AIMS For a better birth...

Epilepsy and pregnancy

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Kim Morley is a nurse and midwife with advanced qualifications who has been instrumental in providing specialised care for women with epilepsy since 2000. Her service uniquely supports women from their teenage years through motherhood, ensuring continuity and specialised care.

Kim's initiatives include establishing two further hospital and community-focused epilepsy services, enhancing accessibility and tailored healthcare support. Academically and professionally, she prioritises safety and aims to reduce avoidable harm, which is evident in her involvement with MBRRACE-UK. This organisation plays a critical role in improving maternal and newborn health outcomes through research and information dissemination.

Moreover, Kim's advisory role with the MHRA (The Medicines and Healthcare products Regulatory Agency) highlights her expertise in the safe use of medications like valproate during pregnancy, an area of significant concern. Kim's dedication extends beyond direct healthcare; she actively contributes to epilepsy charities and delivers lectures both nationally and internationally, specifically targeting low and middle-income countries.

In this article, Kim describes the maternity epilepsy toolkit (www.womenwithepilepsy.co.uk). This is her own creation and a testament to her commitment to empowering women with epilepsy and healthcare professionals along the maternity pathway.



By Kim Morley

The maternity epilepsy toolkit

The maternity epilepsy toolkit is a crucial resource for expectant mothers with epilepsy and their healthcare providers, aimed at improving epilepsy management from conception to childbirth. It offers a personalised, informed care approach, incorporating detailed records of medical history, medication plans, seizure management, and risk assessment and prevention strategies. Additionally, the toolkit includes access to a website that provides the latest research and guidelines to ensure care consistency and align with best practices for supporting maternal and newborn health. Empowering women with epilepsy to have ownership of the toolkit, and sharing it with all members of their team, helps develop trusted health partnerships.



Developing trusted healthcare partnerships

> **Developing professional trust in healthcare, particularly in areas like pregnancy and chronic conditions such as epilepsy, hinges on several foundational principles and strategies. Key among these is active listening and empathy.**

Active listening and empathy allows healthcare providers to fully understand and appreciate the woman's perspective, fostering a trusting relationship. Personalised and informed care is crucial, with treatment plans tailored to each woman's unique health needs and based on current evidence, ensuring relevance and sensitivity. Consistency in care from a dedicated team prevents the woman from having to repeatedly share her story, deepening understanding and trust over time. Education and continuous professional development for healthcare providers about conditions like epilepsy are essential for offering expert, non-stigmatising advice. A collaborative approach, involving a spectrum of healthcare professionals, ensures effective communication and management of the condition, placing the woman at the centre of care provision. Such strategies not only improve health outcomes but also enhance the overall care experience, making women feel respected, heard, and valued, while reducing risks associated with non-disclosure and non-adherence of treatment regimes.

So what is epilepsy?

Epilepsy is a complex neurological condition characterised primarily by the occurrence of seizures, which are the result of abnormal electrical activity in the brain. This condition is diverse in its presentation and varies significantly from one person to another, both in symptoms and in the severity of seizures.

Seizures are categorised mainly into three types: Generalised, Focal, and Unclassified. Generalised seizures affect the entire cortex from the start, displaying widespread electrical activity across both brain hemispheres. This category includes various forms such as tonic-clonic seizures and absence seizures, which manifest as sudden muscle control loss or brief attention lapses. Focal seizures originate in a specific brain area and may spread, leading to sensory disturbances like unusual smells or involuntary muscle jerks, and potentially impacting awareness. Lastly, Unclassified seizures are those that defy categorisation as generalised or focal, often reflecting limitations in diagnostic precision regarding the location or nature of brain activity during the seizure onset.

The pre-conception journey

> **Having a proactive approach to support ensures that women and girls with epilepsy receive the best possible care through their childbearing years, particularly when planning and during pregnancy.**

While most women with epilepsy have a healthy baby after a normal pregnancy and labour, it is crucial to plan pregnancy carefully to minimise risks. Anti-seizure medicines (ASM), for example, can increase the risk of birth defects to varying degrees. Further information is available from:https://uktis.org/, a website that provides evidence-based safety information about medication, vaccine, chemical and radiological exposures in pregnancy.

