Watford General Hospital, where Laurie Irvine is a Consultant Obstetrician and Gynaecologist) free.

Yes, he says, yes he probably should have more women on board, but I can sense that this is more of an issue for me than it is for him. His goal (unadulterated by political correctness or outward appearances) is, as it has been since he treated his first ruptured ectopic pregnancy in 1981, to reduce the morbidity and mortality associated with the condition. Nearly 30 years on, he still recalls that early experience vividly. "I was struck," he observes, "by the fact that she had become so unwell so suddenly". The patient's blood pressure had fallen, her pulse rate had risen and she became semi-conscious, requiring emergency surgery to remove the pregnancy and save her life. In due course the woman recovered well… but the diagnosis and the case made a lasting impression on the young doctor, and fuelled a career-long interest in ectopic pregnancy.

Laurie is a mine of odd pieces of general pregnancy-related information, as fascinating to the non-pregnant, never-pregnant layperson as they are to his professional colleagues. Did you know, for example, that the ancient Egyptians are the first to have recorded pregnancy tests? The process was rudimentary – they tied a reed around a woman's neck; if the reed snapped, she was pregnant. It's all to do with slight enlargement of the thyroid, which is a characteristic of pregnancy, so it has a scientific basis, even if it sounds a little less certain than the modern thin blue line method. At least we've moved on from the toad test, though, used only sixty or so years ago, in which in which the injection of urine from a pregnant woman made the toad lay eggs. Sadly, the toad needed to be killed in order for the result to be assessed.

Sophisticated as modern methods of determination are, it's still true, unfortunately, that the months from conception to birth can be fraught with mishap. A misplaced pregnancy (the literal meaning of 'ectopic' is 'an event that occurs away from its usual location') is just one of the things that may go wrong, but it's one in which the diagnosis can be easily missed. Often a woman may be experiencing the pain of an ectopic pregnancy without even knowing that she is pregnant, without even having missed a period yet.



The symptoms, as Laurie explains them to me, are not particularly distinctive in themselves – abdominal pain, shoulder tip pain, diarrhoea, dizziness or fainting… all easily attributable to a variety of other conditions. There will probably also be abnormal bleeding, though, and (ironically, since this will never be viable) a urine pregnancy test will prove positive.

The charity's newly revamped website (ectopicpregnancy.co.uk) explains the symptoms, the risk factors and the three different types of treatment. The Foundation also sends out posters and letters to A&E departments twice a year – "when the new junior doctors start, in February and August" – to highlight ectopic pregnancy as a possible diagnosis. It aims to do the same for all the GP surgeries up and down the country. It's a big ask, and demands big funding. There's a link on the website for those who want to donate.

Laurie has dedicated the Foundation to the memory of Dr Robert Lawson Tait – "fascinating man, absolutely fascinating man" – in recognition of Lawson Tait's profound influence on the development of gynaecology.

Tait's approach was innovative. He used soap and water to wash his hands, for example; it sounds simple enough, but back in the 1870s, it was revolutionary. He kept detailed records of his operations and methods; he was the first to perform a successful salpingectomy for ectopic pregnancy and reported only two deaths out of 42 operated cases, a remarkable achievement, given that the condition had been almost always fatal until that point. He also, as it happens, performed the first appendectomy for acute appendicitis.

Lawson Tait founded the Medical Defence Union, smoked and drank to excess in the style beloved of the Victorians, was accused by one of his nurses of being the father of her child, and was sued for libel. An eccentric, then… but a man with a far reach, a man who shares with Laurie Irvine a passion for upsetting the status quo. Women dying in pregnancy? Can't have that. I can hear either – or both – of them saying it…

…and while it's true that maternal death as a result of ectopic pregnancy is rare, it is still possible. It's one of those overlooked, under-appreciated risks that can easily be overcome by greater knowledge.

Laurie set up the Ectopic Pregnancy Foundation in the 1990s, but only recently applied for (and received) charitable status.

While there are other ectopic pregnancy charities both here in the UK and abroad, he believes that his organisation is different "in a number of ways". For a start, the EPF funds and runs a helpline, charged at local call rates, that is answered 24/7 – "answered by a human being," Laurie stresses, "not an answerphone" – and the website features Frequently Answered Questions ("things that patients *really* want to know…") in nearly 30 languages, from Arabic to Zulu.

I like the way in which the site is shared between professionals and patients, recognising that ectopic pregnancy is both academically interesting and emotionally intense, and that the experience is on a shared spectrum. There is a 'multimedia' section, for example, with some fairly graphic photographs of surgical procedures, and video clips of operations such as salpingostomy and tripolar diathermy. Although these were originally intended purely for the professionals, Laurie tells me that, to his own surprise, some patients also find it comforting. Ghoulish, maybe, but if you'd just been told that you'd be having a salpingostomy in a day or two's time, maybe you would like to see *exactly* what that means.

Different patients do, of course, approach the experience in very diverse ways; some explore all the professional content of the site, reading the perspectives provided by medics – from GP to Genitourinary Specialist, from Scanner to Surgeon – and running the video clips again and again; others care nothing for the medical, technical, intellectual approach, but instead seek comfort from those FAQs – When will I stop bleeding?, Will my next baby be abnormal? for example – and some alleviation from despair. I'm reminded of some lines from an old Leonard Cohen song, *Heart With No Companion*, 'And I sing this for the captain, Whose ship has not been built, The mother in confusion, Her cradle still unfilled'. Laurie Irvine and his Foundation's supporters recognise, I think, the desolation of that empty cradle.

Of course, the first port of call for support and information will always be a woman's own medical team, the people who are treating her condition as it happens – but in the dark watches of the night, when there is no baby to hold, www.ectopicpregnancy.co.uk offers a helping hand – realistic, preactical, reassuring. ■

Fiona Crawford, pictured above with her daughter Martha, has plenty to smile about now. It wasn't always the case, but Fiona is proof that the trauma of an ectopic pregnancy doesn't have to presage a life of childlessness. Her story features on the EPF website; she's delighted to share it, because, as she explains to me, when she was diagnosed with an ectopic, "there was nowhere to go, nowhere to turn for information".

Fiona shudders as she recalls the dark days at the end of December 2002 when one glimpse of a white line flickering on a screen was all she would ever see of her baby's heartbeat. Previous pelvic problems meant she was at risk of an ectopic; eight weeks into her pregnancy she began to bleed, and felt light-headed. Her GP sent her for a scan… "and I knew instantly that something was wrong".

The words "your baby is in the wrong place" made no sense. Like many people Fiona assumed that the foetus could be transplanted into the womb; sadly, it's not the case. Just a few hours later, Fiona was taken into theatre, where Laurie Irvine removed the pregnancy, plus half of the right fallopian tube. The left tube was also damaged and bleeding, and some months later that too had to be removed, along with the remainder of the right tube. Fiona's chances of conceiving naturally went from slim to non-existent. "I sobbed for hours," she says.

The experience was both emotionally and physically draining, but Fiona and husband Brian held on to a promise that Laurie Irvine had made to them after the second operation: "I'll see you at my antenatal clinic."

And he did. Fiona conceived via IVF – a complicated but ultimately successful procedure – and was, of course, thrilled to be able to share the news with Laurie Irvine. She supports his website whole-heartedly. "It's really important," she says, "because now there's somewhere to go, and someone to phone…" ■