

MOMENT^{BY} MOMENT

Rosie's story

*Learn about being diagnosed with
Childhood Absence Epilepsy
Authors Annie Page
with Professor Deb Pal*



Contents

Rosie's Story

Rosie's story runs through this booklet in the following sections.

What's going on?	page 3-4
School	page 6
Getting a diagnosis	page 8
Early Days	page 10-12
Practicalities	page 13-14
The new normal	page 17
Rosie's view	page 19-20

From the Professor

The purple text is further information from Professor Deb Pal

What is Childhood Absence Epilepsy?	page 5
Seizure diary	page 7
Diagnosis	page 9
Keeping safe	page 15
Medication	page 16
Want to know more?	page 18

MOMENT^{BY} MOMENT Rosie's story



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What's going on?

We'd always thought of Rosie as a deep-thinking, daydreamy child. She would often seem to be in her own little world. From around the age of 8 onwards, we can remember times when we'd have to ask her questions several times even when we were right next to her.

"Rosie, jam or honey on your toast?" (NO response)

"Rosie, jam or honey on your toast?!" (NO response)

"ROSIE, for goodness sake, we'll be late, JAM OR HONEY ON YOUR TOAST?"

"wait, what, were you asking me something?"

These were absence seizures, although we wouldn't know about it for another eighteen months.

Rosie is a ballet addict. She is planning a career as a dancer and in April 2017, aged 9, she was dancing for about 7 hours a week. In the year leading up to this point we had been able to watch some lessons and small performances and noticed that Rosie would often 'zone out' or appear to freeze as if she had

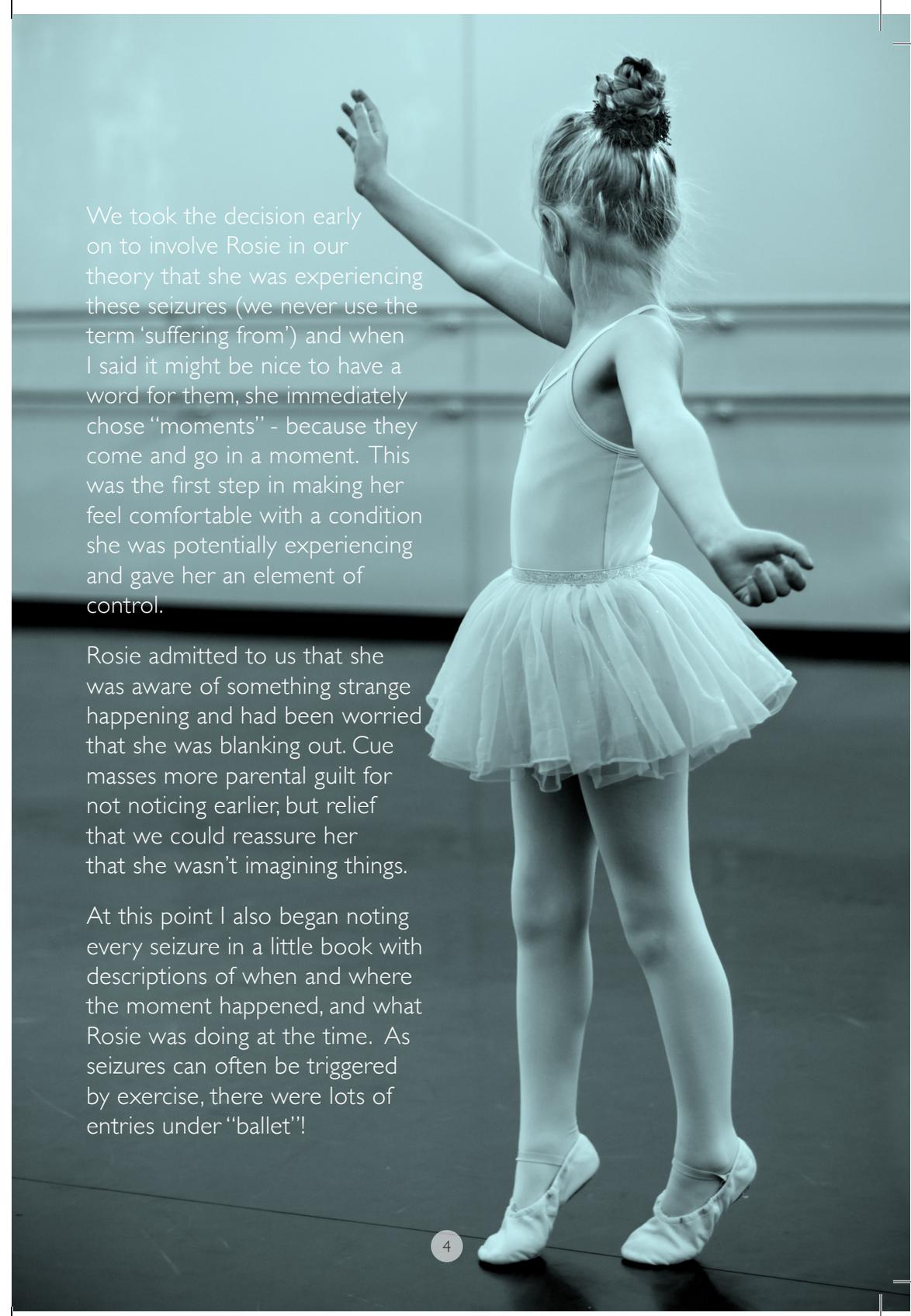
stage fright. This was surprising as she has been acting or dancing since she was three and loves being on stage! Instead, we saw someone who sometimes looked confused or rooted to the spot. Her teacher had said that Rosie had a habit of "concentrating so hard she forgets what she's doing" but we didn't really think anything more of it - she was only young and we wanted her just to enjoy her dancing and not feel under pressure to be perfect.

