

Ben has epilepsy



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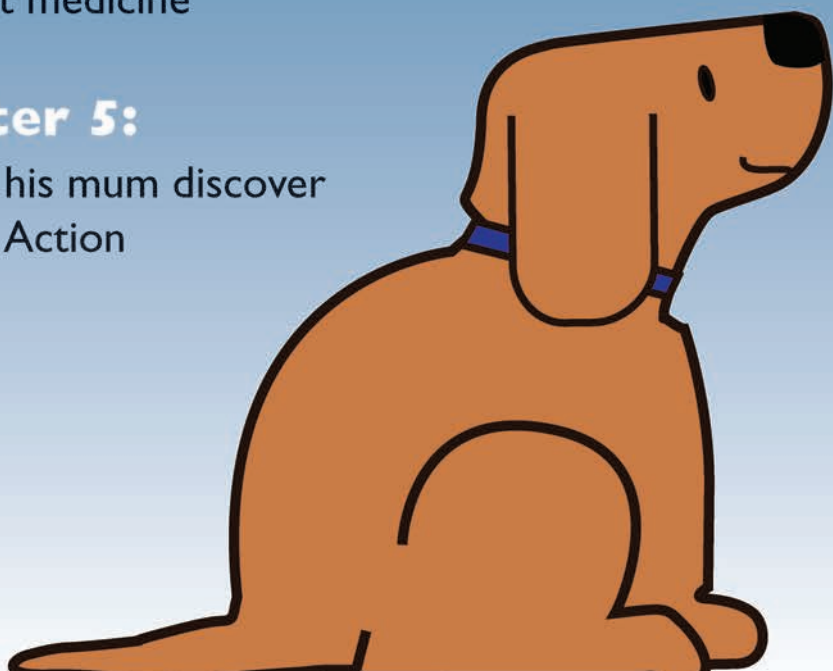
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Chapter 1

A football game
goes wrong



My first seizure

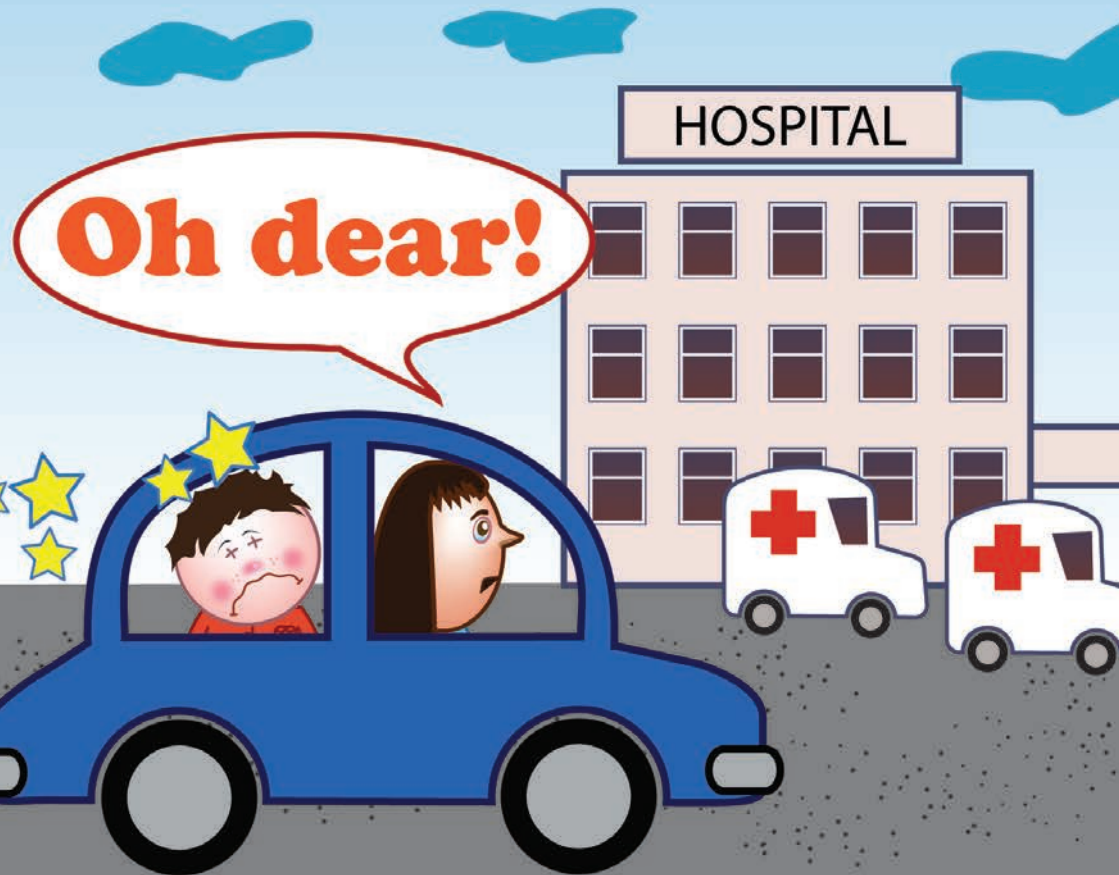
My name is Ben. I am 10 years old and I live with my mum. I have epilepsy. When I was eight I was playing out with my friend Sayed in his garden. We were playing football and seeing who could score the most goals. It was great.

