Women and epilepsy

A diagnosis of epilepsy is difficult for anyone but even more so for women of childbearing age.

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Epilepsy is the most common serious neurological disorder in young people affecting an estimated 50 million people worldwide.¹ A recent Irish prevalence study estimated that up to 37,000 people over the age of 5 years in Ireland have the disorder, which gives a point prevalence of about 0.8% in line with other industrialized nations.²

It is defined as the tendency to have recurrent seizures. Recurrent is generally defined as two or more episodes. As many as 1 in 20 people will have a single isolated seizure at some point in their lives whereas 1 in 1:15 will subsequently be diagnosed with epilepsy. It is estimated that there are as many as 10,000 women of childbearing potential in Ireland with epilepsy.³

Epilepsy is individual and affects each person differently; to date there is no single cure for all those people affected. Medication is the first line of treatment, in some cases surgery and a vagus nerve stimulator are employed.

SYMPTOMS
A seizure is a brief burst of excessive electrical activity within the brain that causes a range of symptoms which may be described as seizures. How the seizures are described depends on where they happen in the brain and how and whether they spread. There are two broad categories of seizures identified; these are referred to as generalised and partial.

DIAGNOSIS
The diagnosis of epilepsy is primarily made on an accurate eyewitness account, however in addition some investigations conducted by both the general practitioner (GP) and neurologist will include lying and standing blood pressure, electrocardiogram (ECG), an electroencephalogram (EEG) and magnetic resonance imaging (MRI) may be conducted in an effort to seek further clarification. Prior to diagnosis a specialist may also request a home video of the person’s events.

The diagnosis of epilepsy can have a devastating effect on an individual and their family; alongside this impact it has certain implications and particular lifestyle repercussions depending on the person’s age and sex. In particular, women with epilepsy (WWE) and their partners, as appropriate, must be given accurate information and counselling about contraception, conception, pregnancy, caring for children, breastfeeding and menopause.⁴ If we are now to adopt a multidisciplinary team approach to caring for this cohort of women as suggested by the NICE and SIGN guidelines then we as health professionals owe it to these women to keep ourselves fully informed.
In 2001 the Irish Epilepsy and Pregnancy Register was commenced for pregnant women with epilepsy in Ireland. A major objective of the register is to obtain and publish information on the frequency of major malformations such as heart defects, spina bifida and cleft palate among infants whose mothers take one or more anti-epileptic drugs to prevent seizures. Women with epilepsy who become pregnant, whether or not they are taking anti-epileptic drugs for their epilepsy are eligible to register their pregnancy. They are required to register before outcomes are known.

Since 2007 the Irish register has formally joined up with the United Kingdom Epilepsy and Pregnancy Register (which was established in 1996 for pregnant women with epilepsy in the UK). The ongoing running of each register remains unchanged, however, anonymised information from both registers will be joined regularly. It is estimated that there are approximately 672 women registered in the Republic of Ireland - all on a voluntary basis.

As part of my role and interest in this condition I attend the epilepsy clinic at the Rotunda Hospital, Dublin together with Dr Mary Holohan. On average we meet between 100-150 pregnant women with epilepsy in a year. Although it is our aim to meet with these women prior to pregnancy to counsel them on the effects of epilepsy in pregnancy and on the unborn child, it is often too late at our initial meeting.

EDUCATION
Issues that need to be addressed with these women include:
- folic acid,
- contraception
- preconception counselling
- pregnancy
- labour and delivery
- post natal advice
- ongoing monitoring of their condition and identifying the correct health professional to do this.

Ideally all involved with caring for WWE should begin to educate these women about their epilepsy at the initial contact and reinforce the information at all the various life stages: information should be tailored to that specific life stage.

All women from menarche are advised to take folic acid before they become pregnant and during the first three months of pregnancy in order to reduce the risk of spina bifida. This is usually a dose of 400 micrograms. In women taking anti-epileptic drugs (AEDs) they are advised to take a five milligrams dose of folic acid once a day; this is a result of some studies where the levels of folic acid were lower in some women taking AEDs.

COUNSELLING
Preconception counselling should be available to all women with epilepsy who are considering pregnancy and again this information should be reinforced regularly at patient consultations. The main aim of preconception counselling is to ensure that women embark upon pregnancy with a minimum of risk factors, fully aware of any risks and benefits of treatment, and able to make informed decisions about the pregnancy.

