Feature 1: Epilepsy and Pregnancy

Introduction
Like the general population, many women with epilepsy would like to experience motherhood. Having epilepsy does not mean a woman cannot fall pregnant and have a baby. In fact, in Australia, approximately 1500–2000 women taking antiepileptic medication (AEDs) become pregnant each year and more than 94% of these women with epilepsy deliver a healthy baby. However, the care of a pregnant woman with epilepsy needs to start well before pregnancy occurs, especially if she is on AEDs.

It is only natural to have concerns for your unborn child and yourself during pregnancy. Epilepsy and its treatment can cause concern about the risks to the unborn baby. The disease and these medications can also impact a woman's reproductive function and contraceptive choice. Pre-pregnancy planning and counselling, the best possible seizure control, plus folic acid supplements can all help improve outcomes.

Antiepileptic medications during pregnancy
Certain drugs such as alcohol, some illegal drugs, and some prescription and over-the-counter medications are known to cause birth defects if taken during pregnancy. Drugs that can cause birth defects are called ‘teratogens’ and medical science cannot always predict how exposure to these drugs will affect a foetus. Often with AEDs, it is closely related to a (high) dose of the medication or taking more than one AED at a time.

AEDs have borne the brunt of the blame for foetal malformations, and effects on behaviour and cognition of the child, but in addition to these possible effects of AEDs on the unborn baby, there may also be other contributions such as low folate, injury or lack of oxygen to the baby associated with severe seizures, and genetic predisposition. In reality, about eight per cent of all pregnant women need to take ongoing medication for an existing health problem and without these medications, the health and welfare of both mother and child could be put at increased risk.

As pregnant women are excluded from clinical studies on AEDs for ethical reasons, observational studies are the only way to identify the effects of AEDs on the mother and baby during pregnancy.

The Australian Pregnancy Register, established by Professor Frank Vajda in 1999 has been designed to fill this information gap however as newer medications come onto the market, more women taking these medications are needed to register for the study to help assess the risks to babies exposed to AEDs during pregnancy and define safer treatment choices.

Recent studies and epilepsy pregnancy registries have shown that:

- Any degree of congenital malformations in babies is relatively uncommon, about 3% in the general population and 3-6% in the offspring of women with epilepsy taking AEDs.
- AEDs in high doses pose the greatest risk of congenital malformations.
- As the dose of the AED is decreased so too does the risk of the more serious malformations.
- Sodium Valproate had the highest rate of congenital malformations, at doses above 1100mg/day. Many neurologists aim to prescribe lower doses for women hoping to fall pregnant.
- Combining more than one AED during pregnancy can also raise the risk.

These things need to be considered and choices need to be made well before falling pregnant. What to do with your medications prior to falling pregnant is an informed joint decision made between you and your doctor. Because there are individual circumstances for each person, the management will be adjusted to each person’s situation and choice as there is no ‘best’ AED for women with epilepsy during the child bearing years. Some options the doctor may suggest include:

- Try reducing your existing AED dose gradually to have it at the lowest dose to maintain seizure control.
- Convert any poly-drug therapy (two or more medications) to mono-therapy (a single medication) if possible.
- If you are in seizure remission, then withdraw the AED under supervision several months prior to pregnancy.

**Pregnancy**

Pregnancy is associated with vigorous changes in the body, and for women with epilepsy who are taking AEDs there can be unique management issues. Many people are concerned that pregnancy will affect seizure control or epilepsy and seizures may affect the pregnancy.

A recent report by the American Academy of Neurology (AAN) found that an increase in seizures during pregnancy is not common and neither is status epilepticus or an increased risk of seizure relapse for women who are already seizure-free. For most women with epilepsy, seizures do not increase during pregnancy, and women who have a prolonged seizure free period before pregnancy aren’t likely to have seizures during pregnancy.

If seizures do occur or worsen, there can be many different reasons for this happening. Physical and emotional stress, not taking AEDs as prescribed due to worry about the effects on the baby, different absorption of the drug, or changes in sleep habits. The physiologic changes of pregnancy such as changes in weight, metabolism and hormones, can alter both the seizure threshold and absorption of AEDs. So this can alter the blood levels of AEDs and contribute to change in seizure frequency during pregnancy.