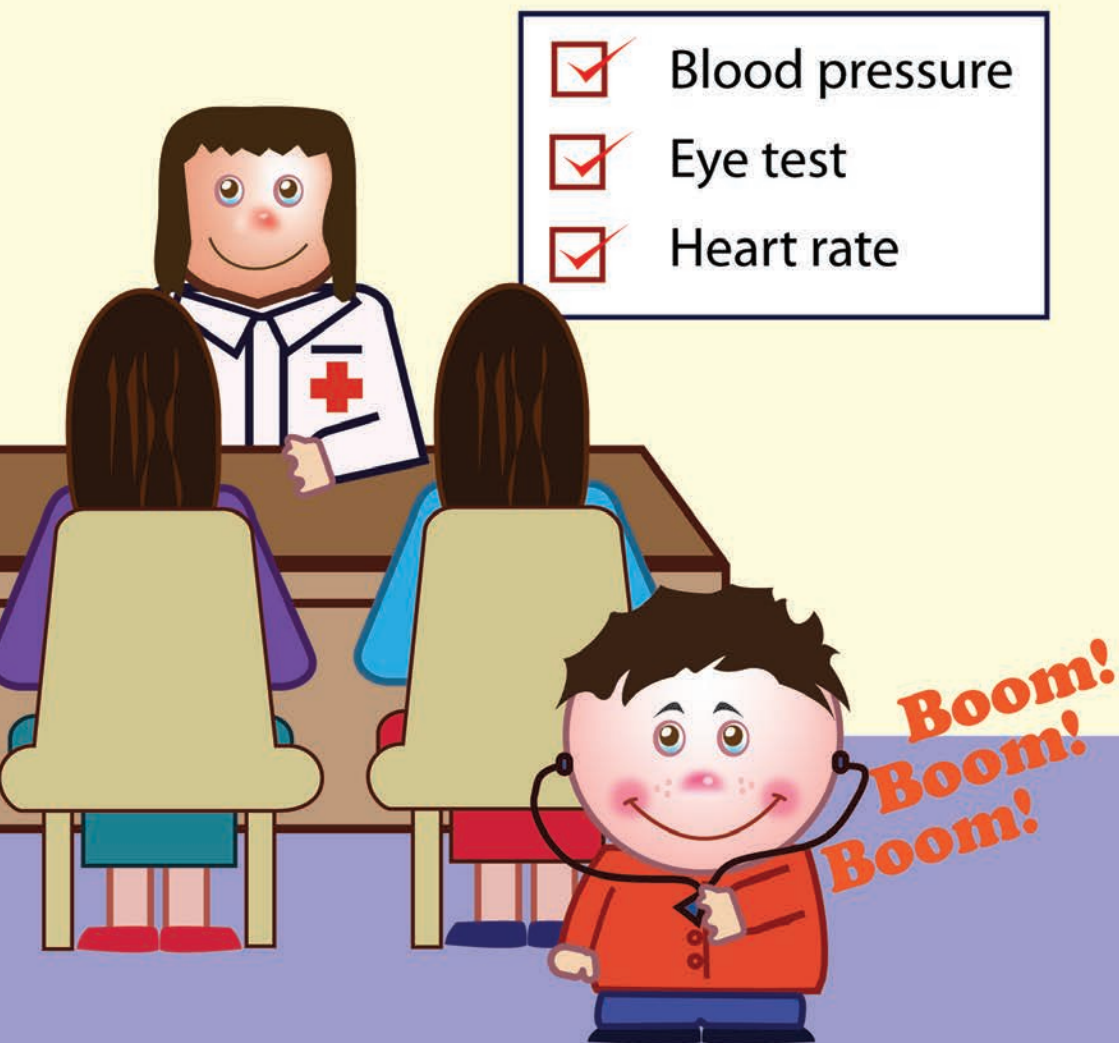


Then I felt really strange. I couldn't see properly.
Sayed seemed miles away. Luckily he noticed I
wasn't well. He quickly went to get help.



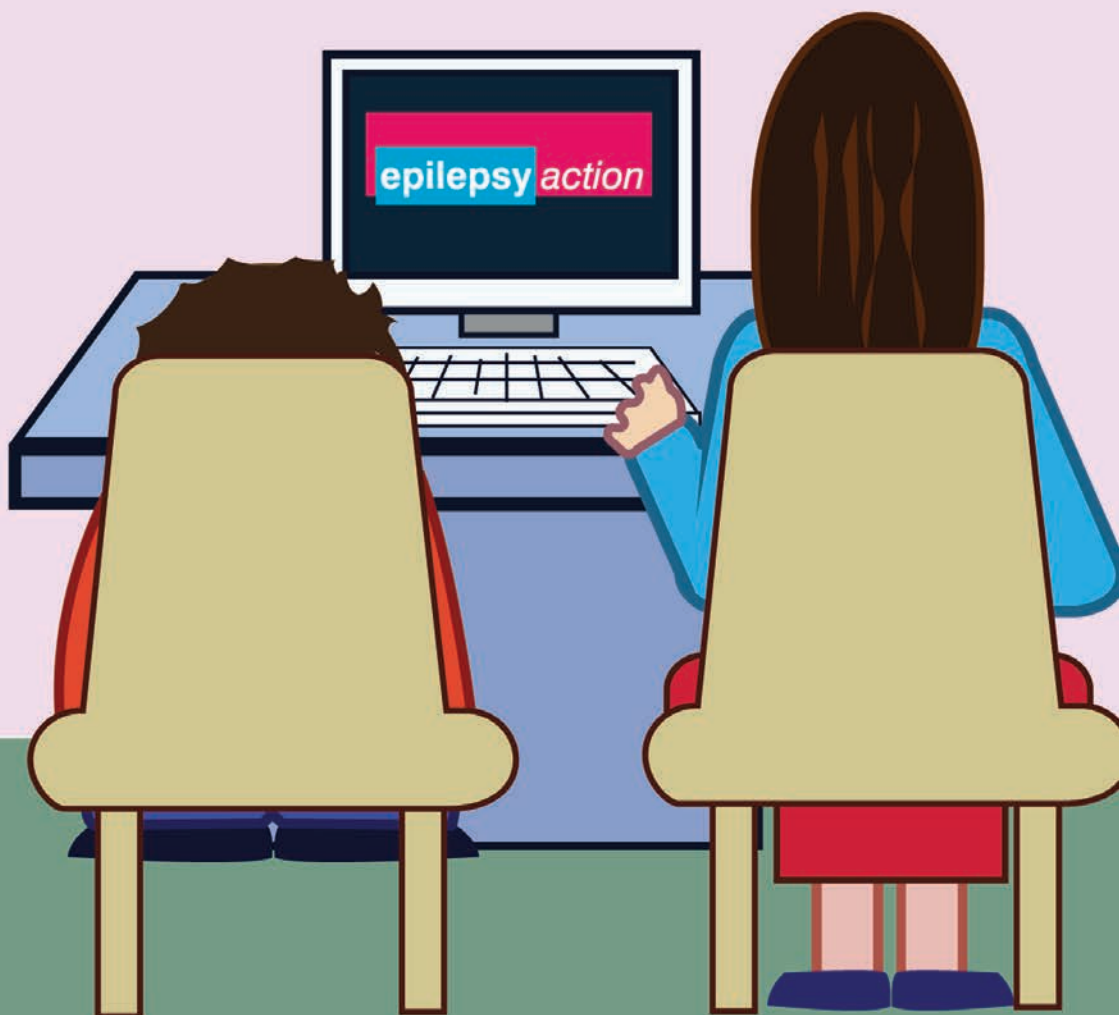
Sayed's mum called my mum. When she came back I was on the floor. She said I had to go to hospital because I'd hit my head. She was very worried. But mums always worry, don't they?