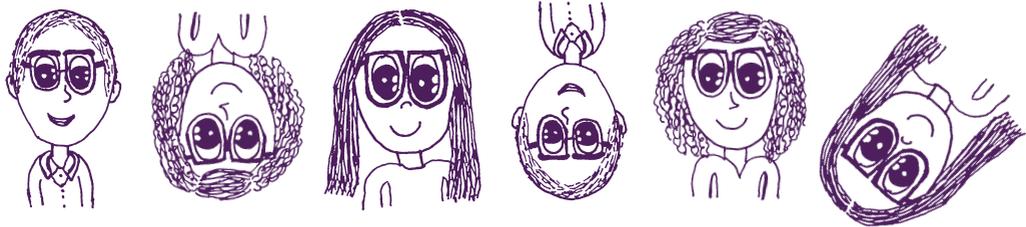
Back to April 2017 and her teacher mentioned that she'd "lost" Rosie a few times in one class. And then a week or two later the teacher called me to one side and asked if I had ever heard of absence seizures. At this point I had no idea what they were, let alone that they are a type of epilepsy. I jumped on the internet and very quickly realised that the descriptions of absence seizures could have been written about Rosie. I was very aware of the dangers of diagnosing something based on internet searches, but while we waited to see the GP, it was so very obvious to me that there was no other reasonable explanation.

We took the decision early on to involve Rosie in our theory that she was experiencing these seizures (we never use the term 'suffering from') and when I said it might be nice to have a word for them, she immediately chose "moments" - because they come and go in a moment. This was the first step in making her feel comfortable with a condition she was potentially experiencing and gave her an element of control.

Rosie admitted to us that she was aware of something strange happening and had been worried that she was blanking out. Cue masses more parental guilt for not noticing earlier, but relief that we could reassure her that she wasn't imagining things.

At this point I also began noting every seizure in a little book with descriptions of when and where the moment happened, and what Rosie was doing at the time. As seizures can often be triggered by exercise, there were lots of entries under "ballet"!





