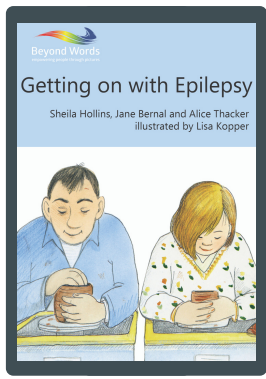


Using 'Getting on with Epilepsy' to support people with learning disabilities and epilepsy



'Getting on with Epilepsy' is a book which uses pictures to tell the story of a man who has epilepsy. WIELD 2 was an independent research study which looked at how the book could be used by doctors and nurses (supporters) with people with learning disabilities and epilepsy (readers). People were video-recorded using the book and asked questions about this. This information was used to produce guidance for using the book. Real life examples are used to explain how to use the book successfully. The full guide can be downloaded from <https://www.herts.ac.uk/research/centres/centre-for-health-services-clinical-research/health-research-methods/wield-2> and an accompanying video can be watched online https://youtu.be/9Zo3VCa6_ng

Why use 'Getting on with Epilepsy'?

The book can be used for different reasons, including:

- Promoting discussion about epilepsy
- Sharing information about epilepsy and its management
- Finding out what people think about epilepsy and its effects on their life.

In our research, people reported benefits including:

- Increasing understanding of epilepsy for themselves and others
- Promoting new conversations about epilepsy
- Supporting epilepsy self-management
- Reducing anxiety about epilepsy

How to use 'Getting on with Epilepsy' : An overview

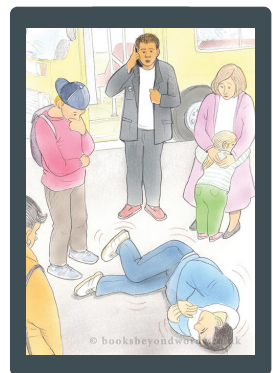
Readers and supporters reported that the book was easy to use. The book could be used by people who have different types of seizures, whether they have them often or not very often.

The reader should always hold the book and turn the pages, if able and willing to. A supporter was a healthcare professional in this study but could be a carer, friend or family member.

Our research suggests that the book is useful because it explains epilepsy and the reader can use their own experiences so it becomes a personalised conversation.

There are three levels of engagement when reading the book, shown in the table below.

We recommend all three levels where possible. Readers may need prompts or they may not. If they are needed, then open prompts are recommended.



	Details	Reader example	Prompt example
Describing	Describing events in the pictures, at a surface-level	"I think he's having a seizure there"	"What's happening on this page?" "I wonder what they are doing?"
Inferring	Inferring how characters might be feeling or why they are acting in certain ways	"He's feeling really down"	"How do you think he might be feeling?" "How does his face look?"
Relating	Relating the book to their own lives	"The next day after I have a seizure, I stay in bed"	"Has that happened to you?" "When do you take your medicine?"