The doctor was great. She let me have a go with the thing for listening to people's hearts. It's a stethoscope. I heard my heart beating. She asked us loads of questions. She did some tests too. She did a blood test. Then she looked into my eyes. Finally she said we could go home.

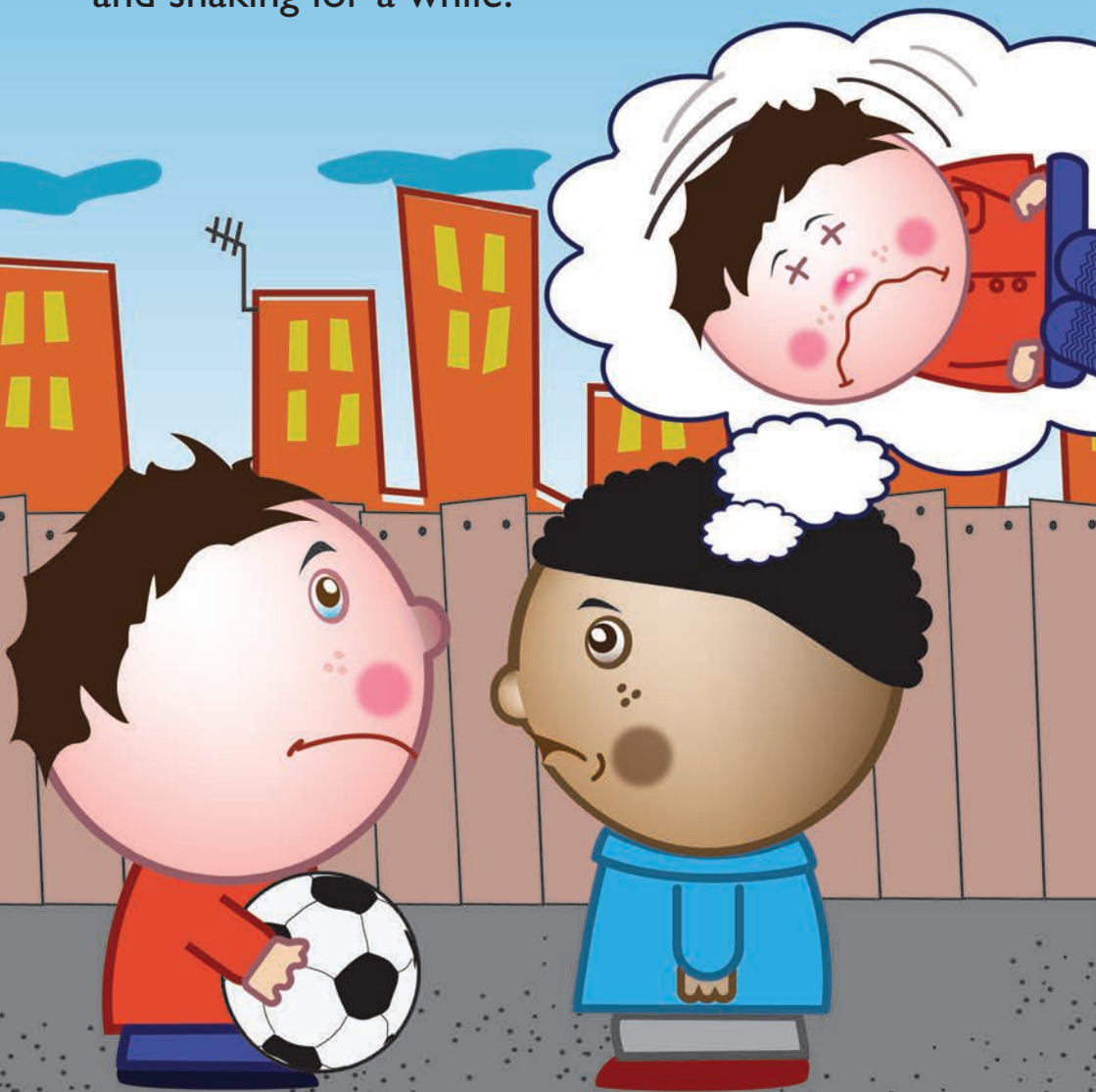
Mum told me the doctor said I had had a seizure. This was why I fell over. We didn't know what a seizure was so we looked it up. My mum says it's best to know as much as you can about things. I agree.



