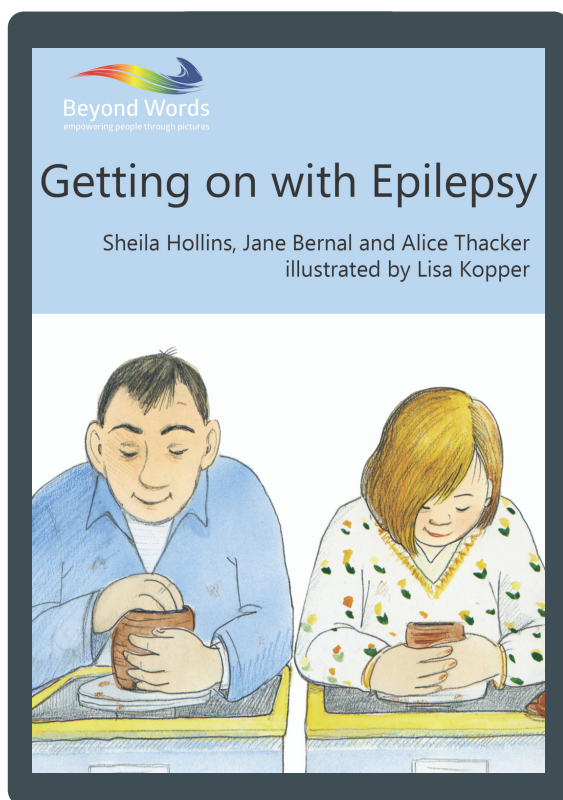


# Guide to reading 'Getting on with Epilepsy'



University of  
Hertfordshire **UH**

**NHS**  
Hertfordshire  
Partnership University  
NHS Foundation Trust

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# Section 1

## An introduction to the 'Getting on with Epilepsy' book and our Guide

'Getting on with Epilepsy' is a book produced by the charity, Beyond Words, which uses pictures to tell the story of a man who has epilepsy. It includes the man having seizures, going to the doctor, having investigations and taking medication, as well as his daily activities.

More information about the book can be found on the Beyond Words website

<https://booksbeyondwords.co.uk/>

**Getting on with Epilepsy, by Sheila Hollins, Jane Bernal and Alice Thacker. Illustrated by Lisa Kopper. 2014, 2nd edition. Books Beyond Words.**



The material in this Guide has been drawn from independent research conducted by the University of Hertfordshire and Hertfordshire Partnership University NHS Foundation Trust. Our research focused on how the 'Getting on with Epilepsy' book is used by people with learning disabilities and epilepsy and epilepsy nurses and doctors, and the potential benefits. The examples we provide in the Guide are based on how people used in the book in our research.

We have produced other Guides too, which can be found at

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



A one-page version of this Guide



A Guide aimed at people with learning disabilities and epilepsy



A video accompanying this Guide

[https://youtu.be/9Zo3VCa6\\_ng](https://youtu.be/9Zo3VCa6_ng)

For more information about our research, please see the Acknowledgement' section at the end of this Guide.



## Who can use the 'Getting on with Epilepsy' book?

- People who wish to use the book ('supporters' e.g. family members, support workers, healthcare professionals) with people with learning disabilities and epilepsy ('readers')
- People who would like to read the book by themselves or with a range of other people including support workers, family members and friends.
- Many readers, even those with different seizure types, are able to recognise the seizures depicted in the book and relate them to their own experience.
- People who have used the book think that it may be particularly useful for those people with recently diagnosed epilepsy, poorly controlled seizures or poor understanding of epilepsy. However, it is important to note that the book is reported to be useful for people with long-term stable epilepsy too.



## Why use the book?

Different people may choose to use the epilepsy book for a variety of 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.



## Potential benefits of the book

- People, both readers and supporters, generally like the book, and think that it is easy to use.
- People feel that the pictures are clear and support their understanding of epilepsy, and other people's understanding of epilepsy.

- During book reading, new conversations about epilepsy may be prompted particularly for people who do not talk about their epilepsy much. Readers may also continue to talk about their epilepsy after using the book, both with familiar people and new people such as new support workers.
- The book highlights key points of epilepsy management, which may help with aspects of self-management such as risk management, safety, relaxation and medication.
- The book has also been highlighted to reduce readers' anxiety, and increase their confidence and their acceptance of their epilepsy



## How to use this Guide

It is important to note that there is no right or wrong way to use the book, and this Guide provides suggestions for people to consider. Based on our experiences, this Guide is primarily aimed at:

- Supporters who wish to use the book with people with learning disabilities and epilepsy.
- People using the physical version of the book.
- People primarily reading the whole book as a story
- People focusing on telling the story using the pictures, rather than using the text at the back of the book

We acknowledge that there are many other ways of using the book, and it is likely that this Guide can also support this. Readers may choose to read the book alone and people without epilepsy and/or learning disabilities may read it. Digital versions of the book are available and this may suit some people better, for example if they already use tablets a lot. Our research suggests most people like to read the book as a complete story, but it may be more appropriate to use some pictures in isolation or as a subset depending on the reader or situation. Many people using the book in our research commented that they liked the pictures and preferred this to text, however some people may wish to consult the suggested storyline and/or additional written information at the back of the book.