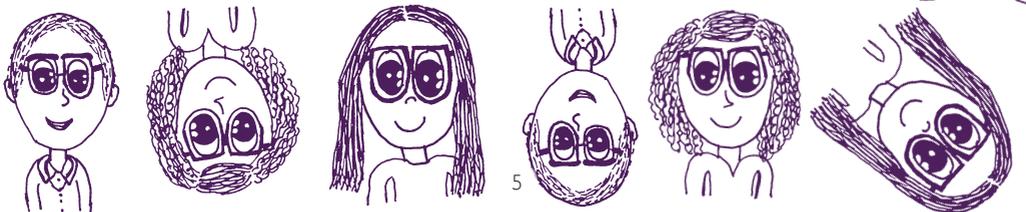
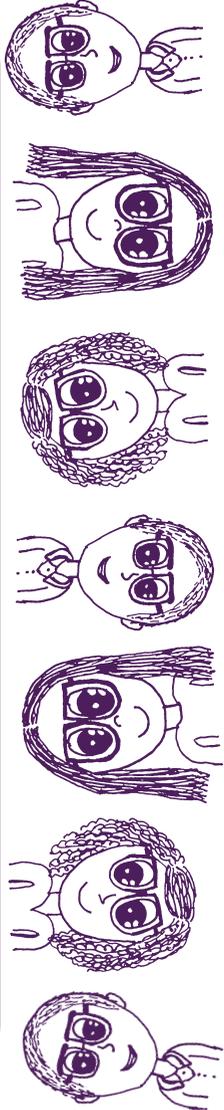
What is CAE?

Childhood Absence Epilepsy (CAE) is a common form of epilepsy affecting several thousand young people in the UK. It is a generalised epilepsy meaning it affects both sides of the brain at the same time. Absences cause a brief loss of consciousness and can occur without warning. Children with **CAE** can experience anywhere from a handful to over 100 seizures every day.

An absence seizure is a sudden spell of impaired consciousness, usually with a blank facial expression, rarely lasting more than 15 seconds. Some children may have blinking or mouthing movements at the same time, but many do not.

It is different to day-dreaming, which of course is far more common, because the start and finish of an absence seizure are abrupt, like a switch being flicked on and off, and they are always brief. Since consciousness is reduced, there is no awareness or memory of the event, and they can't be 'snapped out of it'.

CAE usually starts around 3 or 4 years of age but can be later. Two-thirds of children grow out of it usually by the age of 9 or so. One-third will develop a different type of teenage epilepsy.



School

Even though absence seizures were just a theory at this point, a very important step was talking to school. We needed to know from them if seizures were happening there, and also ensure that she wasn't being treated unfairly for something she can't help. Absences can look so much like daydreaming, or downright rudeness if someone is talking to her, that I couldn't bear the thought of Rosie being told off because of a 'moment'.

I made an information sheet, with what to look out for and what Rosie needed if she did have an absence. It asked for teachers and other staff to be aware that an absence might happen and to give Rosie a little time or assistance to catch up if she'd missed something.

At the same time we made sure that all her dance teachers knew what to look out for too.

Our school was very supportive but I felt like I had to make some effort to make sure that the message got across.

ABC

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Seizure diary



There are lots of ways to keep track of seizures.

Some people have a calendar on the wall or use a paper diary and just make a mark or a tick for every seizure.

There are also lots of apps available and you might find one to suit you.

If your child is having many absences in a day, it might feel like you can't keep up. Don't worry – just try to record all the ones you or they notice.

There are quite a few devices marketed as seizure monitoring devices that look like fitness trackers, but none of them detect absence seizures as yet.

Make a note of things that might be affecting seizures like 'very tired today' or 'guitar lesson' which can help work out potential triggers.



