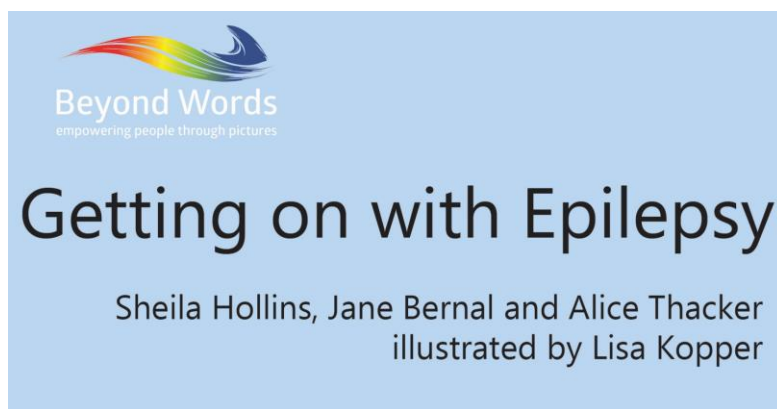


Getting on with Epilepsy:

A guide for how to use the book
for people with epilepsy and
learning disabilities



About the 'Getting on with Epilepsy' book

'Getting on with Epilepsy' is a book produced by the charity, Beyond Words.

The book uses pictures without words to tell the story of a man who has epilepsy.

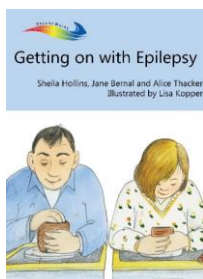
It includes a man having seizures, going to the doctor, having investigations and taking medication, as well as his daily activities.

You can find out more about the book from Beyond Words:

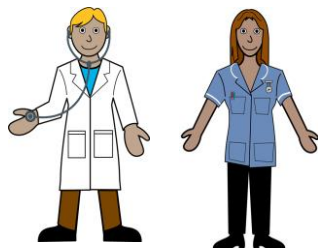
<https://booksbeyondwords.co.uk>



About our research



We wanted to find out how people with epilepsy and learning disabilities could use the book in the best way.



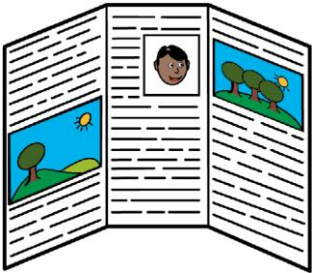
Twenty people used the book with a nurse or doctor. We video-recorded this.



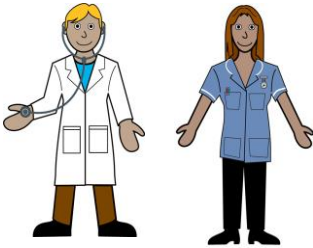
People took the book home to use.



People told us about their epilepsy and what they thought about using the book.



We wrote this guide to help people with learning disabilities and epilepsy to use the book.



We wrote a guide for doctors and nurses about how to use the book too. This is on the University of Hertfordshire's website

<https://www.herts.ac.uk/research/centres/centre-for-health-services-clinical-research/health-research-methods/wield-2>

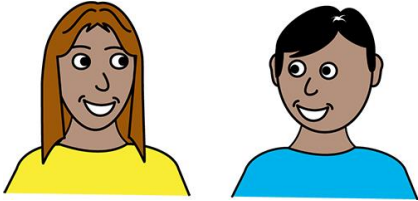


We filmed a video to show what is like to use the book.

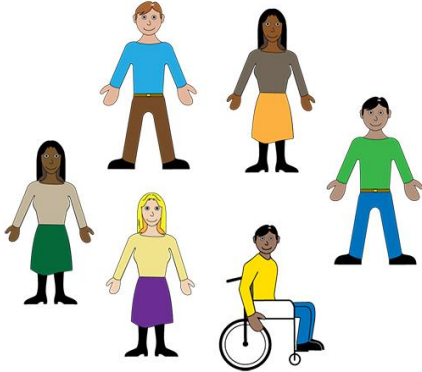
You can watch the video on youtube

https://youtu.be/9Zo3VCa6_ng

Who can use the 'Getting on with Epilepsy' book and this guide?



This Guide is written for people with epilepsy and learning disabilities (the reader) using the book with a doctor, nurse, support worker, friend or family member (the supporter).



People with different types of epilepsy can use the book.



People who want to understand their epilepsy or who have lots of seizures might find the book particularly helpful.



It is important to remember that there is no right or wrong way to use the book. It is up to you how to use it.