## Our Video Guide

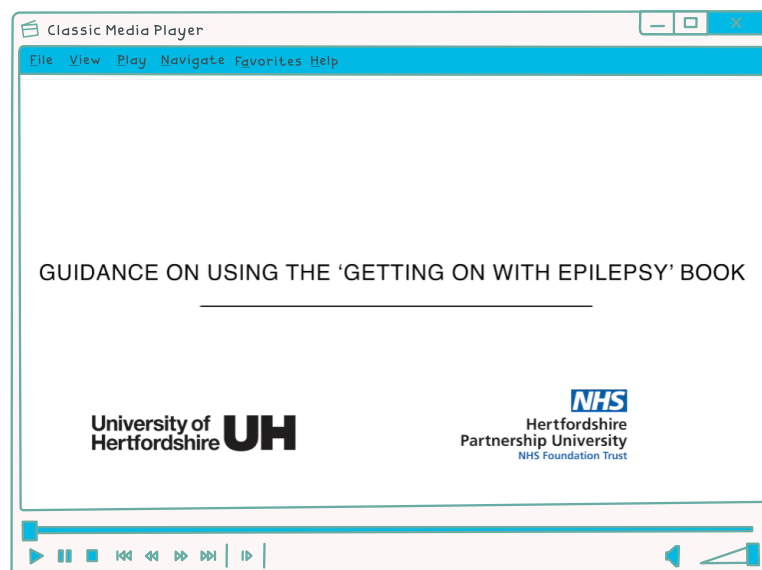
Based on our research findings and the suggestions provided in this Guide, we have produced a Video Guide. This does not cover all our guidance but we hope it brings some of our examples to life.

You can view our video here:

[https://youtu.be/9Zo3VCa6\\_ng](https://youtu.be/9Zo3VCa6_ng)

Here are the different sections of the Video Guide and when they occur in the video to help you find the section you would like to watch:

- **Introducing the Book** – 35 seconds
- **Having a Seizure** – 1 minute, 25 seconds
- **Epilepsy Tests** – 7 minutes, 50 seconds
- **Talking about Lifestyle** – 8 minutes, 55 seconds
- **Epilepsy Medication** – 10 minutes, 25 seconds
- **Ending the Book** – 12 minutes, 32 seconds



# Section 2


## How to read the book: An overview



### Introducing the book

The book should be introduced by the supporter as a picture-based story about getting on with epilepsy, referring to the cover. If the reader can read, then the supporter could consider asking them to read the title. Depending on the reasons for reading the book, the supporter may wish to highlight that they will talk about the reader's epilepsy too or that the book shows how to live with and manage epilepsy.

As characters first appear in the pictures, the supporter may wish to ask the reader if they would like to name the characters. There are suggested names in the storyline at the back of the book, and throughout this Guide, we have used those names i.e. Jack for the main character.



*You can see an example of introducing this book in our [video](#) from 35 seconds in*



### Holding the book and turning pages

Where possible, readers should hold the book and set the pace of the reading by choosing when to turn a page. If readers prefer supporters to hold the book, then the supporter should check with readers before turning the page. In some situations, supporters may wish to encourage the reader to turn the page and this can be done by prompts such as 'let's see what happens next'. It can vary significantly how long it takes to read the book, but an estimate is 30 minutes.



## Adapting the book

The suggestions in this Guide are likely to need to be adapted for people with different communication styles. For some readers, it may be that supporters narrate the story and check their interpretation with the reader, for example ‘I think he has fallen down and had a seizure – what do you think?’, or present different alternatives for the picture and ask the reader whether they agree.

We have included examples throughout this Guide of readers with different communication styles, including largely nonverbal communication, but it is important to note that the majority of people who took part in our research communicated verbally and had a mild-moderate learning disability.

The supporter’s relationship with the reader may affect the nature of the conversation and prompts, particularly when relating the book to the reader’s experience. Where the supporter does not know the reader well, this can be a good opportunity to find out about the reader’s experiences and views. Where the supporter does know the reader well, their shared experiences can enrich their conversations but it is still important for the reader to be the primary narrator.

The character in the book experiences seizures that cause him to shake and fall over, and it may be that the reader does not experience these seizure types. The section in this Guide on ‘understanding that the book is about epilepsy’ explains what to do in these situations in more detail.

The pictures outline various stages of the character’s epilepsy journey including diagnosis, being prescribed medication and learning about risk management. Depending on how long the reader has had epilepsy for and how well-controlled it currently is, this may be more or less relevant for them, and this may guide the choice of pictures to focus on.





## Levels of book reading

Readers may engage with the book in different ways, which we categorise in three broad ways:

Level of reader engagement	Example	Details
<b>Describing</b>	I think he's having a seizure there	Describing events in the pictures, at a surface-level
<b>Inferring</b>	He's feeling really down	Inferring how characters might be feeling or why they are acting in certain ways
<b>Relating</b>	The next day after I have a seizure, I stay in bed	Relating the book to their own lives.

