Epilepsy Ireland

Women with Epilepsy

www.facebook.com/epilepsy.ie @epilepsyireland
www.epilepsy.ie **Email:** info@epilepsy.ie

This booklet has been written for women with epilepsy, to help them to navigate the many concerns and challenges they face in managing their health and well-being. Women with epilepsy are unique and require special management tailored specifically to them. They face many challenges from adolescence through to the menopause. Women with epilepsy have to consider the effects the condition has on sexual development, the menstrual cycle, contraception, fertility, pre-pregnancy, pregnancy, baby care and the menopause.

Of all the individuals diagnosed with epilepsy in Ireland, about 25% – or 10,000 – are women of childbearing potential. In today's society choice is of vital importance for women, including those affected by epilepsy.

Please note: this booklet is provided to give information to women relating to their epilepsy. It is an information booklet and does not substitute for specialist medical knowledge provided by neurologists and epilepsy nurse specialists. Your particular situation and concerns should be discussed with them so that you can be assured of the right information for you. In this booklet, we endeavour to provide fully comprehensive coverage of all current considerations; this may change over time and Epilepsy Ireland recommends that you seek current medical advice for any concerns that you may have.

Printed March 2018

Epilepsy Ireland
249 Crumlin Road, Dublin 12

Tel: 01 455 7500
Email: info@epilepsy.ie
Web: www.epilepsy.ie

Facebook: www.facebook.com/epilepsy.ie
Twitter: @epilepsyireland

Charity Number: 6170 CRA Number: 20010553

Contents

Folic acid

If you are a woman of childbearing potential and have been diagnosed with epilepsy, it is important to be made aware of the potential benefits of taking folic acid. By taking the higher dose tablet of folic acid 5 milligrams **(5mg)** as prescribed by your doctor (it cannot be acquired over the counter) prior to conception you may reduce the risks of neural tube defects such as spina bifida. Women should be informed that folic acid is not effective in reducing the risk of neural tube defects when taken after conception. Once pregnant, folic acid should be continued for a minimum of 14 weeks and started again (if it has been stopped) immediately post pregnancy.

Epilepsy and Periods

Your period is individual to you; some women have regular cycles occurring at the same time every month while others have irregular cycles or none at all. Having epilepsy can affect your menstrual cycle; women with frequent seizures tend to have irregular periods. Irregular periods can be caused by having seizures and in some cases by epilepsy medicines. It is advisable to keep a strict seizure diary recording both your seizures and your menstrual cycle. If you have any concerns regarding your cycle you should discuss them with your GP.

Catamenial Epilepsy

Catamenial seizures refer to an increase in seizures around the time of menstruation, either just before or during the first few days of the period. It is caused by the hormonal changes that affect women each month. These changes can occur at the start of a period, during ovulation (around the middle of your menstrual cycle), or in the week before a period.

If you think that your seizures are worse around certain times of the month you should keep a strict epilepsy diary for at least three months to see if there is any relationship between your epilepsy and your period; you should discuss this with your neurologist or epilepsy nurse specialist.

Contraception

Different types of planned contraception

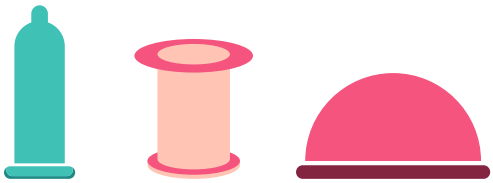
There are three main types of planned contraception:

- Barrier methods
- Hormonal treatment
- Natural birth control (rhythm and persona)

Barrier methods

Barrier methods are used during sex to prevent the sperm reaching the egg. These barriers include:

- Caps
- Condoms
- The coil
- Diaphragms
- Femidoms

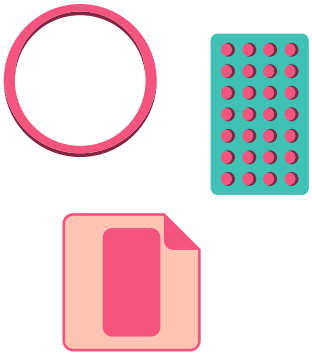


Hormonal contraception

Some methods of hormonal contraception use the two hormones oestrogen and progesterone, or just progesterone alone, similar to those produced by women, to control menstruation.