The level of risk from ASM depends on the number, type and dosage. The use of sodium valproate particularly (Brand names: Epilim, Epilim Chrono, Epilim Chronosphere, Episenta, Epival, Depakote,

Convulex, Kentlim, Syonell, Valpal & Belvo) in pregnancy is associated with a significantly higher risk of birth defects and *fetal valproate spectrum disorder* characterised by developmental and intellectual disabilities. Women of childbearing potential who are taking valproate must undergo an annual risk assessment by specialists to ensure adherence to a pregnancy prevention plan. Utilising long-acting reversible contraception that does not interact with their ASM is crucial to prevent unplanned pregnancies and is a mandatory component of the pregnancy prevention plan.[1] Contemplating the change of treatment presents multiple dilemmas:

- Valproate may be the only anti-seizure medication (ASM) that effectively controls their seizures, yet its use necessitates strong advisories against conception due to significant risks to the baby.
- Switching to a safer ASM to take in pregnancy, such as lamotrigine or levetiracetam, is a slow process.
- During the switch, they are advised to stop driving and continue to avoid driving for six months post change. If a seizure occurs they will not be permitted to drive for 12 months
- Side effects from the added ASM can be unpleasant and include life-threatening rashes and the possibility of seizure recurrence.
- If a woman conceives during the ASM transition, the risk of birth defects in the baby markedly increases.
- If valproate needs to be reintroduced to regain seizure control, it may not be as effective as before.

Clearly, it is important that all women have the opportunity of discussinghow epilepsy and their medications could affect pregnancy and vice versa. Talking to epilepsy specialists about the best time and way to plan a pregnancy is optimal for good health outcomes. Epilepsy support groups, counselling, and educational resources specifically designed for women with epilepsy can help empower and inform women in this process.

The provision of pre-conception care also helps identify personal seizure triggers and lifestyle behaviours that may be affecting seizure control. Mothers-to-be can help improve their health through eating a balanced diet, taking regular exercise, avoiding cigarettes, vapes, illicit substances and managing sleep and stress effectively. If they are taking other prescribed medicines that could lead to harm of a developing baby, this is also a time for re-evaluation.

Before contraception is stopped, Folic Acid supplementation is recommended to start before conception and during the first 12 weeks of pregnancy to reduce the risk of birth defects, as advised byRCOG guidelines.

Managing epilepsy during pregnancy

This requires a nuanced approach that balances women's health needs and those of their unborn child. Management involves a delicate balance between controlling maternal seizures and minimising potential adverse effects from ASM on the baby. Simply knowing that a pregnant woman has epilepsy doesn't provide full insight into the accuracy of her diagnosis, the appropriateness of the ASM for her seizure type or whether the dose is correct. It also doesn't reveal the characteristics of her seizures, her individual risk factors related to those seizures, or the overall impact of epilepsy and its treatment has had on her and her family's life.

Women's individual healthcare needs are complex. Care should not just be about managing seizures and adjusting medications. It requires a personalised approach that considers the full narrative of the woman's experiences — her medical history, and the physical, mental, and the social impacts of her condition. Comprehensive, tailored care should address a woman's personal concerns, and fears, ensuring a holistic approach to her support.

Here's a deeper look at the key components

When women with epilepsy become pregnant, specific guidelines and protocols are implemented to ensure their health and the safety of the baby. These protocols include:

- Immediate referral of pregnant women with epilepsy to specialised care pathways is advised to ensure they can access their designated epilepsy care team within two weeks. This enables timely interventions to prevent complications for both mother and baby.
- Urgently discuss women's treatment options with epilepsy specialists. Abrupt changes in medication can be harmful, and specialist advice is essential to assess treatment whilst ensuring both maternal health and fetal safety.
- Rapid access to specialist care allows for timely interventions, which are critical in preventing complications both for the mother and the baby, especially if seizure control becomes an issue.
- Regular planned antenatal and neurology/epilepsy care and assessments to help monitor seizure risks, medication adherence (possibly compromised by vomiting or fear of taking ASM in pregnancy), and seizure frequency, crucial for managing health effectively during pregnancy.

- Educating women and families on first aid and risk prevention strategies including safety around water, safety inside and outside the home. Women are also educated on the importance of not discontinuing medication without medical advice, as doing so can increase seizure activity and risks like SUDEP (Sudden Unexpected Death in Epilepsy).

- Minimising the risk of SUDEP, a rare yet devastating event where an individual with epilepsy dies suddenly and unexpectedly, is crucial in epilepsy care. Although the exact causes of SUDEP are often unclear, key preventive measures include raising awareness, regular risk assessments, and continuous education and support. This care extends throughout pregnancy and postpartum, with a strong emphasis on medication adherence to prevent tonic-clonic seizures, which pose the highest SUDEP risk when occurring during sleep particularly if sleeping alone. If sleeping alone is necessary, risk mitigation strategies such as a social care assessment for home safety and arrangements to live with family or friends should be considered. Further information available from: https://sudep.org/

- If a woman discontinues ASM suddenly, primary care providers, midwifery and obstetric teams must act swiftly to ensure she receives specialist epilepsy care to prevent increased seizure frequency and potential risks to her and her baby's health. This comprehensive approach helps manage epilepsy in pregnancy safely and effectively, balancing the health needs of the mother and her unborn child.