Getting a diagnosis

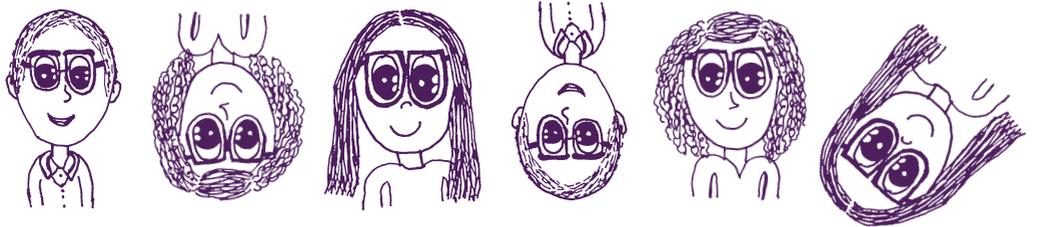
We were able to see the GP within a few days and she listened to our description of what was happening. She gave Rosie a brief examination and then arranged a referral to our local hospital. In our area this meant seeing a paediatrician with a special interest in neurological conditions (like epilepsy).

Rosie was quite nervous about going to meet the paediatrician, so we looked at the hospital website and found that there was a picture of him. We asked Rosie what questions she would want to ask and wrote them down so if she didn't feel able to ask herself, Daddy would ask on her behalf.

The children's outpatients staff were wonderful - very caring and supportive as you would expect. Rosie came home very smiley and telling me how many lovely people she had met! The actual appointment was mostly taking a history and showing the seizure diary I had kept.

The paediatrician asked Rosie to blow over and over on a paper windmill to try to trigger a seizure and it worked after about a minute. Thankfully they didn't want any more tests as they felt this was a clear enough sign of absence seizures. Ethosuximide was prescribed immediately.

An unexpected service was the Epilepsy Nurse. She had time to talk through the options for medication (tablets vs. syrup) and the pros and cons of each. She had information leaflets and is on hand to talk about any worries or problems which we found enormously reassuring. Rosie opted for the syrup, which we felt was the easier option than swallowing big tablets, even though we were warned it isn't that pleasant to take.



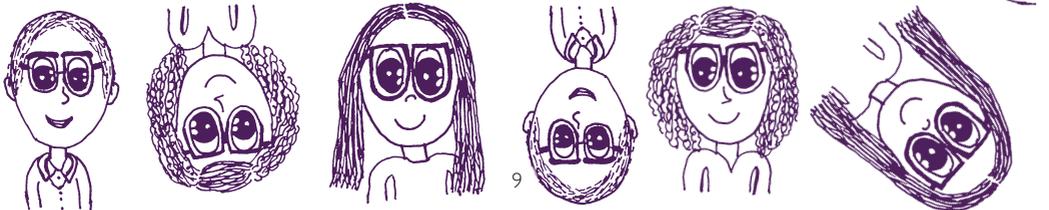
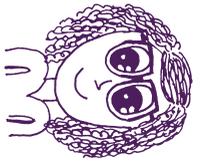
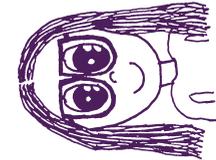
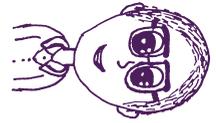
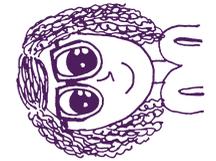
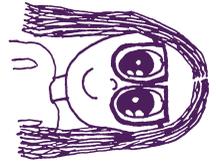
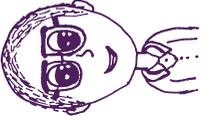
Diagnosis

A good history and a video (if you are able to take one on your phone for example) can be very helpful to the paediatrician in making the diagnosis of childhood absence epilepsy.

Quite often, your paediatrician or the **EEG** technician will ask your child to blow on a toy windmill. Overbreathing changes the blood acid-base balance, which triggers an absence in children at risk of **CAE**.

An **EEG** or brainwave test will usually show one of the tell-tale patterns that help to make a clear diagnosis, and is considered essential in current practice.

Although **CAE** is a common diagnosis, a paediatrician with expertise in epilepsy, or a paediatric neurologist need to make the diagnosis as there are many other conditions that need to be considered and excluded. **EEG** is considered essential for diagnosis and monitoring.



Early days

My initial feelings were relief. I was right to listen to the ballet teacher; I was right to research on Google; I was right to make that GP appointment. Having a definite diagnosis meant I could start to make my little girl better.