Hormonal contraception includes:

- Combined oral contraceptive pill (COCP)
- Contraceptive implant
- Contraceptive patch
- Depo-Provera contraceptive injection
- Mirena coil
- Contraceptive injection
- Progesterone-only pill (the mini pill)
- Vaginal ring



The Combined Oral Contraceptive Pill (COCP)

The hormones in the COCP prevent your ovaries from releasing an egg (ovulating). They also make it difficult for sperm to reach an egg, or for an egg to implant itself in the lining of the womb. There is no evidence to suggest that taking the pill adversely affects epilepsy. However, it is of vital importance that if you are considering taking the pill you tell your GP that you are taking anti-epileptic drugs (AEDs).

Some of the anti-epileptic medication can break down the COCP faster, therefore reducing its effectiveness. These particular medications are known as enzyme inducing anti-epileptic drugs (Table 1, see page 6). If you are taking any of these drugs, you should be started on a single COCP or a combination of COCPs to obtain a minimum dose of 50 micrograms (50ug) of oestrogen/day.

Your doctor might suggest you follow these steps, to make it work better:

- Take a version of the Pill that contains at least 50 micrograms of oestrogen **and**
- Take the Pill all the time, without the usual seven day break each month

If you have bleeding during the time that you are taking the COCP, this is called breakthrough bleeding, and could be a sign that the pill is not working very well. In this case your doctor may wish to increase the dose of oestrogen to a maximum dose of 70 micrograms.

If you still have breakthrough bleeding even after the dose is increased, it might not be the most reliable form of contraception for you.

For this reason, your doctor might advise you to use condoms as well. They can also check if you are at risk of getting pregnant by giving you blood tests at certain times of the month. Or, they may advise you to change to a different type of contraception.

If you are on a non-enzyme inducing anti-epileptic drug (See Table 1, page 7) the lower dose pill (25-35mcg of oestrogen) can be taken as usual. Any evidence of breakthrough bleeding would suggest that this method is not effective and should be reported to your GP immediately.

Depo-Provera contraceptive injection

Depo-Provera is given as an injection once every three months. Depo-Provera typically stops ovulation, keeping your ovaries from releasing an egg. This medication can speed up bone loss, as can some epilepsy medicines. This may lead to a condition called osteoporosis, which causes bones to become thinner and more brittle, so they break more easily. For this reason, the World Health Organisation (WHO) has suggested that Depo-Provera injections should be used with caution by women who are under 18 and over 45. However, WHO also say that the advantages of using Depo-Provera generally outweigh the disadvantages. If you are considering using Depo-Provera injections, it is advisable to seek advice about osteoporosis from your doctor first. A bone health scan may also be considered

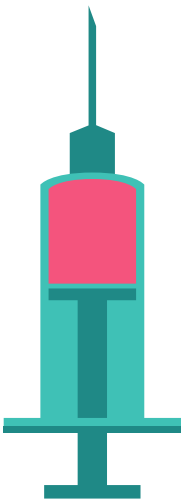
The Progesterone Only Pill (Mini Pill)

This pill has to be taken at the same time every day as per the instructions. There is a risk of pregnancy if this is not adhered to.

Emergency Contraception

This type of contraception can be used after unprotected sex or when a planned method of contraception has failed. The main types are:

- The morning-after pill
- Levonorgestrel (Levonelle)
- Ulipristal acetate (EllaOne)
- The coil



Natural birth control

Natural birth control methods rely on accurately tracking your menstrual cycles, and not having sex when you identify that you are fertile. The two main methods are:

- The Rhythm method
- The Persona method

Monitoring the body's hormone levels is an important part of natural birth control. Some epilepsy medicine, and epilepsy itself, can affect hormone levels: therefore natural birth control methods are not recommended for any women with epilepsy.

Mirena Intrauterine Systems (IUS)

There are no contraindications to the Mirena coil in women with epilepsy, because progesterone acts by being released locally into the uterus.