Our research suggests that the book is useful as it explains epilepsy, but also because readers can consider this in the context of their own experience, therefore we would recommend the use of all three levels of engagement, where possible. Readers may vary as to how much they would benefit from prompts to do this. It is also important to note that it may take several readings to explore the different levels of the book.



## How to prompt

The layered reading approach recommended by Books Beyond Words involves asking open prompts to help readers to interpret pictures in a meaningful way, encourage deeper reflection, and build trust between the reader and supporter to create a safe space. This Guide draws on this recommendation.

Where prompts are given, it may be helpful to build up through different levels of reading, for example from a surface-level description of the picture, to considering how the character might be feeling or why they're acting in a certain way, to if the event in the picture has ever happened to the reader. Supporters

may choose not to prompt for the different levels of book reading if they feel it would not be appropriate for the reader.

Target level of reader engagement	Prompt examples	Prompt details
<b>Describing</b>	What's happening on this page? I wonder what they are doing? What is in her hands?	Often prompts are not needed for this as many people are able to describe the events, but if they are, then generic prompts are suggested Elements of the picture can also be used as a 'clue' if needed
<b>Inferring</b>	How do you think he might be feeling? How does his face look?	Signposting to certain elements of the picture to support inferences may be helpful
<b>Relating</b>	Has that happened to you? When do you take your medicine?	Generic prompts may be sufficient, or more specific prompts might be needed depending on the reader or if the supporter wishes to prompt discussion about a particular issue



## Open versus closed prompts

In line with the layered reading approach, we recommend the use of open-ended prompts in most circumstances where possible, for example, 'I wonder what's happening here?', 'Has this ever happened to you?' or 'What happens when you have a seizure?'. However, closed or forced-choice prompts can work well in some scenarios, for example:

- If the reader has been unable to answer an open prompt e.g. 'How do you think he might be feeling?', followed by 'do you think he looks sad or happy?'
- To elicit a yes/no answer from a reader who has more limited communication.
- A leading question to show that the supporter has listened to the reader and/or is referring back to shared experiences e.g. 'I bet you've been in this situation before haven't you?'

# Section 3

## Supporting the reader as a narrator

It is important to the ethos of the book that the reader is positioned as the narrator, and that the book reading is centred around their understanding of the pictures and storyline. The supporter can use prompts to promote the description of the pictures, address misunderstandings and keep the story-telling on track.



### Telling the story

In our experience, many readers are able to offer a description of the events in the pictures with no, or limited, prompts.

Following our advice on prompts as suggested above, if the readers do not describe what is happening, then the supporter can help to provide a description. It is recommended that this is done by suggesting, rather than stating, a description, for example:

- Providing partial information to give the reader an opportunity to contribute to the description e.g. 'I think he's going somewhere'
- Providing a description but posed as a question or with some uncertainty e.g. 'Do you think he might be going out with his friends?'
- Providing a limited number of options for the reader to choose e.g. 'Is he going on the bus or coming off?'

Supporters could also expand on the reader's description, in a conversational style, and this gives the sense that they are sharing the story, for example the reader stating 'he's saying hello to his friends' followed by the supporter suggesting 'so someone has come to see him and maybe they've heard what happened'

Supporters can promote the position of the reader as the person driving the story-telling, by offering



#### Example 1

##### Using the reader's experiences to help understand the picture

Page 34 – Jack being given tablets by the doctor

This is an example of a reader with more limited verbal communication, and prior to this excerpt, they have not responded to the supporter's initial prompts.



Supporter



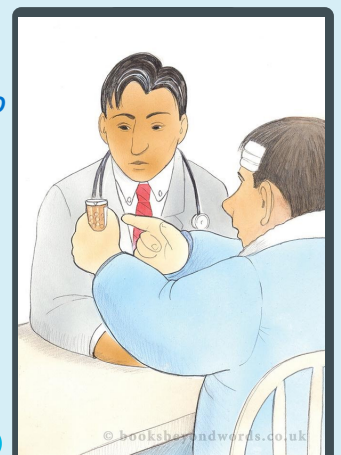
Reader

"What's the doctor going to offer Jack?"

"He's giving some...?"

"What do you take? In the morning and night you take your....?"

"Tablets"



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confirmatory responses such as 'I think you're right', 'yes, it does look like that'

If a reader is unsure what is happening in a picture following prompts at the 'describing' level, then the supporter could consider relating the picture to the reader's experience to help them



## Misunderstandings

If the reader interprets a picture differently to how the supporter expected, it may be that it is not critical to 'correct' them e.g. if the mother is described as the grandmother or if the picture is not considered crucial to the aims of using the book.

If the supporter feels that it is important that the reader has a particular interpretation of the picture, for example on pages portraying seizures or epilepsy management, then the supporter could offer the alternative scenario as a suggestion.

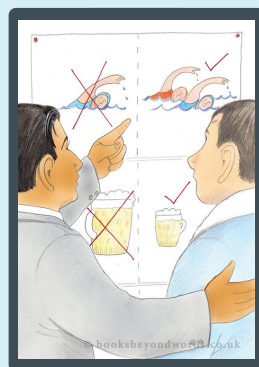
If the supporter is not clear what the reader has said, then they may wish to summarise what they think the reader said, and ask if that's right.