Safety advice from women with epilepsy for maternity hospital admission



Acknowledging women's concerns

It is important for healthcare professionals to understand and address any concerns that pregnant women with epilepsy may have regarding their condition and treatment. Addressing these concerns can lead to better adherence to medication regimes and, consequently, better outcomes for both the mother and the baby.

If monitoring of anti-seizure medication levels is carried out during pregnancy, the results should be discussed with the woman to inform choices about any necessary dose adjustments. Balanced discussions ensure that women feel supported and valued in their care decisions, enhancing trust and adherence to their prescribed treatment plans.

By prioritising women's safety, informed decision-making, and collaborative care, healthcare providers can significantly reduce anxiety and fears and improve outcomes.

Giving Birth and Monitoring Protocols

Women with active epilepsy or those on epilepsy medication are advised to give birth in a consultant-led maternity unit.[2] Although the risk of seizures during labour is low, additional monitoring for both the mother and baby may be necessary. This also allows expert care and appropriate intervention should complications arise during labour, safeguarding both mother and child.

Normal Birth and Healthy Baby Outcomes

Most women with epilepsy can expect a normal birth and a healthy baby.

> **Only in extreme cases is epilepsy an indication for induction of labour or caesarean section.**

This information provides reassurance to expectant mothers, helping to reduce anxiety about the potential impact of epilepsy on childbirth. It is essential they continue their ASM as prescribed during labour and avoid pethidine as it has the potential to lower seizure threshold. If they feel sick an anti-sickness injection can be administered. Further information, guidance, and checklists to help optimise the birth experience are available from: https://www.womenwithepilepsy.co.uk/labour-birth/

Postpartum Safety and Ongoing Care

Postpartum mother and baby safety advice, including strategies related to breastfeeding, potential worsening of seizures, and ongoing medication management, should be discussed thoroughly during both antenatal and postnatal phases. These discussions prepare women for the postpartum period, emphasising the continuation of care and vigilance required to manage their condition while caring for their newborn. The woman's epilepsy specialist team should be informed of the birth of the baby in order they can continue to guide medicine management and epilepsy support into the postnatal year.

Feeding and Medication Considerations

1. Babies exposed to ASM through breast milk should be monitored for adverse effects such as excessive sedation. Urgent medical advice is crucial if the baby shows signs of breathing difficulties, rash, excessive drowsiness, or poor feeding.

2. Breastfeeding is generally encouraged and considered safe with most epilepsy medications, but it is important to be aware of medications that might pose risks. Further information is available from LactMed, the drug and lactation database: https://www.ncbi.nlm.nih.gov/books/NBK501922/?report=classic

Safety and Support in the Hospital

1. Ensuring the postnatal medicine plan is followed. If the ASM have increased during pregnancy, there should be a plan in place to start reducing these, often as early as three days postnatal.

2. Continuing ASM as prescribed is essential to avoid seizures, which could be risky for both the mother and the baby.

3. If the mother is at risk of having unwitnessed seizures, staying alone in a single room is not advised. Hospital staff should be informed if additional support is required to optimise safety.

Advice from women with epilepsy to reduce postnatal risk



The Postnatal Year

To manage seizure risks postnatally, women with epilepsy should maintain their prescribed medication regimen, stay hydrated, eat healthily, and get enough sleep. It's critical to treat any infections like mastitis promptly since they can provoke seizures. Changes in seizure patterns should be reported immediately. Sleep deprivation, common in new parents, can also trigger seizures; thus, establishing a routine for early night sleeping and sharing nighttime feeding duties can help.[3] Resources like the NHS guide on baby sleep offer further guidance. Ensuring the care team is informed post-birth and implementing risk assessments and avoidance strategies are essential to minimise the risk of seizures during the postnatal year.

Further resources and information to help support women through the pregnancy continuum are available from: www.womenwithepilepsy.co.uk

1 Editor's note: Use of sodium valproate in people who can father children within the 3 months prior to conception may increase the risk of neurodevelopmental disorders in the child. www.medsafe.govt.nz/safety/Alerts/Sodium_valproate_Epilim_use_in_people_who_can_father_children.asp

2 Editor's note: Some women with epilepsy may feel strongly about giving birth at home or in a midwife-led unit. They may feel that they are in better control in familiar surroundings. Determining the place of birth is a human right. This page from Epilepsy Action addresses this possibility. www.epilepsy.org.uk/living/having-a-baby/labour-birth-and-after-the-baby-is-born The chance of

having a seizure in labour is generally given as being 1-2%.
https://www.rcog.org.uk/media/rzldnacf/gtg68_epilepsy.pdf

3 Editor's note: Creating a strong support network seems important. Having good breastfeeding support will help avoid the extra stress of mastitis for example. Family support may reduce sleep deprivation, and engaging a postnatal doula, mother's help or overnight support would also help with sleep, if funds permit.