When I went to bed that night it took ages to get to sleep. I was worried I might have another of these seizures.

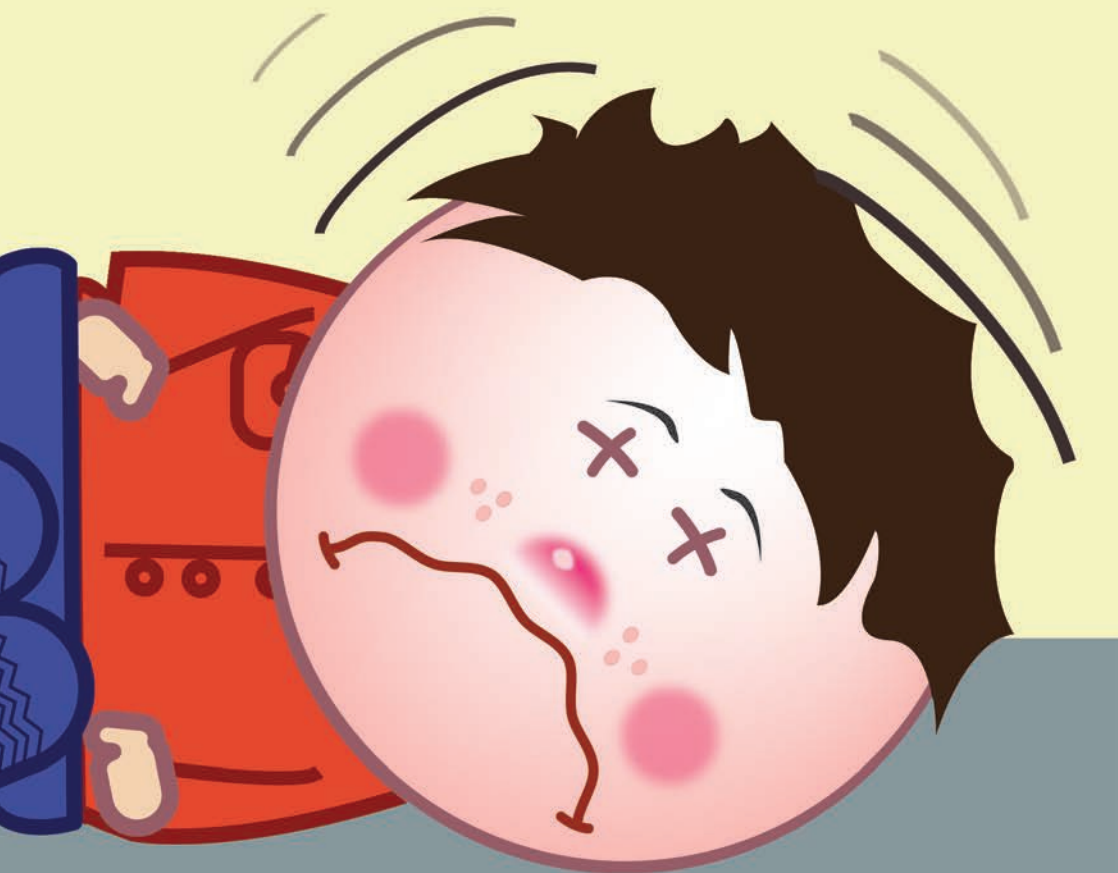


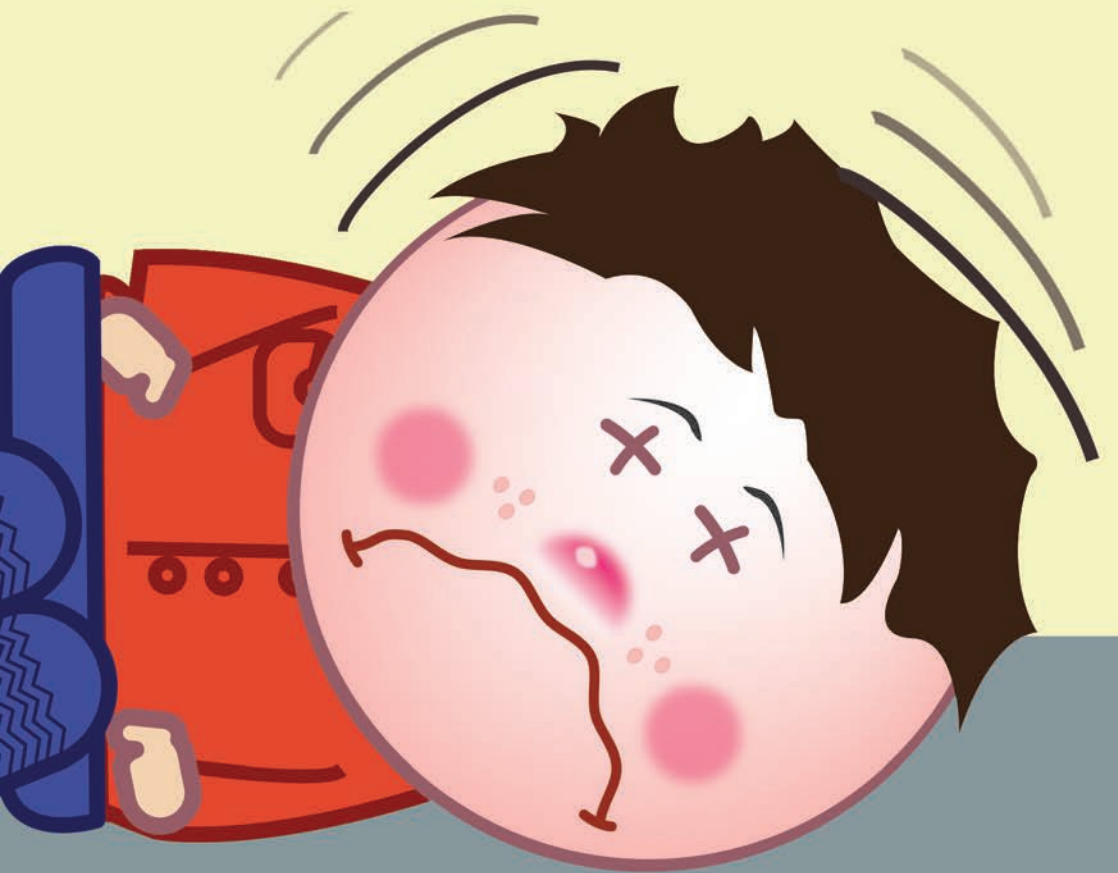
The next day I decided to ask Sayed to tell me what had happened. He said I went kind of still. When he came back with mum, I was on the floor and shaking for a while.



