

# EPILEPSY TOOLKIT

For Newly Diagnosed Children and Youth



We know a new diagnosis of seizures and epilepsy can feel overwhelming. The Epilepsy Foundation wants you to know that you have our support. **Your family does not have to manage this new diagnosis alone.** We are here to answer questions and provide you with the best resources. We can also help you connect to other families who have overcome the challenges of a new diagnosis.

This toolkit was designed with you in mind to help you navigate a new diagnosis. It outlines the steps you can take to ensure you are getting the care you need, and provides advice to keep you healthy and live life to the fullest.

# Section 1

## Your Healthcare Team

Managing seizures and epilepsy needs teamwork between members of your healthcare team, your family and you. An important first step is ensuring you have a healthcare team that will provide you with the medical help you need to accurately diagnose and treat your child's seizures and refer you to specialists as needed. Equally important is learning how to communicate with your healthcare team so that you can participate in important treatment, seizure management and lifestyle decisions that influence your health and wellness from day to day.

Get started here:

**WHO ARE THE MEMBERS  
OF AN EPILEPSY  
CARE TEAM**

**COMMUNICATING  
WITH OUR EPILEPSY  
CARE TEAM**

**INDIVIDUAL AND  
FAMILY SERVICES**

**CONNECTING WITH AN  
EPILEPSY COMMUNITY**

# Section 2

## The Basics of Seizures and Epilepsy

There are many different types of seizures and epilepsy syndromes. A key part of understanding your diagnosis is learning about the type of seizures you have and what the diagnosis means. Learning about the basics of seizures and epilepsy will help you communicate with others about your diagnosis. It will also point you in the right direction for managing your seizures and what to do when a seizure happens.

Start building your knowledge here:

WHAT IS A SEIZURE?

WHAT IS EPILEPSY?

TYPES OF EPILEPSY &  
SEIZURES DISORDERS

HOW IS EPILEPSY  
DIAGNOSED?

HOW IS EPILEPSY  
TREATED?

EPILEPSY AND  
GENETICS

KEEPING TRACK  
OF SEIZURES

Will I ALWAYS  
HAVE SEIZURES?

# Section 3

## Seizure Safety

For some people seizures can be unpredictable. For others, however, there are known behaviors or situations which make a seizure more likely to occur (seizure triggers). In all cases it is important to feel well prepared to respond to a seizure if one should occur. Preparing your family, school personnel and other adults who may be responsible for your child during, or after, school will allow for everyone to feel well prepared to respond to a seizure. This section covers information on Seizure First Aid, safety at home, at school and with recreational activities. It will also help you understand seizure triggers and share information about disclosing an epilepsy diagnosis.

Start building your knowledge here:



# Section 4

## Living with Epilepsy

Living with epilepsy is different for each child and family impacted. This section provides information about the challenges that may arise for some children, as well as resources from the Epilepsy Foundation that can help to support your child's wellness, their siblings and your entire family.

Start building your knowledge here:

**EPILEPSY AND  
WELLNESS**

**EPILEPSY  
AND SLEEP**

**LEARNING,  
BEHAVIOR,  
EMOTIONS, AND  
COGNITION**

**DRIVING AND  
TRANSPORTATION**

**SUMMER CAMP**

**MANAGING YOUR  
CHILD'S EPILEPSY**

**TRANSITIONING  
FROM PEDIATRIC TO  
ADULT CARE**

# Section 5

## Resources and Support

Building a network of support is important. Read through this section to learn more about resources for learning, advocacy, connecting with your local Epilepsy Foundation office, and the national Epilepsy Foundation's 24/7 Helpline.

**EPILEPSY  
FOUNDATION  
24/7 HELPLINE**

**LOCAL EPILEPSY  
FOUNDATION  
SUPPORT**

**EPILEPSY  
ADVOCACY**

## Links to Additional Toolkits

**DEVELOPMENTAL &  
EPILEPTIC  
ENCEPHALOPATHY  
TOOLKIT**

**DIFFICULT  
TO TREAT SEIZURES  
TOOLKIT**