### Example 2

#### Clarifying and checking misunderstanding

Page 46 - Doctor explaining about swimming and drinking alcohol



"Ah yeah, don't have anything to drink"

"Don't have a big drink"

"A big drink"

"Whereas maybe a half is OK?"

"Yes"

"Do you think?"

"Yeah"



## Keeping the story on track

Where readers ask the supporters questions about the book, it may be appropriate to provide a direct answer, for example if they are asking what a stethoscope is called. In other situations, it may be more appropriate to turn the question back to the reader to highlight that it is their views that are important.



### Example 3

#### Supporting story-telling

Page 49 - Jack is taking medication

The reader has already identified that Jack has a drink in one hand.

"What is he having?"

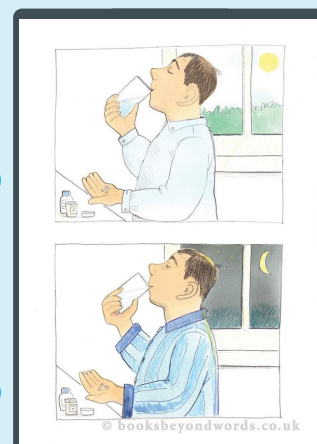
"Is there anything else in his other hand?"

"I don't know"

"Want to have a look?" [The supporter holds the book up closer]

"Tablets"

"It looks like he's got tablets doesn't it?"



If readers are distracted or are thought to be off-topic, then an effective way of returning to the story is to refer to the picture, for example 'what is happening in the picture' or 'what can you see on this page', or the supporter can link the off-topic discussion to the picture. Supporters may also wish to summarise what is happening on that page before moving on to the next picture.



### Example 4

#### Keeping the story on track

Page 8 – Jack going in an ambulance



"Holby City is on the telly tonight"

"Is that where Jack is going in the ambulance?"



### Example 5

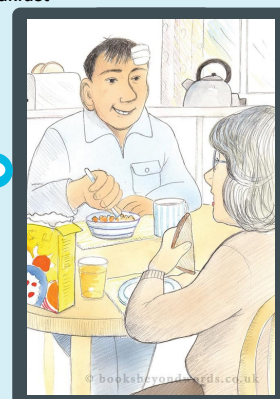
#### Keeping the story on track

Page 22 – Jack having breakfast

"What would you have in the morning?"

"I had green tea this morning"  
[Talked at length about their healthy eating]

"Okay so green tea for you in the morning where Jack has had a cup of tea by the looks of it"



# Section 4

## Understanding that the book is about epilepsy

In our research, the majority of readers were able to recognise that the book depicted seizures, either independently or when the clinician suggested this. Generally, the key pages in the book for depiction of seizures are pages 4, 5, 25 and 33. Depending on the reader's experiences, different pages may be more or less relevant to their experience and understanding of epilepsy.



### Describing seizures

Many readers describe events as a seizure with no prompting or generic prompting such as 'what is happening in this picture?'. Even if readers do not have the seizure types depicted in the book, most are able to identify the pictures as seizures

Some readers may provide alternative explanations for seizures. This could be for various reasons e.g. they are unsure what is happening, dramatic story-telling or not wishing to talk about epilepsy. Supporters may choose to gently question this e.g. by repeating the participant's statement as a question or prompting them to consider if there could be another explanation e.g. 'do you think so?', 'is there anything else that could have happened?'. It may be that the reader is still not sure what is happening in that particular picture, but this may change how they interpret later pictures.

If, after prompting, the reader does not label the image as a seizure or it is unclear to the supporter that they understand it is a seizure, then the supporter could consider suggesting this e.g. 'I wonder if he could be having a seizure'.

In some cases, we would not recommend labelling seizures, for example if the reader is reluctant to talk directly about epilepsy or the



#### Example 6 Describing a seizure

Page 4 – first picture of Jack having a seizure

*In this example, the reader has said that they do not know what is happening, and their seizures do not resemble those in the picture. In later pictures, the reader labelled events as seizures independently.*



**Supporter**

"Have you ever seen somebody have a seizure before?"



**Reader**

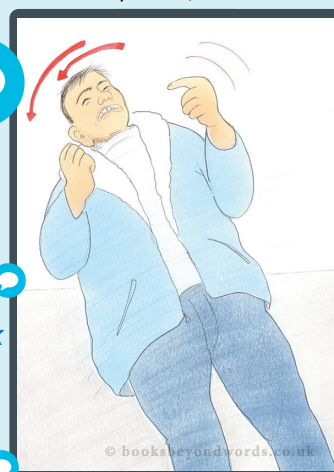
"No"

"So it looks to me like Jack has fallen over.... because he's laid on the floor"

"Yeah"

"And do you think he might be having a seizure?"

"I don't know.....I bet it would be scary to have one"



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supporter feels they would not benefit from this. Instead, the supporter may wish to provide open-ended prompts on pages depicting seizures such as 'what is happening on this page' or 'I wonder why he has fallen over'.

Some readers may benefit from several readings of the book to recognise and relate to the seizures. It may be that on the first reading, the supporter chooses not to refer to seizures and to revisit this discussion during later readings.



