Weighing the risks

Epilepsy is a serious condition and seizures can have profound effects on maternal health at any stage. Pregnancy is a bitter sweet time for any prospective parents torn between excitement and worry regarding what the future might hold. During pregnancy WWE often consider that the risks posed by their medication on their unborn child to be of greater significance. However WWE should be very reassured that the risk of medication in general is very small compared to the risk of possible complications during pregnancy, delivery and in the immediate post partum period. WWE should be counselled about the dangers of abruptly stopping their seizure medication and should seek medical advice regarding this.

Conclusions

To conclude, WWE of childbearing potential are indeed a special group of patients and should be treated with respect and allowed to make an informed decision concerning their epilepsy, pregnancy and medication. They should be warned about the dangers of abruptly stopping or reducing their AEDs unless under medical supervision. It is my opinion that WWE should be continually educated about the known risks of medication and offered on-going preconceptual counselling. Medication should be reviewed by an epilepsy specialist at every opportunity and a plan put in place that includes folic acid taken daily and adequate contraception. WWE should be encouraged to plan a pregnancy in consultation with their epilepsy specialist. They should also be encouraged to contact their specialist once a pregnancy is confirmed and register with the Epilepsy & Pregnancy Register.

Key Points

- Women with Epilepsy (WWE) should be prescribed Folic Acid 5mg once an anti-seizure medication is commenced and should be continued until at 3 months into the pregnancy.
- WWE should be counselled on adequate methods of contraception and informed of the benefits of planning a pregnancy.
- WWE should attend for preconceptual counselling and educate themselves about the most up to date information when planning a pregnancy.
- WWE planning a pregnancy should attend an epilepsy specialist for a review prior to planning a pregnancy and anti-seizure medication drug levels measured if necessary.
- WWE should never stop taking their anti-seizure medication without discussing it with their doctor/nurse first.
- WWE should be encouraged to register their pregnancy with the Epilepsy and Pregnancy Register - 1800 320 820.

Further Information:

Epilepsy Nurse Helpline
01 4554133

Epilepsy Ireland regional offices
Cork: Tel: 021-4274774
Dundalk: Tel: 042-9337585
Galway: Tel: 091-587640
Kilkenny: Tel: 056-7789904
Killarney: Tel: 064-6630301
Letterkenny: Tel: 074-9168725
Limerick: Tel: 061-313773
Sligo: Tel: 071-9141858
Tullamore: Tel: 057-9346790

First published in Epilepsy News Spring 2014

Epilepsy Ireland
249 Crumlin Road,
Dublin 12.
01 4557500
info@epilepsy.ie
www.epilepsy.ie
facebook.com/epilepsy.ie
@EpilepsyIreland

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Epilepsy, Pregnancy & AEDs

Important information for women with epilepsy

By Sinead Murphy

Clinical Nurse Specialist in Community Epilepsy Services

Epilepsy, Pregnancy & AEDs

Written by: Sinead Murphy,
Clinical Nurse Specialist in
Community Epilepsy Services
February 2014

Epilepsy is a common neurological condition affecting 1-3% of the population at some stage in their lives. It is a chronic disorder, characterised by recurrent unprovoked seizures; this is usually taken to mean two or more seizures. Epilepsy is the most common neurological disorder (after migraine) affecting 50 million people worldwide. The figures from the Republic of Ireland suggest that there are approximately 37,000 people affected by the disorder. It has been suggested that about 10,000 of these (25%) are women of child bearing potential. However, as the stigma, prejudice and negative image surrounding this chronic condition persist, accurate figures are hard to obtain, as many are reluctant to reveal their diagnosis or seek help.

Women with epilepsy represent a group of individuals seeking specialist care. I currently work as the first appointed Clinical Nurse Specialist in Community Epilepsy Services in the Republic of Ireland. As part of my role I work to educate all members of the allied health professions who care for individuals with epilepsy. As a qualified midwife I have taken a special interest in caring for women with epilepsy (WWE) prior to, during and post pregnancy. In today's society women with epilepsy need to be given accurate, up to date and individualised information regarding treatments available for epilepsy; in particular those who are planning a pregnancy.

