Recommended reading list for children
Stories about living with epilepsy

“So Matilda’s strong young mind continued to grow, nurtured by the voices of all those authors who had sent their books out into the world like ships on the sea. These books gave Matilda a hopeful and comforting message: You are not alone.”

Roald Dahl, Matilda

The Epilepsy Foundation believes that reading is important, when a child learns to read and then reads to learn they expand their understanding exponentially. The world becomes less scary, the unknown becomes known. They learn that they are not alone.

Reading is about turning learning into fun, making learning exciting and engaging.

This reading list is filled with books that have been selected as suitable reading for children of all ages. The books cover a range of subjects related to living with epilepsy, enabling the child to learn about epilepsy through stories that they can relate to.

If you need help sourcing these books please contact the Information Line on 1300 761 487 for assistance.

A small boy tells of his experiences coping with the aftermath of an accident which left him with a brain injury. Although not epilepsy-specific, it explains diagnostic tests well and is written in an easy, rhyming style.

And Down Went Poss by Anne Little. Fortitude Valley, Qld: Epilepsy Association of Qld, 1994.

This delightfully illustrated book tells of little Poss’ feelings when he is first diagnosed with epilepsy. Explores the topic of epilepsy and looks at the impact of being different. It is accompanied by ideas for activities which complement and enhance the reader’s understanding of the story. This title is also available in ‘giant’ format for group storytelling.


A nine year old girl describes her epilepsy and how it affects her. She tells of different seizure types and the need for support and understanding.

A good teaching aid for families and schools. This title is also available in ‘giant’ format for group storytelling.

Becky the brave; a story about epilepsy by Laurie Lears and Gail Piazza. Morton Grove, Ill:A. Whitman, c2002.

When Becky becomes frightened of going to school in case she has a seizure her younger sister Sarah braves Becky’s classroom and explains about epilepsy. The warm response is an encouragement to Becky.


The personal journey with epilepsy, of a teenage ‘epilepsy activist’ who possesses a very positive attitude to her future. Includes good explanations of epilepsy for young people.

Brian learns about epilepsy by Epilepsy Scotland. Glasgow: Epilepsy Scotland, c2009.

Brian returns from a party where he had seen a small friend have a seizure. He relates to his Mother what he had learned about first aid from watching how his friend’s father had handled the situation. His Mother tells him that it’s good that he knows, for she has epilepsy too. A delightful little book which can be printed from Epilepsy Scotland Website.

This book is based on the true story of a little girl and her family whose lives changed when their beloved father became disabled with "intracranial hypertension". Her mother wrote Caitlin's wish - a story of her namesake's magical visit to fairyland- where she was helped to focus on the positive things in life, making it easier for her to cope with the isolation and sadness she felt.


'Features Ellie - a young girl with epilepsy. In this excellent book, Ellie invites readers to learn about epilepsy from her perspective. It is full of useful information about absence seizures, focal epilepsies and tonic-clonic seizures and may be an ideal introduction for children from the age of 7. It can also help parents, friends, and professionals to make sense of the condition in its varying forms.'

Day by day by me [seizure diary] by National Centre for Young People with Epilepsy. Lingfield, Surrey: National Centre for Young People with Epilepsy, c2009. An excellent, imaginative, interactive seizure diary for children

Dinosaur friends by Jacinta Cummins and Elizabeth O'Brien, Canberra: Epilepsy Association of ACT Inc., c2012.

'This booklet is written for young children to start a conversation between parents and children, about either the child's or the parent's epilepsy.' In a clear and simple manner and with delightful illustrations a little boy tells how he deals with the diagnosis of tonic-clonic seizures and how he loves to play with his friends.

Dotty the dalmation has epilepsy : from the Dr. Wellbook collection. Gladstone, NJ:Tim Peters and Company, 1993

This delightful story is about Dotty the Dalmatian who discovers she has epilepsy. At first, Dotty feels embarrassed and afraid. Once she accepts and learns how to control her seizures, she helps firefighters save lives. This is an excellent story for explaining epilepsy to children.
**Down down down** by Jacinta Cummins and Elizabeth O'Brien; Jade Chan illus. Canberra: Epilepsy Association of ACT Inc., c2012.

'This booklet is written for young children to start a conversation between parents and children, about either the child's or the parent's epilepsy.' With clear and colourful illustrations this simple story tells how a young fish, Jess, learned she has complex partial seizures.


This book addressed to teenagers and including personal stories of young people, discusses the myths and facts of epilepsy, its diagnosis and treatment and offers advice on living well with epilepsy.