You can see an example of how a supporter labels the picture as a seizure in our [video](#) from 1 minute 25 seconds onwards



## Example 7

### Describing a seizure

Page 6 – Jack has an injury following a seizure

*In this example, the reader had described the seizure on p4 and 5 as the character shaking due to fainting.*

*However, later in the book, the reader independently described a picture as showing a seizure. The supporter felt that the reader probably knew the earlier pictures were seizures but due to the reader's anxiety around epilepsy, the supporter judged it was not appropriate for them to label the pictures as such.*

"He's got a lot of blood on his head"

"Oh, how do you think that happened?"

"Probably from the gun, somebody shot him with a gun."

"You think somebody shot him with a gun?"

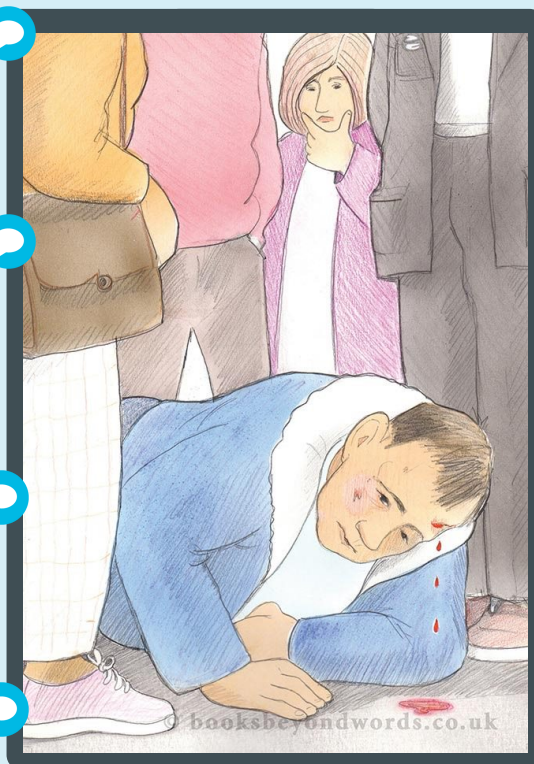
"Yeah. Well he has a scratch there."

"Could it be anything else, do you think?"

"Tripping?"

"That could have caused the scratch?"

"I'm not so sure"





# Inferring characters' feelings or motivation regarding epilepsy

Prompting about the character's feelings may be particularly relevant on key seizure pages, as this may help the reader to consider their feelings in relation to epilepsy, and indeed the supporter may choose to explore this.



## Example 8 Feelings about epilepsy

Page 13-14 – Jack returning home from hospital

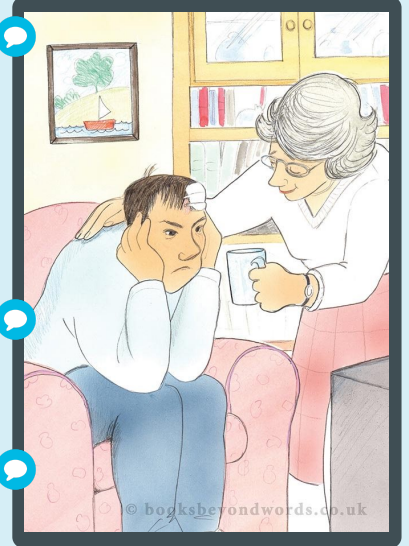
"She makes him get him out the car and put him in the car and make his tea and he don't look happy."

"Why do you think he's unhappy?"

"Because of his seizures."

"Yeah. When you have your seizures how do you feel?"

"I just go quiet when I have mine"



# Relating to own experiences of epilepsy to support understanding of the book

If the reader initially describes picture as falling, shaking, hurting themselves or similar, then a prompt could ask if that has ever happened to them, particularly if the supporter knows the reader experiences seizures where they fall or shake.



## Example 9 Using the reader's experiences to support understanding of the book

Page 5 – Jack having a seizure

The reader has previously described Jack as sleeping and laying down, but has not described the pictures as showing a seizure

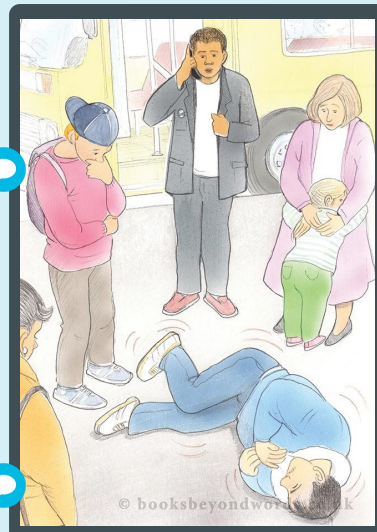
"Have you ever been on the floor like this?"

"Yeah, I've been on the floor. Falling over again and then making myself have a seizure."

"Oh, you had a seizure right. Do you think he was having a seizure here?"  
[Referring to P4]

"Yes"

"Yeah, that's what I thought"







## Recommendations for the wider book

It is likely that epilepsy does not need to be mentioned on every picture, particularly where previous pictures have been related to epilepsy explicitly by the reader or supporter, or where the reader discusses their own experiences and the supporter knows this is about their epilepsy.