With this in mind the Clinical Care Programme in Epilepsy Care has developed a standard operating procedure to support this (SOP 5). This standard operating procedure entitled Effective management of Women with Epilepsy in the non-acute setting sets out a guide to achieve the optimum care for WWE from pre-conception to the menopause. The delivery of this service is the responsibility of the General Practitioner, Obstetricians, Nursing staff, Midwives, Maternity staff, Public Health Nurse, Nursing staff, staff at Family Planning Clinics, Advanced Nurse Practitioners, Clinical Nurse Specialists, Neurologists and administration staff.

Managing epilepsy in pregnancy

Although many have published guidelines on the management of WWE, clinicians in general would agree that each woman should be treated on an individual basis and treatment tailored accordingly. The goal of treatment in general is the minimum dose of medication with no seizures and no side effects; and for those planning a pregnancy a single anti-seizure medication where possible for at least six months prior to becoming pregnant. With this in mind this article attempts to increase the awareness of the need for preconceptual planning and to educate those about the need to review medication at this time.

The management of epilepsy in pregnancy is particularly tricky because the doctor must take into account the needs not only of the WWE but also the potential adverse effects on the unborn child. Exposing the unborn baby to antiepileptic drugs (AEDs) increases the risk of major congenital malformations (MCMs) or major birth defects from a background risk of 1% - 2% to between 4% and 9%. Major birth defects are defined as a deformity that leads to a developmental or physical disability or something that requires medical or surgical treatment after birth.

Effects of medication

Over time we have questioned the effects of medication during pregnancy and with the establishment of Epilepsy & Pregnancy registers around the world, including the UK and Irish Pregnancy Register (www.epilepsypregnancyregister.ie) we have learned about the difficulties associated with individual seizure medications.

A recent publication confirmed that in general there is a low overall rate of major birth defects in women taking anti-seizure medication in single use during pregnancy, with over 96% of pregnancies resulting in a child without an MCM. Women with epilepsy need to be advised about the best course of action for their particular type of epilepsy, weighing up all available facts. WWE in primary care need to be educated about these risks and preconceptual counselling is the key.

In particular we have learned about the use of Epilim (Valproate); use on its own or in combination with other seizure medications. This drug has been associated with a higher risk of birth defects than other seizure medications such as Tegretol (Carbamazepine), Lamictal (Lamotrigine) and Keppra (Leviteracetam). These studies also demonstrate that the dose of Epilim (Valproate) can also have an influence on the outcome particularly in doses over 1000mg day.

Fetal Valproate Syndrome

A lot of concern has been raised in the recent past about Epilim's effect on the child's physical health and in particular what is referred to as Fetal Valproate Syndrome.

The term Fetal Valproate Syndrome (FVS) is used to describe a rare collection of several different congenital birth defects as a result of exposure to Valproic acid during pregnancy. It can involve a number of different conditions and the effect and severity on each child can be different. Some of the characteristics include:

- Trigonocephaly, a structural defect of the skull resulting in a triangular shaped head
- Flat nasal bridge
- Smaller than average mouth that is turned downward
- Thin upper or lower lip
- Cleft palate or cleft lip
- Eyebrow deformations
- Anteverted nostrils
- Spina bifida
- Other musculoskeletal malformations
- Neurological problems.
- Congenital heart defects.
- Facial features that seem to evolve with growth

Some other studies have suggested that exposure to valproate in pregnancy has been linked to several other disorders to include autism and learning difficulties.

FVS is diagnosed by exclusion. Each individual condition should be investigated and treated by the suitable medical specialist and the families of those involved should be supported accordingly.

Some recent research has highlighted that the total major birth defect rate in WWE in the UK has reduced from 4.3%-3.2% from 2000 to 2010 again emphasising the important work of the registers worldwide in influencing changes to prescribing practices.

The need for folic acid

The use of folic acid pre-conceptually for WWE has also been investigated. Folic acid supplementation is generally recommended to reduce the risk of spina bifida and neural tube defects during pregnancy, and although the information to date does not firmly prove that it is effective in WWE, there is no evidence to suggest that it causes any harm and no reason to suspect that it is not effective in this group. Therefore, the recommendation is that all WWE should be prescribed 5mg of Folic Acid before pregnancy and continued throughout the pregnancy.