I was also pretty scared. I had big worries about what this would mean for Rosie's life over the next few years, especially her dancing. More worries flowed about the impact on daily life and changes we'd need to make as a family to keep Rosie safe. Big concerns about the side effects of medication were hard to ignore. The leaflet that comes with the ethosuximide mentions everything from hiccups to serious blood disorders and I really had to be brave to administer this to my child.

Perhaps my biggest sadness was the restrictions on Rosie's independence. She was looking forward to walking to school on her own later in the year and being able to go to the local shops with friends at the weekend; she's old enough to go swimming without an adult; she loves climbing the tree at our allotment to pick apples too.

Now we had to wind this all back as if she was suddenly much younger again.

Humour was a good way of dealing with this settling in period. We christened the medication 'Ethel Suximide' and decided that with her bitter taste and violent red colour she could be a fabulous cartoon villainess - Evil Ethel was born! "Mummy it's time for me to have my Ethel" is the way Rosie reminds me it's that time of day again.

Being able to laugh at some of the more comic absences has been a strange but effective way of helping us come to terms with them. Rosie shouted through to the kitchen one day "Mummy I just had a moment can you put it on the calendar?" I asked how she knew she'd had one "Because I was hula hooping and all of a sudden the hoop was on my feet and I had no idea why!" She's even had a moment whilst staring at the medicine box, ready for a spoonful of Ethel. That genuinely had us helpless with laughter. I was now able to confirm the diagnosis with school and pass on the Healthcare Plan that came from the nurse. I made sure to have a



word with Rosie's teacher and she was able to reassure me that she was on the lookout for moments and would deal with them subtly but supportively.

Rosie wasn't too keen to tell many people; she's quite private. However once we explained that unless people know about absences they might think she was ignoring them, she was happier for some close friends to know. Having her closest friends at school in the loop meant they can give her a nudge or a little support if she has one and they happen to notice.

Almost straight away the side effects began. We joked that there was a new one for every day, but this was pretty much true for the first week. *Hiccups? Check. Nausea? Check. Dizziness? Check. Extreme tiredness? Check.* Thankfully they

started to tail off within a week. The tiredness and increased anxiety have remained, along with memory problems which seem to have appeared as a later side effect.

We've tried hard to find a balance between being sympathetic - providing masses of extra cuddles and reassurance - and not wrapping her up in cotton wool too much. Rosie is for the most part very accepting of the situation, putting up with me telling her she can't climb trees in the park or that she has to go to bed at the same time as her little brother to get in some extra sleep.

Practicalities

Taking ethosuximide syrup is something of a performance art form! We found that these things help:

- **Use a sturdy medicine spoon - a deep sided one is helpful but you will soon manage to dish out exactly 5ml without spilling a drop!**
- **Have a cloth or a wipe handy for spills although it doesn't stain as badly as you'd expect.**
- **Have a nice drink or something yummy to eat for immediately afterwards and try to give the dose with a meal as it's easier on the tummy.**
- **Decant a dose into a small screw top plastic pot when you need to take some out and about.**

(We're working on being able to swallow capsules so that Rosie can swap to these instead.)

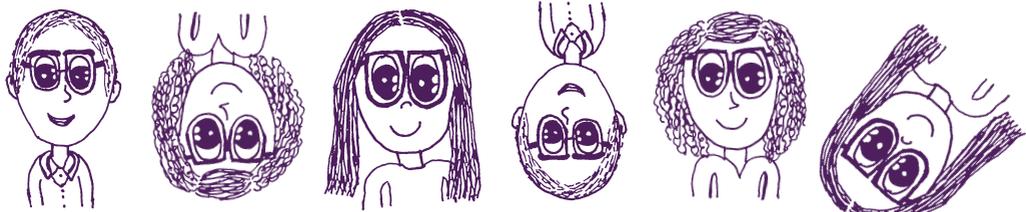
Travelling abroad takes a little extra thought, but if you have a letter from the paediatrician or GP that mentions the medication, and show that and the bottle as you pass through security there should be no problem.