Table of Epilepsy Medications and Recommended Contraception

Please be advised that this table maybe subject to change and you should always discuss your contraception methods with your GP, neurologist or nurse specialist. (This table was completed in March 2018).
If you are taking any of the following enzyme inducing anti-seizure medications then the box below will describe the most suitable method of contraception for you:

- Carbamazepine (Tegretol)
- Esclicarbazepine(Zebinix)
- Oxcarbamazepine (Trileptal)
- Perampanel (Fycompa) >12mg daily
- Phenobarbitone
- Phenytoin (Epanutin)
- Primidone (Myosoline)
- Topirimate (Topamax) >200mg Daily

Contraception recommended	**Contraception not recommended**
Caps Condoms The coil Diaphragms Femidoms Hormonal contraception: • Combined oral contraceptive pill (COCP) • Depo-Provera contraceptive injection (See section in booklet on hormonal contraception for more detail) Mirena coil Noristerat contraceptive injection Unplanned (emergency) contraception: The morning-after pill called Levonorgestrel (Levonelle) (Other types of morning after pill are not recommended)	Contraceptive Implant Contraceptive Patch Progesterone only pill Vaginal ring Natural birth control Emergency contraception Ulipristal (EllaOne)

If you are taking any of the following non-enzyme inducing anti-seizure medications then the box below will describe the most suitable method of contraception for you:

- Biravetracetam (Briviact)
- Clobazam (Frisium)
- Clonazepam (Rivitrol)
- Ethosuximide(Zarontin)
- Gabapentin (Neurontin)
- Lacosimide (Vimpat)
- Lamotrigine (Lamictal) * - **special precautions see next page**
- Levetiracetam (Keppra)
- Perampanel (Fycompa) <12mg daily
- Rufinamide (Inovelon)
- Sodium Valproate (Epilim)**- **special precautions see next page**
- Tiagabine (Gabitril)
- Topirimate (Topamax) <200mg daily
- Vigabatrin (Sabril)
- Zonisamide (Zonegran)

Contraception recommended	**Contraception not recommended**
Cap Condoms The coil Diaphragms Femidoms Combined oral contraceptive pill (COCP) Contraceptive implant Contraceptive patch Depo-Provera contraceptive injection Mirena coil Noristerat contraceptive injection Progesterone-only pill (the mini pill) Vaginal ring Unplanned (emergency) contraception: • Levonorgestrel (Levonelle) • Ulipristal acetate (EllaOne)	Natural birth control

Special precautions

***Lamotrigine:** some research has suggested that Lamotrigine may interact with the COCP, contraceptive patch and vaginal ring reducing the effectiveness of Lamotrigine, thus increasing the risk of breakthrough seizures. You should discuss with your neurologist/ epilepsy nurse specialist if your dose of medication needs to be increased.

In turn Lamotrigine may also interfere with the COCP, contraceptive patch and vaginal ring causing them to work less well. For this reason a second method of contraception should be employed.

****Sodium Valproate: Please see page 14 in this booklet relating to sodium valproate.**

Please note: barrier methods of contraception, or having any type of coil inserted (including the intrauterine system, Mirena®), are usually the most suitable forms of contraception to consider if you are taking an enzyme inducing drug for your epilepsy.

How can I find out more about contraception?

Talk to your family doctor, epilepsy specialist nurse, your local family planning clinic. They can help you choose a form of contraception that will work for you and suit your lifestyle. It's important to be happy with your choice, and to know how to use it properly, if you don't want to become pregnant.

Some women have spoken about their worries about having a seizure during sex. This is in fact rare. But if you notice an increase in seizures relating to sex, it's worth talking to your doctor/epilepsy nurse.

Sexual problems

Any woman can have problems with sex from time to time. These can include problems getting aroused, having an orgasm, or having little interest in sex.

These are some common causes of sexual problems that can affect anyone:

- Stress
- Illness
- Tiredness
- Alcohol

If you have epilepsy and are having sexual problems these could also be related to:

- Your epilepsy medicine
- Anxiety about your seizures
- The way your seizures affect your hormones

If you have any concerns about your sex life, it's worth talking to your family doctor. They can look for physical or other possible causes of your problems. If they think the problems relate to how you are feeling, they may be able to refer you for talking therapies such as counselling or cognitive behaviour therapy.