It is hoped by empowering these women with all the relevant information it will promote a safe and healthy pregnancy.

Now may also be the ideal opportunity to discuss the risks of AEDs in pregnancy, and the risk of non compliance, as often these women abruptly stop their medication without seeking medical advice - this we know to be extremely dangerous.

In one study of Irish midwifery students 31 out of 44 of the midwifery students stated that the woman should not stop taking her medication; 7 stated she should; and 6 stated that they did not know. Some of the midwifery students stated that the woman may need the dose of her medication reviewed but neglected to say whether the medication needed to be increased or decreased depending on the woman’s wellbeing and seizure control.

RISKS TO BABY
We know from pregnancies around the world recorded on the various registers that there are increased risks for these children. These risks can be further subdivided in to major malformations, minor malformations and neurodevelopment problems. This risk is individual and depends on several factors including the amount and type of medication, amount and type of seizures, folic acid supplementation and general lifestyle factors. Hence the importance of encouraging these women to register with the epilepsy and pregnancy register and to seek preconceptual advice.
CONTRACEPTION
Contraception is often a difficult subject to tackle either because of the influence of hormonal methods on the AED or because of the AEDs influence on the hormonal methods. When exactly to address this and by who can also cause concern; if there is confusion the woman should be referred to her specialist for advice. Mothers with epilepsy need to be given the time to discuss their various options with regard to the ideal method of contraception bearing in mind their specific AED treatment and lifestyle. In general the Depo provera, IUD and Mirena intra uterine system provide the most effective method of contraception as they are not affected by AEDs (some AEDs metabolise the oral contraceptive pill much quicker).

When planning a pregnancy most women want to know if pregnancy will affect her epilepsy. Many women with epilepsy do not experience an increase in seizures while pregnant. Of those women who do have an increase in seizures (between 8% and 46% in various studies) the increase can often be attributed to factors such as poor compliance with prescribed AEDs (sometimes compounded by vomiting), inappropriate reduction of AED therapy, a pregnancy-related fall in plasma drug concentrations (phenytoin, carbamazepine, phenobarbitone, and lamotrigine), and sleep deprivation.

There is a debate as to whether AED concentrations should be routinely measured during pregnancy however, in the woman where seizures are not controlled it is advised to get an AED level where possible at around week 12 in pregnancy in order to have a baseline level in case of increased seizure activity later on in pregnancy. All women should be treated as routinely as possible - with priority care given where necessary.

It is not unreasonable to ask the women to consider writing a birth plan and asking all the members of the multidisciplinary team to contribute on their area of expertise, all seizure types should be clearly documented along with regular medication and the management of seizures during pregnancy, labour and during the perpuremia, should be clearly documented. The use of pethidine, over breathing, sleep deprivation, pain, and emotional stress increase the risk of seizures during labour, and it is appropriate to consider epidural anaesthesia early on. The patient’s regular AED should be continued throughout this time. Remember most WWE have event free labours and the majority have normal deliveries.

Whichever method they choose women with epilepsy should be encouraged to feed their baby. That said, while breastfeeding is encouraged, some caution may be exercised depending on the medication and type of seizures; a commonsense approach should be employed and support network in place to support these woman when caring for their newborn. Again in the same study of midwifery students, 30 of them agreed that a woman with epilepsy on anti seizure medication could breastfeed while 13 disagreed and 1 did not know.

Some simple tips should include advising the woman to report any increase in seizures or any adverse side effects from the medication. Her medication is often increased in the later stages of pregnancy to accommodate a lower plasma concentration. Other advice should include information on avoiding bathing the baby unaccompanied; safety at home to include carrying the baby - where possible in a car seat; the use of a playpen if she feels in any way unwell; feeding the baby on the floor surrounded by cushions.

As WWE approach the later stages in their lives they should be encouraged to seek advice on the menopause and bone health. Unfortunately the menopause in WWE in under researched, however, we do now know that certain AED medication can influence bone health therefore these woman should be referred as appropriate for bone density testing.

If you require any additional information on any of the research, however, we do now know that certain AED medication can influence bone health therefore these women should be referred as appropriate for bone density testing. If you require any additional information on any of the information above please contact sinead@epilepsy.ie alternatively you can contact the Epilepsy and Pregnancy Register by phoning 1800 320 820

Some of the midwifery students stated that the woman may need the dose of her medication reviewed but neglected to say whether the medication needed to be increased or decreased depending on the woman’s wellbeing and seizure control.

References
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