Controlling or significantly reducing seizures during pregnancy is essential for the best maternal and baby health. The main seizure type that is of concern for risks to mother and baby is the generalised tonic-clonic seizures (GTCS) because they can possibly cause low oxygen (hypoxia) to the brain, particularly if prolonged or they lead into status epilepticus. The risk of physical injury is also much higher with GTCS.

Another question that is often raised is, does having epilepsy increase the risk of complications such as early labour, high blood pressure and miscarriages? The report by the American Academy of Neurology mentions...
that there is possibly no true difference in the rates of obstetrical complications in women with epilepsy compared to the general population.

**Monitoring during pregnancy**
As a matter of caution, during pregnancy, women with epilepsy should have regular contact with their obstetrician and neurologist and have them take a team approach. The goal is to keep mother and baby healthy - maintaining optimal seizure control using the lowest effective AED dose.

For women with good seizure control, AED blood levels should be checked each trimester, but more frequent checks and doctors visits may be needed in women with complicated epilepsy.

Should any dose adjustment need to be taken, as in all people with epilepsy, it should not be based on blood levels alone, but must take into account seizure control, adverse effects, as well as the expected change of effectiveness due to changes in pregnancy.

**Breastfeeding**
Breastfeeding, where possible, is strongly recommended to promote maternal-infant bonding and to reduce the risk of infectious and immune disorders later in life, not to mention it being part of the whole maternal experience. Studies have shown that breastfeeding, while taking AEDs, is not associated with negative cognitive effects among children at age 3 years, and the concentration of AEDs delivered to the baby through breastfeeding is lower than that during pregnancy. However, AEDs do cross into breast milk at varying levels, depending on the drug. Whilst many AEDs transfer insignificant levels into the breastmilk, some AEDs can be detected at higher levels so it is best to discuss this with your specialists prior to pregnancy if you wish to breastfeed.

A lactating mother must be aware that her metabolism and clearance of AEDs will remain higher while she is lactating. Meaning when you stop breastfeeding, AED blood levels may increase, requiring a dose adjustment.

The benefits of breastfeeding likely outweigh the risk of most AED exposure in the baby but some drugs with age-specific side effects may warrant discussion with your doctor. You should also be aware that the baby may detect the flavour imparted to milk at certain times after taking the AED, so think about timing feeds or pumping milk to optimise feeding with the least amount of AED in the breastmilk. Discussing these options with your specialist or child health nurse will help you decide when and how to feed.

**Key points**
Most women with epilepsy and their baby will have a good outcome. There is a small increased risk of congenital malformation with AEDs, and generalised tonic clonic seizures and status epilepticus pose the greatest risk to the foetus. So some general guidelines include:

Before becoming pregnant

- See your neurologist to review medications and seizures
- Avoid sodium valproate at high doses, or switch to a suitable alternative if possible
- Aim for the lowest effective dose of a single AED

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6 [http://www.neurology.org/content/75/22/1948.short](http://www.neurology.org/content/75/22/1948.short)
• Avoid falling pregnant until the best seizure control is gained
• Take folic acid supplementation for at least 1 month before conception and continue it through the first trimester

Pregnancy and delivery
• Avoid changing AEDs after pregnancy occurs if at all possible
• Early ultrasound scans at 11–13 weeks can be done, and further comprehensive ultrasound scans at 18–20 weeks to check baby
• Monitor the blood levels of AEDs at least once in each trimester, more often if needed
• Be aware there may be a small risk of seizures during labour and delivery
• Register with APR

After the baby is born
• Close monitoring of AED blood levels is recommended
• Breast feeding is usually recommended. Most AEDs are excreted in the breast milk but the benefits of breastfeeding should be considered against the possible adverse effects of AEDs on the newborn. Most infants whose mothers are taking AEDs can be successfully breastfed without complications.
• Speak to your doctor, epilepsy nurse or Epilepsy Action in regards to safety considerations at the home for you and the baby
• Explore contraceptive options with your obstetrician and neurologist

Summary
Women with epilepsy who are considering having children, are usually advised to remain on AEDs throughout the pregnancy and reproductive years. Malformation rates in the general population range from approximately 3% in most sources, and approximately 3% to 6% in women with epilepsy taking AEDs. Careful pre-pregnancy counselling and management of the pregnant woman with epilepsy taking AEDs is important, as seizure frequency and AED blood levels can change during pregnancy, and both seizures and AED drug treatment might have consequences for the developing foetus.