Layla - whose Mummy has focal and tonic-clonic seizures - explains what she must do to help her. With appealing stick-figure illustrations this book is especially suitable for very young children.

**Epilepsy within Indigenous Australians** by Gordon Coleman and Kargun Fogarty. Canberra: Epilepsy Australia, [2002]

Enhanced by symbolic aboriginal art this booklet presents descriptive basic information about epileptic seizures and first aid.


All human diseases have been eradicated by genetic cleansing, but there are still people who are 'unclean' and locked away in institutions. Travis is one of them, until one day Dr Alexander helps him to escape to a world where nothing makes sense. Travis has powerful seizures which take him and his new friend Demi on a quest through time to seek and destroy Chase, the man he hates. Along the way he has to deal with shocks, surprises, traumas, and death, until at last he ends up on a beach, where his fate will finally be decided. A book for teenage boys.

**Everything a child needs to know about epilepsy** by CR. Yemula and F. Besag. Cressing, UK: National Service for Health Improvement, c2008.

This book is written for school-age children to help them understand more about epilepsy, treatment and lifestyle changes. Illustrated in colour and written with humour.

This book is an introduction to epilepsy that discusses seizures, triggers, diagnosis, and medication, living with the disease, treatments, and other related topics.

Farah and Ted visit the hospital by Epilepsy Scotland. Glasgow: Epilepsy Scotland, c2010.

It is suspected that Farah has epilepsy. In this attractive booklet we learn of the tests she had when she and Ted visited the hospital for a diagnosis. This can be printed from Epilepsy Scotland website.

Fighting seizures with surgery; a picture book to help you know what to expect by Kellie Towne. [USA]: Blurb Inc, c2008.

The book walks the reader step-by-step through the entire surgery process, from the beginning tests through to the recovery. Using photos taken throughout her surgery, Kellie lends simple explanations and descriptions, from a patient's point of view. Suitable for a person of any age contemplating surgery.

Fly Danny fly by Chip Gilbertson, Gina Restivo and Michelle Kondrich.
Evanston, Ill.: Pig Up Station, c2011.

Written in gentle rhyming verse complimented by beautiful illustrations, Fly Danny Fly is dedicated to a lively little boy, Danny Stanton, who died through epilepsy. In this thoughtful story we accompany a sensitive boy as he contemplates his imagination. We meet with his pretend friend - a flying pig - and with new kindred spirits who affirm his imaginary companion. Together they joyfully remind us to believe in our dreams and to allow others to do the same in their own way. A delightful, uplifting story which will be enjoyed by children from 3 to 99.


This book describes what it is like to have epilepsy. It aims to help people understand the nature of this widespread and potentially frightening illness and to show that children with epilepsy can lead normal lives.
I have epilepsy by Peter and Catherine Mair; photographs by Mark Coote. Southbank, Victoria: Thomson Learning Australia, 2004.

Tom, a boy with tonic-clonic seizures outlines his life with epilepsy. This book has a special emphasis on the way his classmates and others should cope with a person having a seizure. For primary aged children.


Joshua Rupert's Glitches follows the story of two little boys who love to play with robots. While playing with his friend, Joshua has a seizure and has to be taken to hospital by his mother. With wires stuck to his body Joshua gets to play robot as the doctors conduct all sorts of tests on him. Joshua’s mother visits the other little boy to explain what happened to Joshua, and reassure him that Joshua is the same boy as before.


Toby loves Clemmie, his sister with a disability - no matter what.


At first, at her new school, things don't go well for Karen who has complex-partial seizures but things change when Karen is able to care for her teacher who has a tonic-clonic seizure in class.


A delightful story of Lee, the rabbit, who has absence seizures. It is suitable for young children with epilepsy, their siblings and friends.


This is an activity booklet for children.

*Explains the nature, causes symptoms and treatment of mainly tonic-clonic seizures, for primary school children.

The Lion's secret; a story about epilepsy by Kelly Dicketts. Townsville: Kelly Dicketts, 2011.

Written and delightfully illustrated by the mother of a small boy who has tonic-clonic seizures. In this simple story we meet Aiden, strong as a lion, King of the jungle, who shares the secret of his epilepsy with his animal friends. He explains different types of seizures and tells what to do if they see someone having tonic-clonic seizures. He hopes that revealing his secret will make no difference to their friendship. His hope is fulfilled. (3-10 years.)


Introduces topics such as diagnosis, triggers, first aid and problems in everyday life and at school. For the older primary school child.


Inspired by her daughter who has epilepsy, Leslie Glover has created in her name, Kaylee Marie, a teenage character with epilepsy, the heroine of a series of mystery stories.