Keep a seizure diary - just how many a day is enough and then you can see if medication has an effect. Also note any reasons for unusually 'high' days - we found that tiredness or being out of routine would cause a small increase. We record them on a free printable 'month per page calendar' on the kitchen wall so we can just grab a pen and tally any that happen.

Prioritise sleep. Tiredness seems to be a trigger for Rosie so we do what we can to make sure she gets enough good quality sleep.

Don't be afraid to speak up and make sure that everyone taking care of her knows - although the seizures aren't in themselves serious, the consequences could be, and at the very least it's crushing for Rosie to be told off for not concentrating when she was having an absence. School need to know that seizures could happen anytime - in the dinner queue, in a drama lesson or in maths. So it's important that all adults know about them (not just teachers). Rosie keeps an "all about my

epilepsy" card in her drawer that she can hand to anyone taking the class at short notice. I made a little information sheet for friends' parents or new dance teachers or anyone else who might be looking after her and keep a couple in my bag. I imagine being told that your child's guest or a pupil in your next ballet class has epilepsy would be a little worrying, so hopefully this is reassuring and gives us peace of mind that they are aware of possible risks.



Keeping Safe

Each family will find their own balance between keeping safe and allowing life to carry on as close to normal as possible, and much depends on how many absences your child is having each day.

Any activity that would be dangerous if you suddenly had reduced consciousness should be thought about carefully.

These include:

Swimming

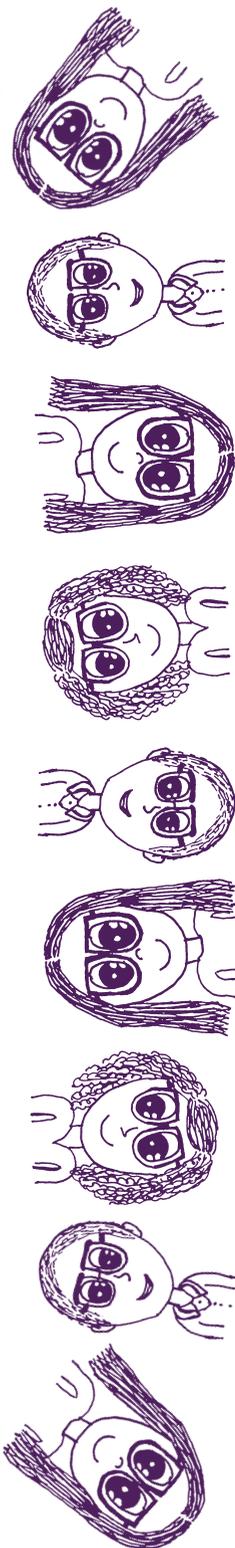
Climbing

Crossing the road

Riding a bike

There are usually ways to make any activity safe enough and epilepsy shouldn't be a barrier to your child enjoying things they love to do.

It can be really helpful to explain your child's condition to some of your child's close friends and their parents so that they can be helpful and understanding if they notice an absence.



Medication

Treatment with antiepileptic drugs (AEDs) is recommended for children with a diagnosis of CAE.

The absence seizures themselves are not life-threatening, nor do they cause any brain damage. However, during an absence seizure the brain's learning capacity is affected for several minutes afterwards, and so just a few absences can wipe out a whole lesson's worth of school time.