Epilepsy Action Australia is proud to announce:

The Australian Pregnancy Register of Anti-epileptic Drugs (APR)
Epilepsy Action Australia recently formed a major partnership with the Australian Pregnancy Register to enable the research to continue and increase the number of women registered.

The Australian Pregnancy Register of Antiepileptic Drugs was established in 1999 and is an ongoing project to continually enhance our knowledge of the use of AEDs during pregnancy.

The APR is a voluntary nationwide study enrolling women who are currently pregnant or have given birth within the last 9 months, and are taking antiepileptic medications. The study aims to collect data about the risk of birth defects from these drugs and define safer treatment choices.

The increased risk of foetal malformations are mostly attributed to the ‘older’ antiepileptic drugs - barbiturates, phenytoin, valproate and carbamazepine. Thanks to the APR, and the many thousands of women who have participated, understanding of the ‘newer’ AEDs – such as lamotrigine, levetiracetam, topiramate, oxcarbazepine, gabapentin, pregabalin, tiagabine and zonisamide is growing. Nevertheless,
more women are still needed to help provide further information so we can gain more knowledge and improve our awareness and treatment protocols.

The findings from the APR have also contributed to Australian doctors reducing the use and dose of valproate in pregnant women, in recognition of the teratogenic hazards of this drug at high doses and likely resulted in zero APR reports of congenital malformations for 2015.

To find out more phone 1300 37 45 37 or email epilepsy@epilepsy.org.au, to register phone 1800 069 722, to support this vital research visit www.epilepsy.org.au

Epilepsy Action Australia is proud to be working in collaboration with the Australian Pregnancy Register. In short:

- The APR aims to assess the risks to babies exposed to antiepileptic drugs during pregnancy and define safer treatment choices for women.
- There have been significant findings since the research began in 1998, such as identification of the antiepileptic drugs and their dosages, that increase the risk of malformations in the developing baby - however ongoing research is required to assess the impact of newer antiepileptic medications coming to market.
- The program needs a significant boost to the number of women participating in the study, as well as increasing the length of the study, to ensure enough evidence is collected for the findings to become treatment protocols.
- Epilepsy Action Australia recently formed a major partnership with the Australian Pregnancy Register to enable the research to continue and increase the number of women registered. The aim is to increase the number from 2,500 to 5,000 women in 3 years.

We are asking for two things:

1. Funding – we are asking people to financially support this critical research.
2. Eligible women to participate – women with epilepsy who are planning a pregnancy, currently pregnant or recently given birth.

To find out more, visit www.epilepsy.org.au or call 1300 37 45 37.

For more information

Women, pregnancy and epilepsy http://www.webmd.com/epilepsy/guide/women-pregnancy-epilepsy
Week by week pregnancy information http://raisingchildren.net.au/pregnancy/pregnancy_and_birth.html

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Bibliography
http://www.medscape.com/viewarticle/530483_1
Feature 2: Epilepsy and Travelling Overseas

Thinking of travelling overseas? Most people with epilepsy are able to travel and should be encouraged to do so. With some simple planning you can have a fun and safe trip. Here are some general travel guidelines and useful tips.

Organise any paperwork

It may help to:

- Carry copies of important documents (passport, credit cards and prescriptions) separate from the originals. Keep them in a waterproof bag or plastic sleeve. Also leave copies with someone in Australia.
- Include in these documents your emergency contact such as next of kin and numbers to call if needed.
- Make or update your will.
- Give friends or family a copy of the itinerary and make regular contact if you can, when away for a lengthy period.
- Carry a letter from your doctor stating your seizure type(s), medications and the doctor’s contact details. The letter can be shown to Customs or a treating doctor, if needed.
- Find out where the Australian Consulate or High Commission is located in the countries you are visiting.