Mike has had epilepsy since he was two. Basketball and the sensitive care of his parents and doctors help him to cope with his epilepsy. The story is based on the author's own experience growing up with epilepsy and is especially suitable for boys up to early adolescence.
Mommy I feel funny; a child’s experience with epilepsy by Danielle M. Rochford and Chris Herrick, Deadwood, Oregon: Wyatt-MacKenzie Publishing 2009

Introduces Nel who is diagnosed with focal seizures as a child. We journey with Nel and her family as they learn about epilepsy and we follow her development into an adventurous, active and involved adult. At 27 years old Nel has successful surgery that leaves her seizure free. (3-12 years)


In this realistic and compassionate tale, David tells what happens in his family and what it is like to be the older brother of Matthew, born with ‘disabilities’.


This is a guide and explanation of epilepsy written especially for children. The children provide sound first aid when Daddy has a tonic-clonic seizure.


A guide and explanation of epilepsy written especially for children. Children need to know what epilepsy is and that it’s nothing to be afraid of. They also need to know what they should do if you have a seizure. This is a story about a young girl whose father has epilepsy. Available from Epilepsy Action UK.

My doctor says I have epilepsy; a child’s journey by Dr.C.R. Yemula and Frank Besag. Bedford: Health Insights 4U Ltd., 2010.

This book tells you the story of Jack, who has epilepsy. Via his journey, described with facts, humour and puzzles you will begin to understand epilepsy, its causes, diagnosis, treatment and life style changes. (6-12 years)


Explains the need of friendship, support, and acceptance and covers principles of first aid for convulsive seizures.
**My lights go out** by Julie Greene. -- Dublin: Brainwave, The Irish Epilepsy Association, 2009.

My Lights Go Out is a story about a little girl named Aoife who was diagnosed with epilepsy at age 4. One day Aoife experiences a seizure, the story explains the journey of what happens when a child is diagnosed with epilepsy, in simple language for young children.

**My mum has epilepsy: a story to help parents explain their epilepsy** by Epilepsy Action; Simplyhealth. Yeadon, Leeds: Epilepsy Action, 2016.

A guide and explanation of epilepsy written especially for children. Children need to know what epilepsy is and that it’s nothing to be afraid of. They also need to know what they should do if you have a seizure. This is a story about a young girl whose mother has epilepsy. Available from Epilepsy Action UK.

**Orchestra in our brain; the story of a child with epilepsy** by Cynthia Fabian. Durham CT: Strategic Book Group, c2011.

In order to promote understanding of a seizure a teacher likens the brain to an orchestra in which one member plays a wrong note. Suitable for primary students.


This cheerful little book explains epilepsy to young children. The book is now out of print but permission has been obtained for EFV to photocopy and distribute it.

**Poss's school days; An activity based story book for young children** by Anne Little. Fortitude Valley, Qld.: Epilepsy Association of Qld, 1995.

This picture storybook includes activities to increase student knowledge of epilepsy, suggesting appropriate responses to seizures and encouraging a caring and accepting attitude to reduce the stigma associated with the condition. Includes worksheets.

Once upon a time there was a Princess. She had everything a little girl could ever want, and she was happy. That is, until the fog came...The Princess and the Fog is picture book to help sufferers of depression aged 5-7 cope with their difficult feelings. It uses vibrant illustrations, a sense of humour and metaphor to create a relatable, enjoyable story that describes the symptoms of childhood depression while also providing hope that things can get better with a little help and support.

Sarah Jane has staring moments by Kate Lambert and Rebecca Morris, illus. [UK]: Kate Lambert, c2012

Sarah Jane has absence seizures. She is feeling very unhappy because nobody at school understands when she stops and stares. Her friend, John, overcomes his shyness to support her in class and together they explain about epilepsy to the children and the teacher. This insightful story 'shows us that through simple communication and understanding children can be empowered to overcome the obstacles they face.' [cover]


Second Hand Art is a children’s book about Henry who wishes he could stop stuttering and be like his sister.


A positive informative book presenting reassuring information for boys, to help them progress through the changes of puberty.


This book ‘provides easy to understand information about the changes of puberty, for girls - most specifically, periods.'
So...what is epilepsy by Children's Epilepsy Service. Swansea: Children's Epilepsy Service, 2006

An excellent interactive booklet - presenting an overview of epilepsy for primary school children. Can be printed from Epilepsy Scotland website


An activity based book to be used with children aged 3-6 years old, in conjunction with a trusted adult. The activities are designed to help young children find the words to talk about the difficult things that have happened to them, express their feelings about it all and find some ways to move forward as positively as they can. There are guidelines on every page for a parent or carer as they help a child with the book.