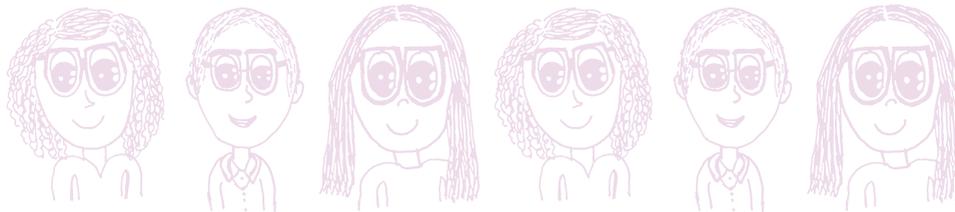
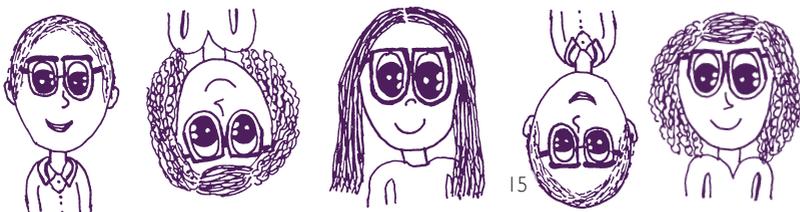
There are many antiepileptic drugs (AEDs) that can be used for CAE.

They have different ways of acting in the brain, and overall work by reducing the synchronisation of electrical discharges. Most of the newer generation of antiepileptic drugs have a lower chance of side effects than the older ones, although ethosuximide, one of the older generation drugs, is also one of the most effective.

The leaflet in the medicine box will list all the possible side effects, but this doesn't mean that your child is

at risk of all or any of them. Some of them may be temporary or dose-dependent, or can be worked around. For example, tummy pain with ethosuximide can be reduced by taking it with food. Many other side effects can be minimised by starting at a small dose and steadily working up – your paediatrician will advise.

Fewer than 5% of people experience side effects that are serious enough to stop the treatment, and there are other drug options that don't have the same side effect profile. At the moment, we can't predict who will experience which side effect (although it's an area of active research) but it's rare that we can't find one that is acceptable at first or second try. It's also worth remembering that we are trying to achieve an acceptable balance between the risks listed above such as injury or learning difficulty and the treatment.



