

# Lack of information and support for pregnant women with epilepsy

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News release

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Women with epilepsy are not being given vital information about contraception, conception and pregnancy, according to a survey released this week by Epilepsy Action. This means that they are unable to make informed decisions about their care and treatment before and during pregnancy.

All pregnancies in women with epilepsy are classed as high risk. Around 2,400 babies are born to women with epilepsy each year. Women with epilepsy and their unborn babies potentially face an increased risk of problems during pregnancy and birth. This is due to changing seizure patterns and taking certain epilepsy medicines. In extreme cases, babies can be born with a malformation, or the lives of mothers and babies can be put at risk. With better information, care and treatment before and during pregnancy, it is possible to minimise the risks for more women with epilepsy. Epilepsy Action has launched a new campaign, HealthE mum-to-be, to provide this information to women with epilepsy and their health professionals.

Epilepsy Action surveyed almost 500 women with epilepsy. The survey reveals that over a quarter (26 per cent 53/204) of respondents who have been pregnant in the last five years or are planning on becoming pregnant, said a health professional had not discussed epilepsy and pregnancy with them. This is despite national guidelines, which state that pre-conception counselling should be given to women with epilepsy. This means that many women are never made aware of the risks associated with epilepsy and being pregnant.

Almost half of these women (49 per cent 99/204) said they had not been given any information about changes to their seizure pattern. Epilepsy medicines may become less effective during pregnancy due to changes in the body, such as an increase in hormone levels. This can lead to breakthrough seizures.

Over a quarter of these women (28 per cent 58/204) said they had not been given any information about possible risks associated with taking certain epilepsy medicines during pregnancy. These include malformations and breakthrough seizures. Health professionals should be providing this information to women with epilepsy before they become pregnant and throughout their pregnancy. This is so that women can be supported to minimise risks to them and their baby, for example by changing their epilepsy medicine.

The findings of the survey coincide with the launch of Epilepsy Action's HealthE mum-to-be campaign. As part of the campaign, Epilepsy Action has developed a new magazine for mums-to-be to make sure they are aware of the issues that may affect their pregnancy. The Pregnancy Diaries features the stories of six mums with epilepsy. It charts the progress of their pregnancies and how they dealt with their epilepsy.

The new magazine will be sent to medical professionals across the UK to highlight the issues women with epilepsy face during their pregnancies. Midwives and obstetricians will also receive an advice pack. The

pack will help them learn more about epilepsy and ensure women with epilepsy get the support and advice they need during pregnancy.

One of the Pregnancy Diaries writers is Clair Cobbold, 28, from Surrey. Clair was diagnosed with epilepsy when she was 19 and had her first child, Riley, in June. Clair said: "When I found out I was pregnant, I was worried about how my seizures and anti-epileptic medication might affect my baby. But regular scans revealed my baby was fine. Throughout my pregnancy my epilepsy specialist worked with the maternity team to monitor me closely and put a detailed plan in place for labour. I found thinking about having a baby, pregnancy, labour and looking after a baby when you have epilepsy, all very daunting. The most important things for me were health professionals understanding these concerns and hearing other mum's experiences, knowing you are not alone. That's why I'm supporting Epilepsy Action's campaign."

Nicole Crosby-McKenna, women's officer at Epilepsy Action, said: "The majority of women with epilepsy enjoy healthy pregnancies and give birth to healthy babies. But it is vital that women with epilepsy are given information about all aspects of pregnancy and epilepsy. This information should be given as early as possible, and ideally before they become pregnant. Women should be encouraged to work together with health professionals so that their care before, during and after pregnancy can be properly managed. This will help reduce the risk of increased seizures, maternal death and malformations in babies born to women with epilepsy."

To order a free campaign pack, including a copy of the Pregnancy Diaries and information about all aspects of epilepsy and pregnancy, visit [www.epilepsy.org.uk/womenscampaigns](http://www.epilepsy.org.uk/womenscampaigns)

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#### Notes to editor

1. Epilepsy Action surveyed 493 women with epilepsy between July and October 2012.
2. For more information about Epilepsy Action, the campaign and patient case studies, please contact the press office on 0113 210 8870, or email at [press@epilepsy.org.uk](mailto:press@epilepsy.org.uk) For media enquiries made outside normal office working hours, please call Stacey Rennard on 07939 084 133.
3. It is estimated that there are approximately 139,000 women with epilepsy of child bearing age in the UK. On average four women with epilepsy will die during pregnancy or giving birth every year, putting them at 10 times higher risk compared to women who don't have epilepsy.
4. Additional source: The Centre for Maternal and Child Enquiries (formerly the Confidential Enquiry into Maternal Deaths.) Both suggest that better care and management of epilepsy and pregnancy before, during and after pregnancy, could potentially reduce the risk of maternal death.
5. Around one in 100 people have epilepsy. Epilepsy Action is the leading organisation working with and for people affected by epilepsy. Each year, Epilepsy Action helps over 1.1 million people understand epilepsy and treatment options through its helpline, website and events. Visit [www.epilepsy.org.uk](http://www.epilepsy.org.uk)

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