Sometimes I get the wiggles: a true story by Andee Cooper Oklahoma City, Okla.: RoadRunner Press, 2016

Kannon comes up with an idea to enlist and train all of his classmates as Seizure Heroes as a way of helping his teacher and his fellow students see Kannon through each school day. Based on a true story and written by Kannon's mother.

The special needs acceptance book; being a friend to someone with special needs by Ellen Sabin.[S.I]: Watering Can Press, c2007.

Written to encourage an understanding of children with special needs, promoting friendship, acceptance and affirmation of these children.


'In this collection of short stories, the heroes and heroines are disabled children who defy the stereotypes associated with being disabled.' It promotes disability awareness and discussion among children aged 4–11, addresses issues such as fear, loss, feeling 'different', bullying, exclusion, joy, success, friendship and emotional growth. It is as well a tool for teachers, parents and professionals to understand the experiences of disabled children.
A story about a young boy who, coming to terms with being diagnosed with epilepsy, looks at the different reactions of his friends and family. He has complex partial seizures.

The story of Dylan, who has JME, and his family's experience of epilepsy. It is a sensitive exploration of the many adjustments made and understandings which have to be developed when a child is diagnosed with epilepsy.

Views from our shoes: growing up with a brother or sister with special needs by Donald Meyer. Bethesda MD.: Woodbine House, 1997.
Covering a variety of special needs, forty five siblings, aged four to eighteen, share their experience as the brother or sister of someone with disability. Helpful and easy to read.

Wally the whale: a tale about a whale with seizures by Sara Manning and Dani Henke, illus. Bloomington, In.: AuthorHouse, c2011.
Wally the whale who has complex-partial seizures learns that, in addition to being careful and sensible, he can still have independence and adventures.

We'll make it by Pierre Genton; Vincent Ringler, illus.[Nairobi, Kenya] : Sanofi, [2012]
Written by a neurologist, this educational comic book tells the story of two African children – Lamine and Keifa – in order to help fight the stigma surrounding epilepsy.

Death is a big concept, and can be confusing and distressing to explain to young children. This simple guide presents 17 'big' questions children might ask about death, and answers each clearly, simply and truthfully. Each question is accompanied by an illustration and a prompt to encourage children to explore their feelings.

Sometimes it can be difficult for children to understand what is happening when they are having a seizure. In addition, it can be very scary for their peers or friends who witness them. Autism Speaks has put together Visual Stories to explain to children how people with epilepsy are just like everyone else! This book is addressed to the person experiencing the seizures.


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Written in comic format which may appeal to children 'MediKidz are a group of larger-than-life, space dwelling characters who live in ...a planet shaped just like the human body...who take children on a journey...explaining complex medical issues in a language and style that they can understand'.


An activity based book which aims to help children find the words and ways to talk about the difficult things that have happened to them, to express their feelings about it all and find some ways to move forward as positively as they can.
Books for parents

*These titles have been included in the Recommended Reading List for Children as information for parents of children coping with grieving.*

**35 Ways to help a grieving child** by the Dougy Center for Grieving Children. -- Portland, Oregon: Dougy Center for Grieving Children, 2010.

This guidebook presents simple and practical suggestions drawn from the experiences of thousands of grieving children and teens about what helps and what doesn’t. Learn what to expect from grieving children at different ages, how to provide safe outlets for children to express their thoughts and feelings, and how to support them during the memorial service, holidays and anniversary times.


This guidebook offers a comprehensive, easy-to-read overview of how children grieve and strategies to support them. You will learn how children understand death, how to talk with children about death at various developmental stages, how to be helpful and when to seek outside help. This book is useful for parents, teachers, helping professionals and anyone trying to support a grieving child.

**Finding out about epilepsy** by Epilepsy Action UK, Yeadon, Leeds, Epilepsy Action 2002.

The book is intended to help people with learning difficulties understand their epilepsy and is made up of illustrations and simple sentences about the causes of epilepsy, triggers of seizures, medication, side effects and first aid. Produced by a project group of professionals it is 'aimed at education and community care staff and carers of people with learning disabilities'.

*This title has been included in the Recommended Reading List for Children as information for parents of children on the ketogenic diet*


A practical guide to the ketogenic diet written by a leading dietician and renowned epileptologists, with tips, information and recipes developed according to commonly used ratios, this beautifully illustrated cookbook presents inspiring meals to entice those on the ketogenic diet.