Preparing for your trip

**Travelling:** Some people’s seizures can be triggered by being very tired, excited or anxious - all of which can happen when travelling, particularly long flights. As tiredness is a common trigger for seizures, allow enough rest time during and immediately after a trip. If the flight is lengthy or travels across time zones, discuss ways to manage jet lag with the travel doctor.

Stop overs are a good way to have a rest on a long haul flight.

**Flying:**

- Before booking: Go to the airline’s website and check their requirements for flying with health conditions as they differ between airlines.
- Inform the airline: Tell the airline about your epilepsy and any other important aspects when booking so the cabin crew will know.
- Medical clearance to fly: You may also need clearance from your doctor if you have had recent seizures. Some airlines won’t let you fly if you have had a seizure within 24 hours.

**Vaccinations:** Some countries require vaccinations before visiting. Most types of vaccine will not affect epilepsy, seizure control or anti-epileptic medication (AED), however some problems can occur when taking anti-malarial and antiepileptic medication together. Well before the departure date, visit your doctor and discuss vaccinations or other health precautions that are needed, and what effect these may have on your seizures.

**Health care:** Standards vary for each country, and if you have poorly controlled seizures it is important to know if you will be able to access reasonable health care, how to access health care and the potential...
costs for the country you are visiting. Some countries have a reciprocal agreement with Australia to reduce costs, but travel insurance is vital for any trip.

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<th>Investigate travel insurance:</th>
<th>Most insurance companies regard epilepsy as a pre-existing condition and will charge a higher premium. Shop around or ask the travel agent for assistance. It may be difficult finding insurance, especially if you have had seizures recently. A pre-existing disclosure form will usually need to be completed. It is important to be accurate and honest. Should a claim be lodged, the insurance company will check if medical treatment has been previously received. If seizures have not been disclosed, it may invalidate the claim.</th>
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<tr>
<th>Seizures: If seizures are likely to occur during the trip, take a travelling companion who is familiar with seizures, or join an organised tour with a trip leader who can assist if seizures occur or medical treatment is needed.</th>
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| Medical ID: | Consider Carrying some form of medical ID. Whether it is in the form of a bracelet or app on a phone. Some identification is always advisable particularly when carrying medications or if seizures are likely. |
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| Medications: | Check that medication is available in, or can be taken to, the countries you are visiting. Medication sold overseas may have a different name or may be slightly different, and the pharmaceutical company can help you with these details. |
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<tr>
<th>Take an ample supply of medications in the original containers in which they were dispensed, detailing your name, the medication name and dose prescribed. Keep a complete supply of medications for the trip and put some it in your carry-on luggage in case your main luggage gets lost or delayed.</th>
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<th>You must always have a letter from your doctor stating what you are taking and why.</th>
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| Driving: | People with an Australian driver’s licence who wish to drive in another country should check local guidelines on driving and epilepsy, as these vary. It may be illegal for you to drive in some countries. |
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### Looking after yourself

#### 1. During the flight

Long haul flights are exhausting for anyone. To reduce tiredness and jet lag try to:

- Be as rested as much as possible before departure.
- Avoid alcohol and other drugs before or on the flight.
- Avoid dehydration by drinking adequate amounts of water during the flight and limit your caffeine intake to a normal level for you.
- Get some sleep to avoid tiredness and possible seizures.
- Eat light meals regularly.
- If changing time zones, it is important to continue to take your AED’s at the prescribed intervals. Set your phone or watch to your home time zone so that you know when to take the medication. If the time zones are quite different, some slight adjustment may be necessary. Any changes will depend on how far you are travelling, how many time zones you pass through and how long you are away. Ask your doctor for help in planning any adjustments.
2. When in another country

The destination you are going to will depend on what you should check.

