

CONSIDERING A SEIZURE ALERT DEVICE?



5

Steps to Help Determine What is Right for You and Your Family

1

DETERMINE BEST METHODS FOR DETECTING YOUR SEIZURE TYPE(S).

It is important to discuss with your child's neurologist which monitoring method is the best for your child's seizure type. When considering an alerting system, an initial step is to look at whether the device can detect the seizure type(s) you want to monitor. Different seizure types can be detected by different methods. Two examples of different methods are movement and oxygen levels. If you are unsure about it, ask your neurologist if your child's seizure type can be detected.

2

DETERMINE YOUR GOALS FOR THE DEVICE.

Knowing the main reason you want to monitor your child's seizures helps to ensure the selected device meets that goal. The following provides two examples of goals:

A. Notify someone when a seizure occurs. Having someone with the child during, or shortly after, a seizure provides the child with a safety check.

For this goal, a major consideration is how the device sends alerts. Examples of alerts are an audible alarm, text message, flashing light, email, or a phone call to emergency contacts. Some additional considerations include:

- What is required to trigger an alert?
- How accurate is detection?
- Is there the option to cancel an alert if it is a false alarm?
- Does the device provide GPS information as part of the alert?

B. Track how often seizures occur.

Some considerations for this goal include:

- Is my child willing to be monitored?
- How does the device store data, and is the data secure?
- Is the data easily shared with medical professionals?

3

CONSIDER THE COMFORT AND APPROPRIATENESS OF THE DEVICE.

No device will be effective if it is not used correctly. Consider if the device will be physically comfortable to wear. Also, will your child be emotionally comfortable to use it? Some children may be uneasy being watched by cameras. Others may feel embarrassed by having any visible sensors or even a watch that isn't "stylish".

Questions to consider include:

- Are there age or weight restrictions?
- Where can the device be used?
- Is the device wearable? If so, what is the comfort level?
- If the device is not worn, is its use restricted to a bedroom or a specific location?
- Is it water resistant?
- How is the device powered? If by battery, how long will power supply last and how long does it take to charge?

4

DETERMINE THE EASE OF USE AND SET UP.

It is important to understand what is required to use the device. For example, are other technologies like Internet, cameras, or smart devices needed to support the monitoring system? Look into whether tutorials are provided. Test whether the manufacturer provides strong customer support before you commit to using their product.



Talk with your child neurologist about whether the device you are interested in fits your families' needs.

5

DETERMINE THE COST OF THE DEVICE.

Monitoring devices can have many costs. Questions to consider include:

- What is the cost to purchase the device?
- Is there a monthly or annual fee?
- Are there set up and maintenance costs for the device, or any other technology needed to support the system?
- Is the device covered by insurance or a medical expense account?

OTHER CONSIDERATIONS:

- Is the device specifically designed to detect seizures?
- Is the device FDA approved, or going through the FDA approval process?
- Is there any published clinical trial data for the device?

One serious safety concern for people with epilepsy is the risk for Sudden Unexpected Death in Epilepsy or SUDEP.

It is important to understand that neither seizure first aid, nor any seizure alert device available, has been proven to prevent SUDEP. The best way to decrease the risk of SUDEP is to have as few seizures as possible.

This information is intended to help facilitate a conversation with your healthcare provider about selecting a seizure alert device best suited for your families' needs.

The Child Neurology Foundation and Danny Did Foundation believe that optimal healthcare decisions are made when a family and provider engage in honest, direct conversation.

LEARN MORE AT
www.childneurologyfoundation.org/programs/SUDEP

If you have additional questions or are seeking financial assistance to purchase a device, the Danny Did Foundation is an excellent resource at www.dannydid.org.

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