Sayed could see I was still worried. He said he thought the doctor would just give me some medicine to help stop the seizures. Sayed takes medicine and he's okay.







Chapter 2

In the supermarket

My second seizure

When I had my second seizure, I was in the supermarket with my mum.

The next thing I knew, I was waking up on the floor. There were loads of people standing around me, staring down. I didn't like that. But then I heard my mum's voice. She was saying that everything was okay. I had just had another one of my seizures.





My mum asked the other people to go away. That felt a bit better. Then a man who works in the supermarket took my mum and me to his office. That meant I could rest until I felt better. He gave me some scrummy orange juice.



When I felt better we went home. Then mum phoned the doctor. The doctor wanted me to go back and see her again. I didn't mind that. She's quite nice, my doctor.

Then Sayed came round and we played football.
I saved two goals!



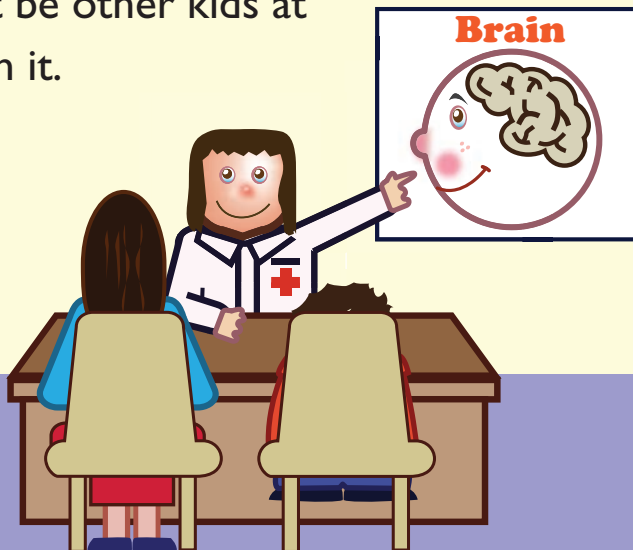


Chapter 3

Ben visits the doctor again

The doctor told me I had something called epilepsy. It's to do with something going wrong with your brain for a few minutes. Then it goes okay again.

The doctor says lots of people have epilepsy. That means there must be other kids at school with it.



I asked the doctor why I had epilepsy. She said it might be because I'd fallen over and bumped my head when I was very little. But I couldn't remember bumping my head. So maybe that wasn't it. The doctor said sometimes there isn't any reason at all. I thought that was pretty strange.



FIT? X

SEIZURE ✓

My mum said ‘So is the thing Ben had, called a fit or a seizure?’ The doctor explained that fit is an old word. Most people say seizure now. I like ‘seizure’ better. Fit sounds like getting angry. I wasn’t angry. I was just poorly.

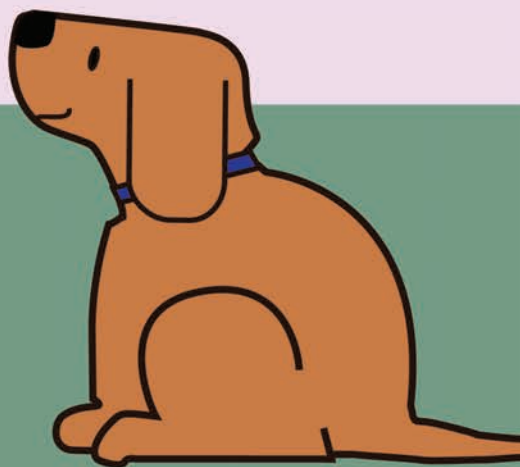
The doctor told me there are lots of different sorts of seizures. I had a tonic-clonic one.

Sometimes people have seizures where they don't fall down. They just feel a bit funny for a while.



Tonic-clonic

I was a bit fed up about having seizures. But the doctor said if I take my medicine, I might not have very many seizures. Or they might even stop completely. I asked the doctor which it would be for me. She said we'd have to wait and see. Grown-ups always say that when they don't know the answer.



My mum wanted to know what to do if I had another seizure. This is what the doctor said.