- Check that water is safe to drink. Contaminated water can cause gastric upset even when it has only been used to brush teeth, wash food or in ice cubes. This can lead to vomiting and diarrhoea which reduces the absorption of AED’s and may cause seizures.
- Follow your usual safety precautions if your seizures are not well controlled. It is best to have a travelling companion in case you have a seizure to reduce your risks.
- Make sure you are aware of where hospitals or health services are, especially if your seizures are not well controlled.
- Wear a medic alert bracelet, once again especially if seizures are likely.
- Your insurance company or doctor may be aware of medical translation services if you need them. If necessary, it may also be worth getting the doctors letter translated into the language of the country you are visiting prior to departure.
- Always take extra medication than is needed in case of baggage loss or theft. Keep the medication in two separate bags so at least you have some supply before replacement.

This is not an exhaustive overview. It is a good idea to plan well ahead and speak to your neurologist and a travel doctor well before travelling.

For Further Information:

The International Bureau for Epilepsy has a Traveller’s Handbook for People with Epilepsy, which can be downloaded in many languages: http://www.ibe-travelhandbook.org/


Travel advice for specific countries http://smartraveller.gov.au/zw-cgi/view/Advice/Index

Travel insurance help http://smartraveller.gov.au/insurance/

Avoiding jet lag http://www.fodors.com/news/10-tips-to-avoid-jet-lag-4457
In the News
The latest on epilepsy

Neurological Disorders National Survey
Calling all adults with epilepsy. Macquarie University eCentreClinic are looking to develop a FREE and ONLINE course to help Australians with epilepsy to manage their psychological wellbeing like anxiety, low mood, memory and attention. Please help us via a simple online survey:
https://www.surveymonkey.com/r/YVYHGQH

Seizures and flying for people with epilepsy
A recent study of thirty seven people looked at whether air travel is linked with an increase in seizures for people with epilepsy. The study found that air travel promotes an increase in seizures for those with a prior history of flight related seizures and a relatively high baseline seizure frequency. Overall, seizures were significantly more common after flying and no seizures were reported during flights.

People with complete seizure control prior to flying did not experience seizures after flying. Distance travelled, time zones crossed, duration of flight and direction of flight were not significantly different for those with seizure increase than for those without such an increase.

For more information http://www.seizure-journal.com/article/S1059-1311%2806%2900061-6/fulltext

New study sheds light on brain function curbing epileptic seizures

The brains cells, neurons, become excited and fire electrical signals when they are working. This is balanced by inhibition to then stop the neurons becoming over excited. Simplistically, seizures occur when the brain cells (neurons) become over excited.

Scientists have discovered insights into a key mechanism by which the brain reduces the excitability of neurons to prevent epileptic seizures. The Rockefeller University team has for the first time been able to provide a detailed picture of the structure of the Slo2.2 ion channel, allowing them to better understand its function and potentially create new approaches for tackling epilepsy.

In a typical brain, neurons can fire hundreds of signals per second, but there is a need for them to go back to their normal electrical state to avoid firing at this high frequency for too long - as this can lead to epileptic seizures.

Slo2.2 plays a key role in helping certain neurons return to a resting state. Before now, it was not known how this particular type of channel functioned, but the new study has made it clearer. Study author Roderick MacKinnon, head of the laboratory of molecular neurobiology and biophysics at Rockefeller University, said: “(this is) – an important step toward understanding the mechanism by which Slo2.2 contributes to the normal function of neurons in the brain and elsewhere.”

Mutations in the gene that encodes Slo2.2 have been linked with intellectual disabilities and epilepsy.

The findings were published in the medical journal Nature.
Q&As
Our service providers answer your questions

How do I tell my friends about my epilepsy?

Q. I recently had a seizure in church and now my parents want me to tell my friends so they know what to do if it happens at school or when I'm out. Can someone give advice about what to do?

A. Probably the best advice is to be honest, keep it simple but accurate, and don’t make it a huge deal. It is a medical condition and doesn’t define you. Explain a bit about epilepsy, what your seizures look like, how long they last and what someone should do if you have one. It’s really important to let them know if or when to call an ambulance, as this is often people’s first response. You will probably be guided by your friends questions as well. You may want to consider letting the school know also.

The point of having a conversation about epilepsy or telling others is to give someone a more accurate and complete understanding of epilepsy, how it affects you, what will support you and how to deal with a seizure. This conversation is not a one-size-fits-all situation and will differ depending upon the people or person you are talking to and the circumstances. It is OK not to share personal information if you choose not to, this does not make it a secret, it is just something you haven’t seen the need or desire to share at that point in time.