Before becoming pregnant

Before becoming pregnant, it is best to seek pre-conceptual counselling from your doctor or epilepsy nurse. If your pregnancy is planned carefully then any risk of complications may be minimised. You should be seen by an epilepsy expert to discuss your treatment well in advance of pregnancy. The primary aim in doing this is for seizure freedom before conception (where possible) and during pregnancy (particularly for women and girls with generalised tonic clonic seizures), while also considering the risk of possible ill effects of anti seizure medication (AED) and using the lowest effective dose of each AED, avoiding multiple medications if possible.

It is advisable for some women on certain AEDs to have an anti-seizure medication drug level taken prior to becoming pregnant. This is measured by a blood sample and it is used as a reference should you run into any problems whilst pregnant. This level should be taken early in the morning by your GP or neurology service prior to your first morning dose of medication. Routine monitoring of AED levels in pregnancy is not recommended unless you are taking the medications Lamotrigine (Lamictal) and/or Levetiracetam (Keppra). If you are on another AED, and seizures increase, monitoring of this other AED may be useful to plan future changes to your seizure medication. The potential risks and benefits of adjusting treatment, if necessary, can be discussed.

Advice on diet, smoking, alcohol, avoiding infection, etc. will be the same for any woman planning pregnancy. However, other things may be pertinent for women with epilepsy, including:

- In some cases it may be wise to change to a different medication which is less likely to cause harm to a developing baby (depending on the medication you are already taking).

- It may be an option to stop or reduce the dose of your treatment before you become pregnant if your seizures have been well controlled. However, deciding to come off antiepileptic medication can be a difficult decision. Factors such as the type of epilepsy that you have can be important. For example, if you have the type that causes severe tonic clonic seizures, there is a risk that you could have a severe seizure when you are pregnant if you

stop your medication.

- You are advised to take 5mg folic acid a day. This should ideally be taken at least 3 months before you become pregnant and continued until you are 14 weeks pregnant. Although folic acid is recommended for all women who are pregnant, the dose for women taking antiepileptic medicines is higher than usual. Taking folic acid has been shown to reduce the risk of having a baby born with a spinal cord problem such as spina bifida.

- You are recommended to notify your pregnancy to the Irish Epilepsy and Pregnancy Register (www.epilepsypregnancyregister.ie). This is to allow information to be gathered to improve the future management of pregnant women with epilepsy. See page 12.

Under no circumstances should a woman with epilepsy stop taking her antiepileptic medication without seeking specialist advice first.

Epilepsy Medicines in Pregnancy

Although your baby has a very good chance of not having any birth problems, epilepsy medicines can sometimes cause some specific problems. These are:

- Minor congenital abnormalities
- Major congenital abnormalities
- Neurodevelopmental problems

These are explained below.

What are minor congenital abnormalities?

Minor congenital abnormalities are birth problems that do not usually need any treatment. They include minor abnormalities of the fingers, toes or limbs. They also include specific facial features. Any woman can have a baby with minor congenital abnormalities, but taking epilepsy medicines means your baby may be at a slightly higher risk

What are major congenital abnormalities?

Major congenital abnormalities are birth problems that need treatment, usually with surgery. They include things like spina bifida, a hole in the heart, or a cleft palate (where the roof of the mouth is not correctly joined).

In women who don't have epilepsy, around 1 or 2 babies in every 100 will have a major congenital abnormality. In women who have epilepsy, but don't take epilepsy medicines, around 2 babies in every 100 born will have a major congenital abnormality. If you take epilepsy medicines, your risks are higher. See table below for approximate level of risk of major congenital abnormalities for women with epilepsy taking an AED.

The Irish Epilepsy and Pregnancy Register

The Irish Epilepsy and Pregnancy Register was set up to find out more about having epilepsy and taking epilepsy medicines during pregnancy. Below is a table of information gathered from the Irish and UK epilepsy and pregnancy register to date. It does not have information about every epilepsy medicine available because, at the moment, there isn't enough information collected.