1. Don't try to hold Ben down. Or stop him moving around.
2. Put something soft under his head.
3. Move things away from his body so he doesn't hurt himself on them.
4. Stay with him and wait for him to start feeling okay again.
5. If Ben is in school, ask him if he needs a rest.
6. Tell him about anything he's missed – especially if it's his favourite TV programme.
7. Don't ring for an ambulance unless Ben has hurt himself, his seizure lasts more than 5 minutes or he has another seizure without waking up inbetween.

My mum thought this was a really useful list. She was going to write it down and give it to some other grown-ups too. Like my teacher and my gran.

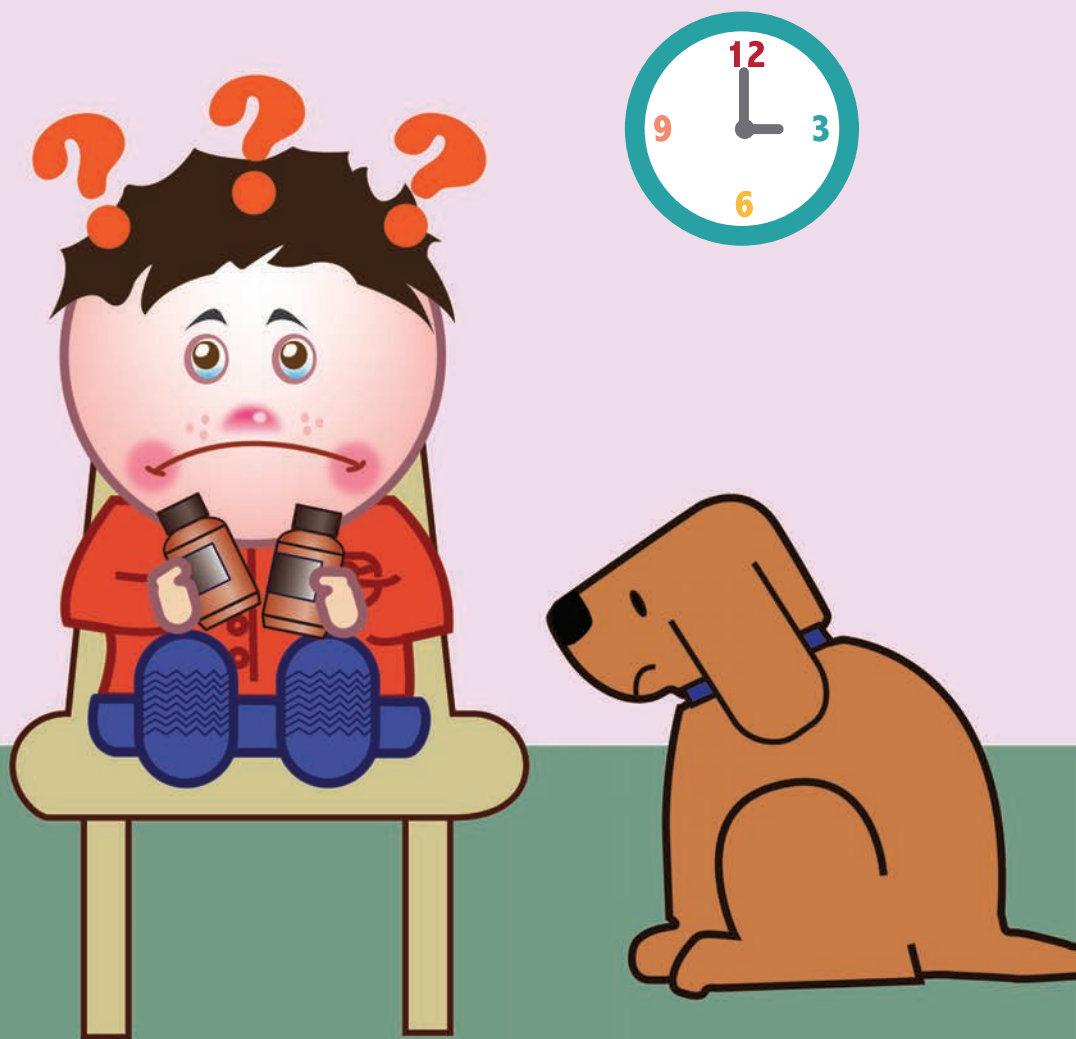
Chapter 4

The right medicine

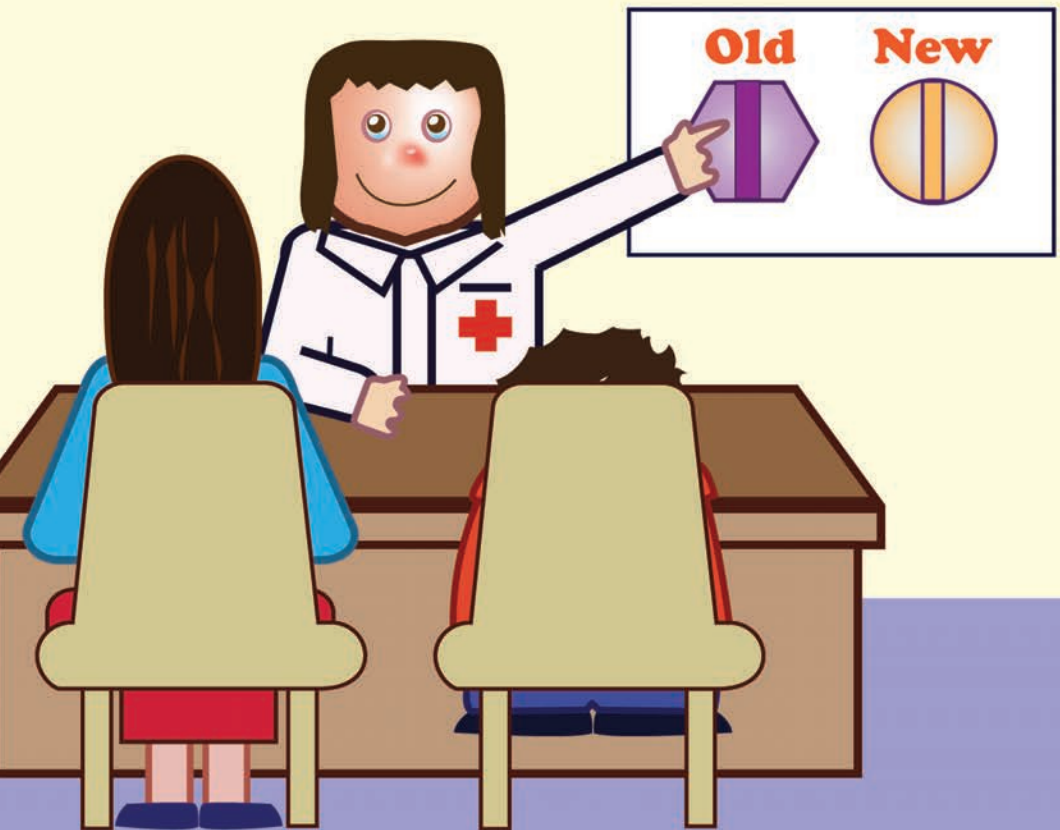


Back to my medicine