Many people worry about telling others, but are then surprised that the reaction they feared often does not materialise. On the whole, when someone learns more about a situation or health condition they have a better understanding and greater acceptance, especially when they have a personal connection to the person with epilepsy.

It is often better to have the conversation about epilepsy on your own terms before it is taken out of your hands with the unexpected event of a seizure.

For more indepth advice go to http://www.theseeprogram.com/EParent_Social_Coping_3a.pdf

Q. I was recently diagnosed with migralepsy. Can you explain it?

A. There is no doubt that there is overlap and similar symptoms between seizures and migraine. The occurrence of both conditions in the same person is quite common. Both disorders are characterised by temporary episodes of changed brain function. However, migralepsy is a rare condition in which a migraine is followed within an hour, by an epileptic seizure. Sometimes the seizure may occur during the migraine. Many people with epilepsy have the reverse sequence where a seizure is followed by a migraine or headache. Diagnosis of migralepsy can be difficult for many reasons including similar symptoms of migraine and seizures. The classification of migralepsy is yet to be recognised by the epilepsy community, but you will find more information regarding this condition in literature based around headache. Have a look at this site http://headacheandmigrainenews.com/migralepsy-symptoms/

Q. Can hayfever medication affect epilepsy medication or seizures?

A. Because antihistamines are widely used and an over-the-counter medication, many people think that they are relatively harmless, and they usually are. However, although it is rare, seizures have been reported. It is possible that some antihistamines may reduce the seizure threshold in some people, and make a seizure more likely.\(^9\)\(^10\)

Hayfever and allergies can be quite debilitating. If you feel that you must take medication to reduce your symptoms, speak to your doctor and pharmacist about the best type of antihistamine for you. Non-sedating antihistamines are the preference. Always take the recommended dose, and be aware that different brands may contain the same ingredient so only use one type at any one time.

For some natural ways to overcome hayfever see

\(^9\) http://www.australianprescriber.com/magazine/24/1/8/9
\(^10\) http://apps.who.int/medicinedocs/en/d/Js4952e/3.7.html#Js4952e.3.7
Taking Action
What’s happening at Epilepsy Action

New Chairman

Epilepsy Action Australia has a new Chairman! We welcome Sean Cortis into the role, Sean has served on our Board as a Director for almost 12 months and brings a wealth of skills and knowledge to the Chair. We take this opportunity to thank outgoing Chairman Jan McClelland for her many years of tireless service. Below is Sean’s biography:

Sean Cortis (since 16 January 2015)

Sean has over 30 years of practice experience with specialised skills in taxation, estate and succession planning, business advisory and family office services.

Sean’s strong tax and business advisory capability has led to his involvement in a number of innovative consulting and corporate advisory assignments, such as public listings, business sales, debt and equity raisings, valuations, mergers and acquisitions. Sean is an experienced meeting facilitator and is a current panellist for MBA sessions conducted by the Macquarie Graduate School of Management.

Sean is a member of the Institute of Chartered Accountants in Australia, a Chartered Tax Advisor and member of the Society of Tax and Estate Practitioners. He has a Bachelor of Commerce in Accounting from The University of New South Wales and has also been awarded a certificate in Fiduciary Governance from the Thunderbird School of Global Management.

Share your story

Do you have a personal experience with epilepsy to share? We have a new page on our website dedicated to inspirational stories and we would love to hear yours! Visit www.epilepsy.org.au/about-epilepsy/share-your-epilepsy-story to read stories and/or send your story to epilepsy@epilepsy.org.au. Below is one story taken from this page, enjoy.

A Long Slow Walk To Rome
By Carolyn Travers

This is a simple story about taking my teenage son for a long slow walk in the hills of Tuscany. Not your usual mother and son adventure I must admit. Ned, who suffers from debilitating epilepsy, has struggled to go to school for several years. His life has been full of doctor’s appointments, endless medication changes and hundreds of seizures. Walking seemed the perfect way for Ned to experience Italy, regain some health and fitness and have a break from the constraints and demands of city life.