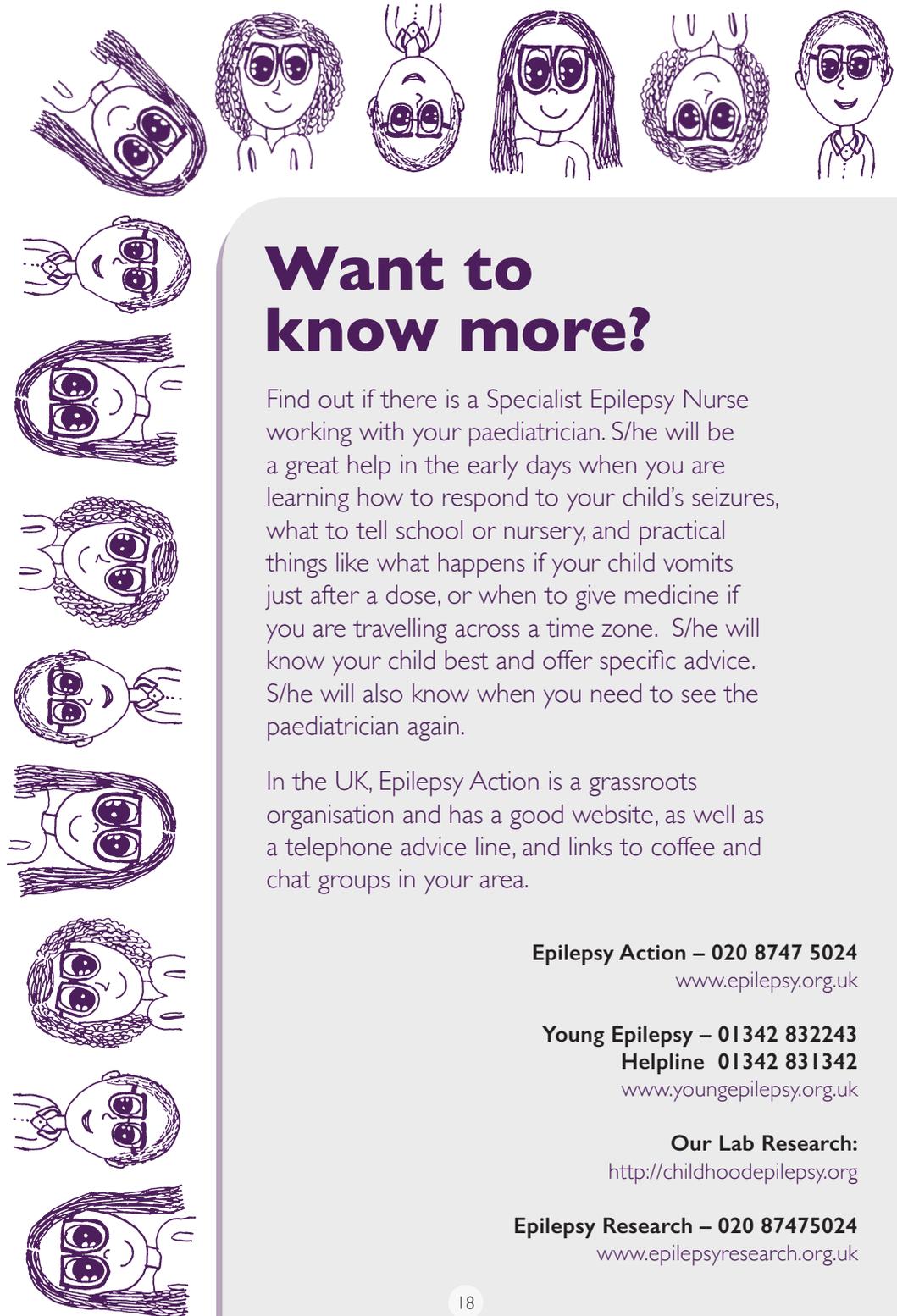
The new normal

About three months into taking medication this is all starting to feel normal. 'Ethel' is part of our routine, although clearly we'd rather she wasn't! There are good days and bad days; days when we almost forget about it and days when we have a cry and a big cuddle because it is slowly sinking in that this is a long-term deal.

Rosie has begun talking about how her experiences might help others and she is aware of how

learning to live with epilepsy might make her a stronger person in the future. There are still some restrictions on her independence but we are keeping it in perspective.

And...since her diagnosis she has successfully auditioned for associate level ballet classes and earned a distinction in her grade exam.



Want to know more?

Find out if there is a Specialist Epilepsy Nurse working with your paediatrician. S/he will be a great help in the early days when you are learning how to respond to your child's seizures, what to tell school or nursery, and practical things like what happens if your child vomits just after a dose, or when to give medicine if you are travelling across a time zone. S/he will know your child best and offer specific advice. S/he will also know when you need to see the paediatrician again.

In the UK, Epilepsy Action is a grassroots organisation and has a good website, as well as a telephone advice line, and links to coffee and chat groups in your area.

Epilepsy Action – 020 8747 5024
www.epilepsy.org.uk

Young Epilepsy – 01342 832243
Helpline 01342 831342
www.youngepilepsy.org.uk

Our Lab Research:
<http://childhoodepilepsy.org>

Epilepsy Research – 020 87475024
www.epilepsyresearch.org.uk



Rosie's View

Having epilepsy is good as well as bad. Some of the bad things are that I can't go swimming on my own or walk to school on my own like I was planning to when I got to Year 5. But sometimes it's good like when we went on an adventure day with school and I got to go in the same canoe as my teacher to keep me safe – she was really good at paddling and we were much faster than everyone else!

Ethosuximide tastes horrible but I get to have a sweet afterwards to take the taste away so that's another good thing! I'm practising swallowing tablets by using little sweets to get used to the feeling. Then I can have my medicine in capsules which won't taste nasty.

I know that if I can learn to live with having absence seizures it will make me a much stronger person and if my friends meet someone with epilepsy in the future then they will know about it already and be able to help that person.



Annie



Rosie



Deb

Disclaimer Statement:

The information and medical advice expressed here are not a substitute for talking to your doctor. This information should not be used in place of a visit, call or advice of a physician or other health care provider. The advice is intended to provide a general guide for a person to discuss their personal medical condition with their health care provider. You should not disregard medical advice or delay seeking it because of something you have read here.

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