The risk of epilepsy medicines causing your unborn baby to have a major congenital abnormality seems to be greatest during the first 3 months of pregnancy.

If you take just one epilepsy medicine

Epilepsy medicine	Daily dose	Approximate risk
Carbamazepine	Any	2 to 3 in 100
Lamotrigine	Any	2 to 3 in 100
Levetiracetam	Any	2 in 100
Sodium valproate (see below)	Below 1,000mg	6 in 100
Sodium valproate (see below)	Above 1,000mg	10 in 100
Topiramate	Any	4 to 5 in 100

If you take Sodium Valproate with another epilepsy medicine

Epilepsy medicine	Approximate risk
Sodium valproate with any other epilepsy medicine	8 in 100

What are neurodevelopmental problems?

Neurodevelopment describes how a child develops skills such as speaking, understanding and behaving. If you take sodium valproate during pregnancy, your child has a higher risk of neurodevelopmental problems than other children. Neurodevelopmental problems have been found to affect between 30 to 40 in 100 babies born to mothers who have been taking sodium valproate during pregnancy. Neurodevelopmental problems become more obvious over time. So you may not know about these problems until your child is a few years old.

Information about sodium valproate

Sodium valproate is associated with an increased risk of harm to babies if taken during pregnancy. If you are a woman capable of becoming pregnant, sodium valproate should only be prescribed if no other epilepsy medicine suits you.

If you are pregnant or planning a pregnancy and you take sodium valproate, seek advice from your doctor and do not stop taking your medication.

- Doctors in the EU are now advised not to prescribe sodium valproate (Epilim) for epilepsy or bipolar disorder in pregnant women, in women who can become pregnant or in girls unless other treatments are ineffective or not tolerated. Those for whom sodium valproate is the only option for epilepsy or bipolar disorder should be advised on the use of effective contraception and treatment should be started and supervised by a doctor experienced in treating these conditions.

- **Women and girls who have been prescribed sodium valproate should not stop taking their medicines without consulting their doctor as doing so could result in harm to themselves and/or to an unborn child**

The Medicines and Healthcare Products Regulation Agency (MHRA) and the Health Services Executive (HSE) have published some more detailed information. If you are taking sodium valproate, or your doctor is considering prescribing sodium valproate for you, the MHRA advise you to read their valproate patient guide along with the patient information leaflet. See www.hrpa.ie.

Sodium valproate may be the only epilepsy medicine that stops your seizures. Do not stop taking it without advice from your family doctor, epilepsy specialist or nurse.

Being Pregnant

Most pregnant women with epilepsy have a normal pregnancy and childbirth. The frequency of seizures may increase in pregnancy in around 3 in 10 women with epilepsy. For women with epilepsy, the risk of complications during pregnancy and labour is slightly higher than for women without epilepsy. The small increase in risk is due to the small risk of harm coming to a baby if you have a serious seizure whilst pregnant, and also the possible the small risk of harm to an unborn baby from some antiepileptic medicines. See page 13.

Note: The risk of complications to both mother and baby is greater with uncontrolled seizures compared to the risks of taking medication. It is not proven that uncontrolled seizures cause congenital abnormalities but there appears to be a risk of increased foetal loss and maternal mortality. In Ireland the guidelines caring for pregnant women with epilepsy suggest that you should be seen by an epilepsy specialist at least once a trimester (i.e every 3 months). If you are on Lamotrigine and Leviteracetam, your AED level should be recorded at each visit or sooner if warranted. Pregnant women and girls who are taking AEDs should be offered a high-resolution ultrasound scan to screen for structural anomalies. This scan should be performed at 20-22 weeks' of the pregnancy by an appropriately trained ultra-sonographer.

Giving birth/Labour

Most women with epilepsy will have a normal vaginal delivery. The risk of having a seizure when you are in labour is between 1 and 2%. If you have a seizure during labour, it does not mean that you cannot continue on to have a normal delivery once the health of you and your baby is fine, you may still be able to have a normal delivery. If the obstetrician has any health concerns about you or the baby they may suggest a caesarean section.