I didn't like my medicine. It started making me feel sleepy. And I was still having those seizure things. After a while the doctor changed my medicine but it didn't make any difference.



So my mum took me to see the doctor again. She said, 'Let's try some different medicine. We need to find some that stops more of your seizures and doesn't make you feel so sleepy.' 'Too right', I thought. The one she wanted me to try was a different colour. I thought that was good.



Guess what? The new medicine worked really well. I haven't had a seizure for three whole months now. And I'm not feeling nearly as sleepy. I don't mind my medicine now.

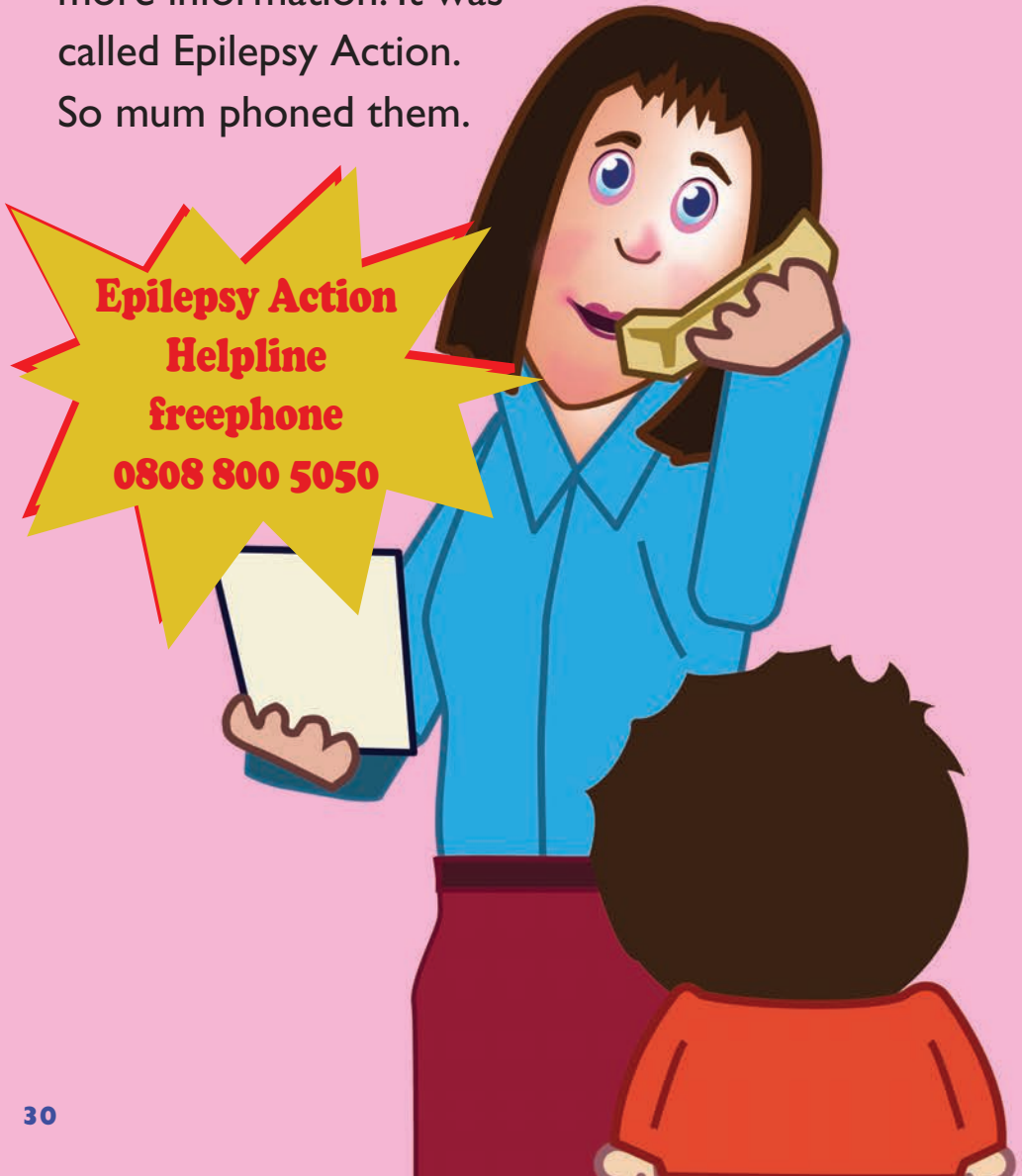


Chapter 5

Ben and his mum discover Epilepsy Action



The doctor at the hospital was nice. But she didn't have lots of time. So she gave my mum a leaflet. This told her about a place she could get some more information. It was called Epilepsy Action. So mum phoned them.