Our walk began at the end of Autumn, a beautiful time of year in Tuscany. The tourist season has slowed down, the olives are being picked and pressed, grapes have been harvested and the land is finally resting. And for people with epilepsy, the heat of the Tuscan summer has gone.
Our long slow walk was a 400km journey from Lucca to Rome on the Via Francigena. The Via Francigena is an ancient pilgrims route starting in Canterbury, England. It winds down through France and Switzerland into Italy. We chose the last section with picturesque hill towns around every turn, plenty of pilgrim accommodation, wonderful food, and if needed, medical assistance. In medieval times pilgrims on their way to the Holy Site of Christianity - Rome, used the Via Francigena. This old road was also the main artery for trading and military activity through the ages. It was the perfect walk for us!

Pilgrims on this journey historically carried a shell as an emblem; today’s pilgrim carries a ‘passport’, which is stamped at each stopover culminating in a signed certificate from the Vatican at the end of your journey. Having your card stamped proved to be a great motivator.

My walking companion is Ned, who I am sure is like most teenagers, not exactly jumping for joy at the prospect of walking 400kms but being a kind, and easy going boy, he relented and embraced my enthusiasm.

At the age of 11, Ned was diagnosed with a rare brain syndrome called Congenital Bilateral Perisylvian Syndrome. His speech is affected and he has issues with eating, drinking and elements of his learning, however his biggest challenge is intractable epilepsy. Ned has taken four, five, and even six drugs in different combinations morning and night for the past three and a half years and still had seizures. Before we started this journey Ned was experiencing up to ten seizures a day. He’d fall to the ground, incontinent, or become unconscious when eating or drinking. Due to the amount of medication, he dribbled. It was a tough time being a teenager, not being able to hang out with friends, ride bikes, go swimming, play sport, have sleepovers. His social life stopped but he never complained.

For a mother watching this happen to your son and not being able to stop it, continually searching to find an answer or help, forever trying to catch him before he falls, is heartbreaking. Taking a long slow walk was so enticing but also a big challenge and keeping him safe was the number one priority. Walking is the perfect way for anyone to see and experience a country and can give the body and mind the opportunity to heal, grow stronger as well as giving someone the chance to experience a sense of achievement – surely a tonic for everyone.

The beautiful walled town of Lucca was our starting point – well known as a walking town. It has a rich pilgrimage history, renowned for its art, music and culture, has fabulous food and also gave me a last chance to embrace the Lucchese art of strolling down Via Fillungo in the evening - window shopping of course. Our backpacks were already full!

Leaving through the gates of Porta Elisa heading towards Altopascio the route is well marked. Walking on paved paths for the first section its not long before you are walking through woodlands, oak and chestnut forests, past olive groves, vineyards and market gardens winding up and down to the hills to the towns of Fucecchio, San Miniato, San Gimignano, Monteriggioni and into Siena, all with their amazing architecture and medieval histories. We watched the Tuscan pigs at play in the mud, listened out for hunters in search of cinghiale (wild boar), met mushrooms pickers with their wicker baskets full and practiced our basic Italian on very kind locals who were out walking their dogs.

On the Via Francigena you sleep in pilgrim’s accommodation in Convents and Monasteries, Hostels and Churches run by kind and generous Nuns, Sisters, Friars, Priests and volunteers. Payment is by donation or for a small fee. There are warm showers, comfy beds and sometimes the opportunity to share a meal with
your hosts. There are also plenty of B & B’s and agriturismo accommodation on the way if that is more to your liking.

We ate many of our evening meals at local trattorias to enjoy the wonderful homegrown produce and immerse ourselves in the Italian way of life. In Tuscany, the food is an absolute highlight. With the cooler climate comes the rich autumn flavours: hearty meat and game dishes, bean soups, handrolled pasta, silky risotto, freshly picked porcini mushrooms and delicious, earthy truffles. There is also the newly pressed olive oil on the tables to dip your bread into. Ned’s favourites were hand made Pici pasta with Cinghiale ragu and Spaghetti Carbonara with Truffle oil - fantastico!