Lowering risks of seizures when in labour

Here are some suggestions for lowering the risk of having a seizure during labour.

- Take your own epilepsy medicine to the hospital with you, and take it at your usual time. You could ask your midwife or your birth partner to help you remember to take it.
- Consider an early epidural.
- Discuss seizure management with both your epilepsy specialist and obstetrician before your planned hospital admission; have this documented in your maternity hospital notes.
- Typical triggers to including sleep deprivation, emotional stress and pain may increase your risk of having a seizure. Ensure that the team caring for you are aware of your usual triggers and how best to avoid them.
- If you feel nauseous or sick, make sure to ask your midwife for something to help with this as it is very important to continue your seizure medicine as normal during this time. If you cannot take your medication as normal your midwife will have to consider giving it to you via another route (i.e intravenously).

Pain relief during labour

Women with epilepsy have a lot of options available to them. Here are some things to consider:

- High doses of pethidine (a drug used for pain relief in the early stages of labour) can trigger seizures; therefore it is best avoided. An alternative medication can be used instead - please discuss with your Obstetrician.
- An early epidural should be considered in order to promote rest and pain relief.
- Doing breathing exercises and using gas and air may help you manage pain during labour. But you should be careful not to over-breathe. Over-breathing can trigger seizures for some people.
- Unsupervised water births, and having an unsupervised bath during labour are not usually recommended for women with epilepsy. There is a risk that you could drown if you had a seizure.
- TENS machines are often used for pain relief during labour. These are perfectly suitable for you if you have epilepsy.

Vitamin K

All children born to mothers taking enzyme inducing AEDs should be given 1mg of vitamin K by injection at delivery. However, in the Republic of Ireland all babies are routinely given 1mg of Vitamin K intramuscular to prevent haemorrhagic disease of the newborn.

Breast-feeding

If you want to breastfeed your baby, there's no reason why you should not. Epilepsy medicine can pass into your breast milk, which means your baby will get a very small amount of your medicine when they feed. This is not usually harmful, as your baby will be used to the medication from being in the womb. However, if your baby is very sleepy, hard to wake, struggling to feed, or has a rash, talk to your doctor. They might advise you to stop breastfeeding and start formula feeds, to see if your baby improves.

While you are breastfeeding, your night-time sleep will be broken regularly. If lack of sleep is a trigger for your seizures, this could be a problem. So, getting your baby into an early bedtime routine can help with this. If possible, express some breast milk, or make up formula milk in advance so another person can help with the night-time feeding and you can get some rest.

Ways to lower the risk of seizures when you are looking after your baby or young child

It's easy to forget to take your epilepsy medicines when you are looking after a baby or young child. And you will probably have disturbed sleep. Both are common triggers for seizures. Some people also say they have more seizures if they miss meals or get over-tired. These are some suggestions about avoiding these triggers:

- Use an alarm clock, alarm on your mobile phone or a pill reminder to help you to remember when to take your epilepsy medicine. You could also ask your pharmacist to blister pack your medication.
- If possible, share nighttime feeds with your partner, family member or a friend, to avoid interruptions to your sleep. Don't sleep alone, for safety reasons.
- Try to make meals in advance, so you always have a supply of something ready to eat.
- Try to avoid getting over-tired.
- If you want to lose any weight that you have gained in pregnancy, seek advice from your family doctor about a well-balanced diet.

- If your baby doesn't sleep well, talk to your public health nurse or GP about setting a good sleep routine for them.
- Accept any help that is offered, especially in the first few weeks.

Advice to help care for your new baby

Women with epilepsy can feel particularly anxious when caring for a newborn. You should be reassured that there is little published evidence concerning any risk to the newborn from the mother's epilepsy. The risk of the child being harmed depends on the type of seizure and its severity and frequency, and this risk is probably small if you take time to educate yourself in safety precautions.

Mothers with uncontrolled juvenile myoclonic epilepsy (JME) appear to be at most risk. This is usually because of sleep deprivation. You should be advised on common safety precautions before you are discharged from the maternity hospital. This advice should include instructions on not bathing the baby alone, and instructions on the safest way to carry the baby; baby slings are not recommended. The safest way to feed the baby is on the floor surrounded by cushions. We would encourage the use of an enclosed area (e.g. a playpen) for when mum does not feel well. Bed sharing with your new born is best avoided.