If the supporter is not clear whether the reader is relating a picture to epilepsy, and they feel this is important for their understanding, they may wish to clarify this, for example:

- By prompting for more detail e.g. ‘Why do you think he might be taking tablets?’
- By repeating what the reader has said but providing the link to epilepsy e.g. ‘yes, he’s taking tablets for his epilepsy’
- By asking if this is what happens to the reader in relation to their epilepsy e.g. ‘do you take tablets for your epilepsy?’
- By suggesting a new description of the picture e.g. ‘I think he might be taking tablets for his epilepsy’

Some pages may be considered less important to link to epilepsy by the reader or supporter, such as pages where the character is having breakfast or getting on a bus.

# Section 5

## Relating the book to own experiences

In our research, many readers related aspects of the book to their own experience, although most required prompting to do this. This is an important aspect of using the book, as it can help to prompt discussions about their own epilepsy, feelings and management. The book can act as a tool for a supporter to find out more about how the reader experiences epilepsy, for example using the seizure pictures to ask what happens to the reader when they have a seizure, and this can be a useful way to share experiences and for the reader to explain what epilepsy is like for them.

In our experience, readers were most likely to relate the book to their own experiences on key seizure pages, but it is important to note that this may depend on when the supporter chooses to prompt.



### Prompts to support the reader relating the book to their own experiences

Some readers may talk about their own experiences with no, or little prompting. This may be most likely for readers who are able to confidently express themselves through spoken words.

For readers who are able to describe the pictures easily and with detail, supporters may wish to mainly prompt regarding their own experience rather than the storyline.

Following the levels of book reading, some readers may benefit from being prompted to consider their own experience after they have discussed the character's feelings or actions (also see example 8).

Supporters may wish to prompt more about the reader's own experiences on pages of particular importance and relevance e.g. seizure pages, visiting the doctor, taking medication, diagnostic tests.

*You can see an example of a reader and supporter discussing the reader's experiences in hospital in our [video](#) from 5 minutes 32 seconds to 6 minutes 28 seconds*



## Example 10

### Experience of diagnostic tests

Page 38 – Jack having an EEG

Supporter

Reader

"He's going into hospital, isn't he?"

"Gestures a wire, and things being put on body"

"Have you had things put on you?"

[Nods]

"Was it all right? Were you scared?"

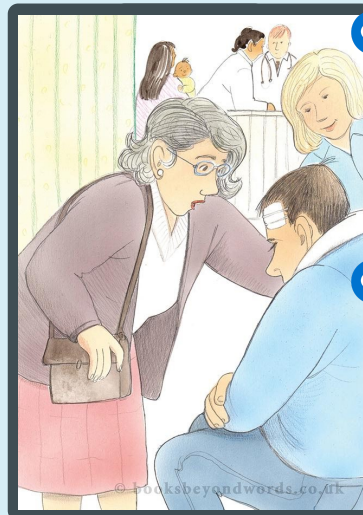
[Nods then shakes head]



## Example 11

### Supporter finding out about reader's experience of seizures

Page 12 – Jack sitting down in the hospital with a bandage on his head



"What would you say his expression is there?"

"Saying I'm not okay my head really hurts and I'm just very exhausted."

"And exhausted"

"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."

"You were that tired after the seizure?"

"Yes"

"Is it just feeling tired or pains?"

"Usually tired and pain to the head."

Some readers may find it challenging to relate the book to their own experience. It may be that several readings of the book are needed to increase understanding, and gradually supporters can build to encouraging inferences about the characters and then to the reader's own experience, as per the levels of engagement outlined earlier.

If readers do not have seizures like those depicted in the book or do not know what their seizures look like, then the supporter could explore with the reader what their seizures look like. The supporter could also discuss how seizures make the reader feel, which may be similar to the book and may open up conversations about epilepsy.



### Example 12 Feelings about epilepsy

Page 13-14 – Jack returning home from hospital

"He looks frustrated with that happening and embarrassed"

"Do you feel like that with your absences?"

"Some things I can't do"

"Okay that must be frustrating for you to have restrictions, is it because of the epilepsy?"

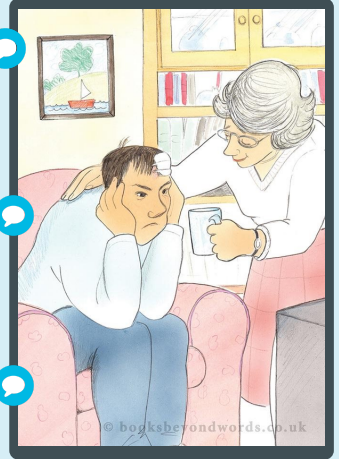
"Yeah"

"So what sort of things would you say you can't do because of your epilepsy?"

"Driving"

"If people don't have seizures for a year, they can actually get their license back for driving."

"Is it a year?"



### Example 13

Reader engaging a carer

Page 49 – Jack taking medication

Family Member

Supporter

Reader

"Jack takes his medication and night-time he takes his medication."