There was plenty of time to explore each town’s rich history, its churches, which contain beautiful frescoes along the way but Ned made the comment early on in the walk after a seizure, “Mum, I don’t know where I’ve been or where I’m going”. It clarified for me what this walk was all about - about walking and experiencing nature, being in the fresh air, eating the local food and talking to locals and about just being together and enjoying each other’s company. The art, history and churches are for another time. Simple.

Our pace was slow. With a little under 10kgs in our backpacks, we covered an average of 13kms a day for a month. This allowed us time to wake when rested, enjoy a caffé and cornetto from the local bakery, buy pecorino cheese, focaccia and salami for lunch, and hit the track when ready. Ned did experience seizures along the way - plenty of them - but being just the two of us and with no time constraints and no other distractions it meant coping with each situation became easier. As time went on he got stronger and fitter, the seizures became fewer and fewer. By the time we arrived in Rome he was only having one seizure a day, mainly when eating.

From Siena we headed through the Val di Orca region. The views along this section of the Via Francigena are spectacular. Classic rolling Tuscan hills with stone villas and rustic farmhouses in every direction. Avenues of Italian Cypress Pines standing erect as far as the eye can see. Large Vineyards like Est. Est. Est. and high producing award winning olive groves are all a part of the landscape. We stayed in the walled towns of Buonconvento, San Quirico d’Orcia, Radicofani and Abbadia San Salvatore where its two remaining Cistercian monks offered wonderful hospitality. We walked in the sunshine, walked in the pouring rain, walked with sticks. We ate our rustic lunch in deserted corn fields, befriended other walkers with dogs, wandered through private hazelnut groves eating chocolates and got lost once or twice - always with lots of laughter, conversation and the wonderful feeling of freedom.

Part of the route down the slopes to Acquapendente following the water of Lake Bolsena is on original roman stone roads. We soaked in the thermal hot springs of Bagnaccio and walked through the Etruscan city walls of Viterbo and Vetralia. As we neared Rome Ned was fitter and stronger and a much faster walker than I. He was motivated. Hitting the 100km sign came the realization that he was actually going to walk to Rome and nothing was going to stop him. We walked to Sutri past the 1st Century Amphitheatre, onto Formello through olive groves, past sheep grazing on pastures; we crossed rivers, wandered through nature reserves with wild horses and shared a meal with other pilgrims. Our final night on the outskirts of Rome was in Convento La Storta where the nun who welcomed us walked up to Ned and kissed him on the forehead. “Random Acts of Kindness” exemplified.
Heading down into Rome was truly exciting and the views from the ridgeline were a wonderful reward - but it was tough. Busy roads with no footpaths – Epilepsy and roads with cars don’t mix. It was a long and stressful section of the walk and as we stood on the corner across from the Vatican all the relief and emotion of finally making it hit Ned and he had a seizure. Luckily landing on his trusty backpack. Tired and dazed, Ned picked himself up and completed our journey – a true pilgrim!

A month of walking, covering 400kms on foot, is an amazing achievement for a young boy. To start and finish something has given Ned a great sense of satisfaction and probably, a great sense of relief. For me, it was a month of laughter, wonderful conversation, amazing scenery, delicious food and wine, seeing the real Tuscany and meeting such kind, caring Tuscans at work and play. But most of all it was an honour and privilege to walk along side such a kind, generous soul. Watching Ned put his backpack on and head down the track each day still leaves me in awe of his strength and resilience.

Sometimes life throws a curved ball when one least expects, and some are less desired than others but we can still enjoy the road ahead. I hope our journey on the Via Francigena sparks a little flame in others to take a long slow walk to better health and fitness - or just to have a break from everyday life with someone you love.

Buon Camino!

Carolyn Travers from Sydney, Australia, now lives in the hills of Tuscany with her family. She is currently writing a book on the walk and planning another walk with Ned – the 800km Camino di Santiago through Spain. Carolyn can be contacted on ct@carolyntravers.com.

Ned is happy and healthy. He goes to a local Italian school, is learning the language and enjoys archery. His epilepsy is better managed. He is on half his previous medication and has fewer seizures. Ned’s Italian doctor says, “A great life with a few seizures is better than no life with no seizures”. We are going for the great life!