Why do people want to use the book?

Easy to use

Enjoy reading the book

Pictures make sense

Helps people to look after themselves

Helps people to understand epilepsy

Helps people to worry less about epilepsy

Helps people to have new conversations about epilepsy

Important things about using the book



The book should be held by the reader.



The reader should decide when to turn the page and how much to talk about each page.



Characters in the story can be given a name.



It can be helpful to read all of the book at the same time. This takes about 30 minutes.

How to read the book



Describe what is happening in a picture.

I think he's having a seizure there

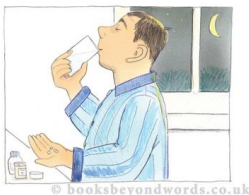


Think about how characters might be feeling.

He's feeling really down



Talk about whether the pictures are similar or different to your life.



I take my tablets in the morning

Describing what is happening in the pictures

Questions to think about:

- What is happening to the characters?
- Are there any clues in the picture?
- Is there anything that reminds you of your life?
- Is there anything that makes you think of epilepsy or seizures?

How can supporters help?

- Provide a clue based on the picture
- Suggest what might be happening in the picture and ask for the reader's opinion
- Ask about a time when something similar happened to the reader



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| | |
|------------------|---|
| Supporter | Want to have a look? <i>The supporter holds the book up closer</i> |
| Reader | Tablets |
| Supporter | It looks like he's got tablets doesn't it? |

Thinking about how the characters might be feeling

Questions to think about:

- How might the character be feeling?
- Why do you think they might feel like that?
- How do you feel when something like this happens to you?
- Why might they have behaved in a certain way?
- Does the picture give you any clues?
- Can you tell how they are feeling from their face?

How can supporters help?

- Ask about the character's face expressions
- Suggest different feelings for the reader to think about
- Ask if the reader has been in this situation, and if so, how they felt



| | |
|------------------|--|
| Supporter | What would you say his expression is there? |
| Reader | Saying I'm not okay my head really hurts and I'm just very exhausted. |
| Supporter | And exhausted |
| Reader | I was so exhausted when I had one that I felt like a hundred-year-old and it felt like I needed a walking stick. |

Thinking about whether it is the same or different to your life

Questions to think about:

- Have similar things happened to you?
- Have you felt like the character feels?
- Are your seizures the same or different as the book?
- Have you had tests like the ones in the book for your epilepsy?
- Do you take tablets for your epilepsy like in the book?

How can supporters help?

- Ask if the things in the book have ever happened to the reader or anyone they know
- Ask about how the reader felt if those things had happened to them
- If the reader's seizures are different to those in the book, ask about what their seizures are like instead



| | |
|------------------|---|
| Supporter | So you're waiting for this to happen yeah. |
| Reader | Yeah. I know I've got to go to hospital but I don't want to go. |
| Supporter | You don't want to go? |
| Reader | I don't want to go but I know I've got to go. |
| Supporter | You've got to go so you're just feeling a bit anxious about it? |
| Reader | Yeah |
| Supporter | And why do you think you have to go? |
| Reader | Because I want to stop these happening on my head. |

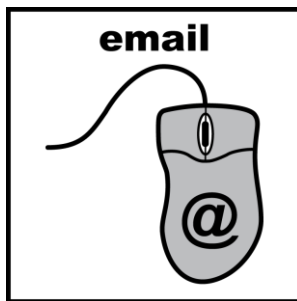
How to contact us



To contact the WIELD 2 study team, please telephone, email or write to Silvana Mengoni at the University of Hertfordshire



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About us

WIELD 2 was a research project at the University of Hertfordshire and Hertfordshire Partnership University NHS Foundation Trust (HPFT).

The study manager was Dr Silvana Mengoni at the University of Hertfordshire and the research team was:

- Dr Georgina Parkes – HPFT
- Dr Charlotte Hamlyn-Williams – University of Hertfordshire
- Dr Marie-Anne Durand – Dartmouth College
- Dr Thando Katangwe – University of East Anglia
- Dr Jamie Murdoch – University of East Anglia
- Dr Indermeet Sawhney – HPFT
- Dr David Wellsted – University of Hertfordshire

Thank you!

We would like to say thank you to:

- The people with epilepsy, their support workers and family members, and the doctors and nurses who took part in our research
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- Beyond Words for training the team and letting us use their pictures in this guide
- Research and Development teams at HPFT and Norfolk Community Health and Care NHS Trust (NCH&C)
- Megan Smith, Simon Robinson and Rachel Batchelor for research assistance
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