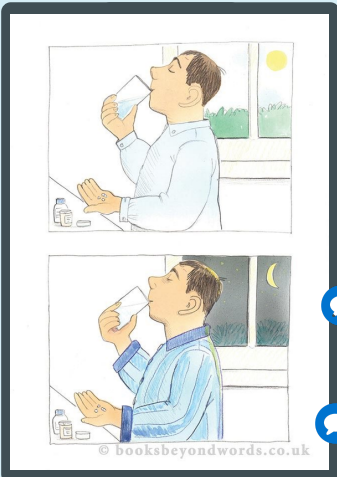
"Is that the same as you?"

"Yeah"

"What time in the morning do you take your medication?"

"Do you know what time?" [Addressed to family member]

"Between 7 and 8"



Supporters, or others if they are present, may join in when talking about the reader's experience. Our experience is that this is generally perceived positively by readers and can be useful for example, if the reader cannot remember particular things or the reader finds it difficult to relate the book to their own experiences.

### Example 14

Supporter engaging a carer

Page 38 – Jack having an EEG

"Have you ever had to have these little things put on your head?"

"Erm"

"Do you remember that?" [Addressed to family member]

"I don't remember"

"Once but when she was very young."



# Section 6

## Education and information

There are several key images that can be used to share information and support epilepsy management, for example:

- Page 19 (at the pub) can be used to discuss whether the character (and reader) should drink alcohol.
- Pages 38-41 (epilepsy tests) can be used to discuss tests that may be needed for epilepsy diagnosis and investigation.
- Page 46 (swimming and alcohol) shows the doctor outlining how the character can safely swim and drink alcohol, and this page is seen by clinicians as being important to discuss.
- Page 49 (taking medication) can be used to discuss epilepsy medication.
- Page 51 (swimming) can be used to recap on the messages in page 46.

A focus on these pages may be useful if an aim of using the book is to provide information, discuss or check understanding about epilepsy diagnosis or management, for example in a healthcare appointment. To do this, the supporter may prompt the reader slightly differently on these pages, for example they may provide more information and may correct the reader more directly if they suggest an incorrect description. However, it is important to do this within the ethos of the book and promoting the role of the reader as the narrator. It is also crucial that the supporter has an understanding about the reader's epilepsy and management (e.g. if they can have any alcohol with their type of medication) if clinical advice is to be given.



## Describing epilepsy management

Some readers may immediately describe elements of epilepsy management without prompting. Where prompts are needed, supporters can use open-ended prompts such as 'what's happening here', but these could also be worded in a way to help the reader focus on the epilepsy management aspect of the picture e.g. 'What do you think the doctor is telling him about swimming?'

The picture can also be used as a prompt, for example the supporter could point at specific parts of the image to draw the participant's attention to certain elements of the image so that they can engage in specific interpretations, for example on page 46, it may be useful to draw the reader's attentions to the ticks and crosses and the activities they relate to.



### Example 15

#### Explaining epilepsy management

Page 46 – Doctor explaining about swimming and drinking alcohol

"Do you think this is telling him that he mustn't swim alone?"

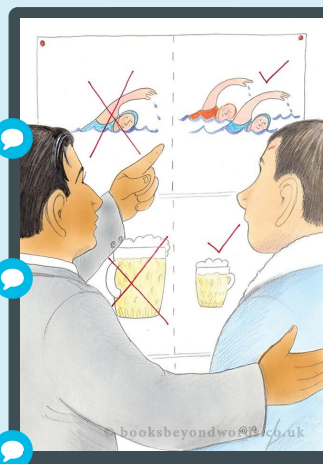
"Yes"

"What's this one saying he can do?"

"The same"

"He can swim with somebody beside him maybe?"

"Yes"



Where the reader has not provided a description of the picture or where they have not fully understood, supporters may wish to provide alternative interpretations. These can be posed as suggestions e.g. by a direct statement followed by asking the reader what they think, or as multiple-choice questions such as 'is he swimming alone or do you think he's with someone?'

Supporters may also provide a new interpretation as factual information, if it is important to correct the reader's descriptions, e.g. 'Not a big drink, but a small drink is OK' when discussing alcohol.

Page 51 can be used to check understanding and contextualise the discussion about swimming on page 46, for example:

- 'He's with someone isn't he....he's doing what you said'
- 'He's with a friend and so he's not alone is he?'
- 'Is he swimming alone?'



## Inferring character's feelings or motivations

Asking for the reader's opinion about the character's feelings or actions may encourage the participant to think about epilepsy management e.g. 'What do you think about that?'



## Example 16

### Discussing epilepsy management

Page 19 – Jack at the pub

The reader has described that Jack is drinking a beer

"Do you think that's a good idea? "

"No"

"Why?"

"Just in case he has a seizure"



## Relating experiences to the epilepsy management pictures

Supporters may wish to relate the epilepsy management images to the reader's own experiences and this can be done by asking the reader if this is what they do (e.g. taking medication at a specific time, swimming with a friend) or asking if they remember a specific procedure (e.g. MRI scan), for example:

- 'Do you swim alone or do you have to swim with someone?'
- 'When do you take your tablets?'
- 'Can you remember having one of these tests?'