They talked for ages. My mum's good at that. But afterwards she didn't seem quite so worried. I reckoned that was a good thing. And a few days later a big fat envelope came through the door. It had loads of stuff from Epilepsy Action in it.

I couldn't understand much of it, but my mum told me one of the leaflets said that more than half a million people in the country have epilepsy. That might even be as many people with epilepsy as stars I can see!



**1 out of 240 kids
have epilepsy**

The illustration shows a woman with short brown hair and a blue shirt sitting at a blue desk. She is holding a yellow piece of paper. Next to her is a young child with black hair and a red shirt, also holding a piece of paper. On the desk are several other papers, some blue and some pink. A speech bubble with a red border points from the child towards the text '1 out of 240 kids have epilepsy'.

Bit by bit I found out things that meant I was more likely to have a seizure. Missing meals was one of them. So was going to bed really late.



It was a bit boring at first, having to be so careful. My mum nagged me sometimes.

One of the best things about that place that mum rang was we became members. Last year they had a sponsored walk. We got to take Ginger our dog. And I met loads of other kids with epilepsy. It was all pretty cool. And we raised heaps of money for Epilepsy Action.



If you want your mum to stop worrying about you, and if you live in the UK, get her to ring Epilepsy Action. It's free! Or she could send an email. I feel like I'm in a really special group now.



Further information

If you have any questions about epilepsy, please contact the Epilepsy Action Helpline.

Epilepsy Action has a wide range of publications about many different aspects of epilepsy. Information is available in the following formats: booklets, fact sheets, posters, books and DVDs.

Information is also available in large text.

To order any of our information, contact the Epilepsy Action Helpline or order online at epilepsy.org.uk/shop

Epilepsy Action's support services

Local meetings: a number of local branches offer support across England, Northern Ireland and Wales.

forum4e: our online community is for people with epilepsy and carers of people with epilepsy. For people aged 16 years or over. Join at forum.epilepsy.org.uk

Epilepsy awareness: Epilepsy Action has a number of trained volunteers who deliver epilepsy awareness sessions to any organisation that would like to learn more about epilepsy. The volunteers are able to offer a comprehensive introduction to epilepsy to a range of audiences.

If you would like more information about any of these services, please contact Epilepsy Action. Contact details are at the back of this booklet.

Ben has epilepsy

Which of these sentences is right for you?

- 1 ☐ The book was fun to read
 ☐ The book was okay
 ☐ I didn't enjoy the book
- 2 ☐ The book was easy to understand
 ☐ I understood some of the book
 ☐ I didn't understand this book at all
- 3 ☐ Before I read this book I already knew all about epilepsy
 ☐ Before I read this book I only knew a little bit about epilepsy
 ☐ Before I read this book I knew nothing about epilepsy
- 4 ☐ Now I understand about epilepsy
 ☐ Now I know a little bit more about epilepsy
 ☐ I didn't learn anything
- 5 ☐ Before I read this book I was worried about epilepsy
 ☐ Before I read this book I was a bit worried about epilepsy
 ☐ Before I read this book I wasn't worried about epilepsy
- 6 ☐ Now I don't feel worried about epilepsy
 ☐ Now I only feel a bit worried about epilepsy
 ☐ I still feel worried about epilepsy

Parent or guardian

Please could you tell us about what has changed for the young person from reading this book. Or any other comments.

Please send the completed form to:

Epilepsy Services, FREEPOST RTGS-LEYK-XGCK, Epilepsy Action, New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY

You can also give us feedback online at epilepsy.org.uk/feedback

Thank you!

FREEPOST RTGS-LEYK-XGCK,
Epilepsy Action
New Anstey House,
Gate Way Drive,
Yeadon,
Leeds LS19 7XY

Registered charity in England and Wales (No. 234343)

Ways to contact the Epilepsy Action Helpline



Telephone: freephone 0808 800 5050

We are usually open 8.30am to 7pm, Monday to Thursday, 8.30am to 4.30pm on Friday and 10am to 4pm on Saturday. Our helpline staff are Text Relay trained and we are able to offer advice and information in 150 languages. To ensure the quality of our service, we may monitor calls.



Email: helpline@epilepsy.org.uk

Email us your question about epilepsy. We aim to reply within five working days



Text: 0747 963 8071

Text us and we will aim to send a text reply back to your phone within 24 hours (on work days)



Post: New Anstey House, Gateway Drive, Leeds, LS19 7XY

Write to us and we will aim to reply within seven working days

About the Epilepsy Action Helpline

We do:

- Provide confidential advice and information about epilepsy to anyone
- Give general medical information
- Give general information on legal and welfare benefit issues related to epilepsy

We do not:

- Tell people what to do
- Offer a medical diagnosis or suggest treatment
- Take up people's legal cases on their behalf

If we cannot help you directly with a query, we will do our best to provide details of other organisations that may be able to help. In doing this, Epilepsy Action is not making a recommendation.

We welcome feedback, both positive and negative, about our services.

Epilepsy Action Helpline:

freephone 0808 800 5050

epilepsy.org.uk



Supported by



Epilepsy Action

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email epilepsy@epilepsy.org.uk

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Epilepsy Action is a working name of British Epilepsy Association.
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Epilepsy Action
Information you can trust
Find out more
epilepsy.org.uk/trust