Remember to watch for triggers, including stress and sleep deprivation, especially in the first 6 weeks after delivery. It is also advised that women with epilepsy should not sleep alone for the first year after birth.

Reducing Risk

Inheriting Epilepsy

Inheriting epilepsy can depend on many factors. In general, the probability is low that a child born to a parent with epilepsy will also have epilepsy. However, it can partly depend on your family history, as some types of epilepsy run in families. The risk is thought to be slightly higher if it is the mother as opposed to the father that has epilepsy. If you have concerns regarding this you should discuss it with your epilepsy specialist nurse or neurologist. Genetic counselling may be an option to consider if you or your partner has epilepsy and also a family history of epilepsy.

SUDEP (Sudden unexpected death in epilepsy)

As you are aware, epilepsy has some risk factors which need to be managed and reduced as far as possible. One of these risks that may be a little higher in women who are pregnant is SUDEP. This is when a person dies suddenly and unexpectedly, and no obvious cause of death can be found. Premature death in people with epilepsy is higher than in the general population, and SUDEP is the most common cause of this. SUDEP has been shown to be connected with seizures, particularly tonic clonic (convulsive) seizures. The exact cause is not known and there may be no single explanation. However, it is thought that seizure activity in the brain may sometimes cause changes in the person's heartbeat or breathing. This, in turn, could cause the person to stop breathing or their heart to stop beating.

Ways to reduce the risks of SUDEP

- Always take your anti-seizure medication exactly as prescribed.
- Never stop taking your epilepsy medicines, or make changes to them, without talking to your doctor first.
- Make sure you never run out of your epilepsy medicines.
- Ask your epilepsy specialist or epilepsy nurse in advance what you should do if you ever forget to take your epilepsy medicines.
- Ask to be referred to an epilepsy specialist nurse for a review of your epilepsy. They may be able to suggest changes to your epilepsy medicines, or other treatment options, which may include surgery.
- Try not to sleep on your stomach as recent research suggests that people with epilepsy who sleep on their stomach may be at higher risk of SUDEP.

Menopause

Menopause, otherwise referred to as 'the change of life,' affects every woman. Before the menopause your periods may happen less often. Some of the symptoms of the menopause include hot flushes, night sweats, and trouble sleeping. Poor quality sleep can cause poor concentration and make you feel irritable. Most women reach the menopause around the age of 51. If you have frequent seizures with your epilepsy, you may have the menopause a few years earlier than this.

You may notice a change in your seizures pattern around the time of the menopause. It is often difficult to predict how seizures will change. Some women have more seizures, and some women have fewer seizures. Catamenial (cyclical) epilepsy is when seizures follow a pattern that is related to the cycle of your periods. Women with this type of epilepsy may have more seizures in the run up to and during their menopause. But after the menopause, they often have less.

About Hormone Replacement Therapy (HRT)

HRT involves taking hormone supplements to control the hot flushes and night sweats of the menopause. Many women do not have severe menopausal symptoms, so do not choose to take HRT. HRT is helpful for women who find that the symptoms of the menopause are worsening their quality of life.

HRT comes in many different forms. Oestrogen alone is used in women who have had a hysterectomy (operation to remove their womb). In women who have not had a hysterectomy, a synthetic progestogen hormone or natural progesterone is added to protect the lining of the womb from overgrowing. Oestrogen sometimes increases seizures. Natural progesterone generally reduces seizures.

There are not many studies looking at HRT and epilepsy, and all of the studies have very small numbers of women. This means there is still not enough information about the risk of seizures when taking HRT. More research is needed.
However, in general the advice is that women with epilepsy should be offered HRT in order to control their symptoms. This can be discussed further with your GP/epilepsy nurse specialist.

Bone Health

Women with epilepsy who take enzyme inducing medicine (see page 6) and sodium valproate on a long term basis should be investigated for osteopenia and osteoporosis on a regular basis by having a DEXA scan completed.