Discussing the reader's experience of epilepsy management can also lead to conversations about how the reader feels about this, and supporters may choose to prompt for this.

Asking the reader what they have learnt at the end of the book might be helpful, and in some cases may lead to the provision of additional information about the reader's experience of epilepsy management. This can also be an opportunity to recap important epilepsy management information e.g. 'Do you think it's important to take your tablets on time?'



## Example 17 Feelings about epilepsy tests

Page 38 – Jack having an EEG

The reader has outlined that Jack is having a test, and through prompts, the reader has shared that they've had some tests, but are waiting for an EEG



"So you're waiting for this to happen yeah."

"Yeah. I know I've got to go to hospital but I don't want to go."

"You don't want to go?"

"I don't want to go but I know I've got to go. "

"You've got to go so you're just feeling a bit anxious about it? "

"Yeah "

"And why do you think you have to go?"

"Because I want to stop these happening on my head. "



You can see an example of a reader and supporter discussing upcoming epilepsy tests in our [video](#) at 7 minutes 50 seconds



## Example 18 Importance of epilepsy management

Page 49 – Jack taking medication

The reader has already described that Jack is taking medication in morning and night

"Do you think that's important?"

"Yeah"

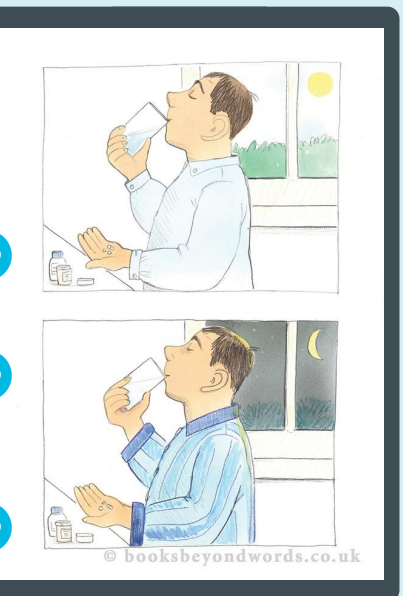
"Important for you?"

"Yeah"

"What do you think would happen if you didn't take your medication?"

"I'd get rushed to hospital "

"So he's obviously listened to the doctor hasn't he and he's taking his meds."



"And I would get poorly"

"And you'd get poorly yes, so it's really important to listen to what the doctor says and to take medication isn't it to help with the seizures. "



# Section 7

## Summary

The 'Getting on With Epilepsy' book can help people with learning disabilities to understand their epilepsy, support management of seizures and decrease anxiety.

The three core 'levels' of book reading are:

1. Describing what is happening in pictures.
2. Inferring how the characters might be feeling or why they are acting in a certain way.
3. Relating the book to their own lives.

Readers will vary as to how they engage with these different levels, and to what extent prompts may be needed to support this. Where supporters use prompts, these should be open-ended where possible.

Crucial to the book's use is a person-centred approach, and the suggestions in this document and the examples in the accompanying video are intended as guidance to illustrate how the principles of the book may be enacted in practice. Ultimately how the book is used will depend on factors such as the reader, the supporter and their relationship with the reader and the aim and context of book use.

## Acknowledgements

WIELD 2 was a research study which aimed to understand the key aspects of book use and barriers and facilitators to routine use in the NHS. Twenty people with learning disabilities and epilepsy took part, and were video-recorded using the 'Getting on with Epilepsy' book with a nurse or doctor. They used the book at home for four weeks, and then took part in an interview with the researchers about their views of using the book. The clinicians also took part in an interview about their experience of using the book. The analysis of the video recordings and interviews have been used to produce this guide and at the time of writing in November 2022, the results are being prepared for dissemination.

The WIELD 2 management group included:

- **Dr Silvana Mengoni** – University of Hertfordshire
- **Dr Georgina Parkes** – Hertfordshire Partnership University NHS Foundation Trust (HPFT)
- **Dr Charlotte Hamlyn-Williams** – University of Hertfordshire
- **Dr Thando Katangwe** – University of East Anglia
- **Dr Jamie Murdoch** – University of East Anglia
- **Dr Marie-Anne Durand** – Dartmouth College
- **Dr David Wellsted** – University of Hertfordshire
- **Dr Indermeet Sawhney** – HPFT

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- Ryan James for supporting with the production of the written guidance

The predecessor to the present study was the WIELD study, which was conducted in 2014-16. This was a feasibility randomised controlled trial, which found that it would be feasible to carry out a large trial comparing the use of ‘Getting on with Epilepsy’ and usual care for people with learning disabilities and epilepsy in the NHS. The findings of this study have been published in academic journals and can be accessed via the links below

- Wordless intervention for people with epilepsy and learning disabilities (WIELD): A randomised controlled feasibility trial’ published in BMJ Open in 2016 - <https://doi.org/10.1136/bmjopen-2016-012993>
- Sometimes, it just stops me from doing anything”: A qualitative exploration of epilepsy management in people with intellectual disabilities and their carers’ published in Epilepsy & Behavior in 2016 - <https://doi.org/10.1016/j.yebeh.2016.09.029>

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