Epilepsy Ireland Services and Further Resources

Epilepsy Ireland Services

For more information, advice and support for women with epilepsy, please contact any of the following services (see back cover page for contact details).

- Epilepsy Ireland Specialist Nurse Helpline.
- Epilepsy Ireland Community Resource Officer in your local area for one-to-one support, information, advice and programmes and events to help you.

Further Resources

Irish Family Planning Association - https://www.ifpa.ie/
Birth Control HSE - https://www.hse.ie/eng/health/az/B/Birth-control/

Notes

Web: www.epilepsy.ie
Facebook: facebook.com/epilepsy.ie
Twitter: @epilepsyireland
YouTube: youtube.com/BrainwaveEpilepsy

Head Office
249 Crumlin Road, Dublin 12
Tel.: 01 455 7500
Email: info@epilepsy.ie
Specialist Nurse Helpline Tel.: 01 455 4133
Monday 9.30am – 1pm
Transitional Care Advice Line Tel.: 01 455 4133
Monday 2pm – 5pm

North West
Covering: Donegal, Leitrim & Sligo
Community Resource Officer: Agnes Mooney
Letterkenny Office, Grand Central Complex, Floor 2B, Canal Road, Letterkenny, Co. Donegal
Tel.: 074 9168725
Email: amooney@epilepsy.ie
Tel.: 071 9141858

West
Covering: Galway, Roscommon & Mayo
Community Resource Officer: Edel Killarney
Westside Resource Centre, Seamus Quirke Road, Westside, Galway
Tel.: 091 587640
Email: ekillarney@epilepsy.ie

Mid-West
Covering: Limerick, Clare & Tipperary North
Community Resource Officer: Veronica Bon
Social Service Centre, Henry St. Limerick
Tel.: 061 313773
Email: vbon@epilepsy.ie

Kerry
Covering: Kerry
Community Resource Officer: Kathryn Foley
9/10 The Paddocks, Ballydowney, Killarney, Co. Kerry
Tel.: 064 6630301
Email: kfoley@epilepsy.ie

Cork
Community Resource Officers:
South Lee & West Cork: Niamh Jones
North Lee & North Cork: Loretta Kennedy
Unit 1, 83 Beech Road, Muskerry Estate, Ballincollig, Co. Cork
Tel.: 021 4274774
Email: Niamh: njones@epilepsy.ie /
Loretta: lkennedy@epilepsy.ie

South East
Covering: Kilkenny, Wexford, Carlow, Waterford & Tipperary South
Community Resource Officer: Miriam Gray
C/o HSE, St. Joseph's, Waterford Rd, Kilkenny
Tel.: 056 7789904
Email: mgray@epilepsy.ie

Midlands
Covering: Offaly, Longford, Laois & Westmeath
Community Resource Officer: Cliona Molloy
The Charleville Centre, Church Avenue, Co. Offaly
Tel.: 057 9346790
Email: cmolloy@epilepsy.ie

East
Covering: Dublin, Kildare & Wicklow
Community Resource Officer:
Dublin North, West & Kildare: Edel Curran
Dublin South & Wicklow: Carina Fitzgerald
National Information Officer: Geraldine Dunne, 249 Crumlin Road, Dublin 12
Tel.: 01 4557500
Email: Geraldine: gdunne@epilepsy.ie /
Edel: ecurran@epilepsy.ie
Carina: cfitzgerald@epilepsy.ie

North East
Covering: Louth, Meath, Monaghan & Cavan
Community Resource Officer: Mary Baker
Unit 1a, Partnership Court, Park St. Dundalk, Co. Louth
Tel.: 042 9337585
Email: mbaker@epilepsy.ie

Training for Success
Manager: Honor Broderick
Institute of Technology Sligo, Ballinode, Sligo
Tel.: 071 915 5303
Email: Broderick.honor@itsligo.ie

Epilepsy Specialist Nurse HELPLINE
Monday 9.30am – 1.00pm
Tel.: (01) 4554133

Transitional Care Information Advice Line
Monday 2pm - 5pm
Tel.: (01) 4554133