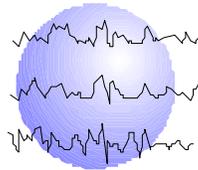


# **THE BENEFITS OF A PEDIATRIC INDIVIDUAL SEIZURE EMERGENCY PLAN – PARENT AND CAREGIVER PERCEPTION**

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## **REVISED ABSTRACT**

### **RATIONALE**

For people unfamiliar with epilepsy, a generalized tonic-clonic seizure is a frightening experience, while more subtle seizures may go unrecognized. We have designed a simple, one page, Individualized Seizure Emergency Plan (ISEP) for children with seizures. The purpose of the ISEP is to help parents and caregivers, (school, daycare, group home, etc.) to understand what to expect and what to do in the event of a seizure. Our hypothesis is: Having a simple, written, child specific plan (ISEP), should prevent delay in appropriate action, decrease emergency department (ED) visits and calls, and decrease anxiety in caring for a child with seizures.

### **METHODS**

The authors asked a parent of 60 children ages 2-16 years seen for an outpatient visit in a 5 week period to complete a brief survey regarding their child's ISEP. They were asked to give a mail-in survey to a caregiver. The survey asked if their child had an ISEP. If so, they were asked to rate on a 1-10 scale (1=not helpful, 10=extremely helpful) the helpfulness of the ISEP, and rate its effect on their anxiety about caring for a child with seizures. If the ISEP had been used, they were asked if they believed that it prevented delay in treatment and/or Emergency Department visits or calls.

### **RESULTS**

60 surveys were distributed. 70% of the parents responded. Of these, 78% had an ISEP. 30% of corresponding caregivers responded. 85% of parent responders rated the ISEP from moderately helpful to extremely helpful, with 45% of parents rating it extremely helpful. 77% of caregivers rated helpfulness between very helpful and extremely helpful with 61% of caregivers rating the ISEP as extremely helpful.

In regards to decreasing anxiety of caring for a child with seizures, 88% of parent responders rated a decrease in anxiety in the very to extremely helpful range with 39% rating it extremely helpful. In the caregiver group, 77% stated anxiety was decreased significantly with 30% rating it as extremely effective in decreasing anxiety.

42% of the parents stated the ISEP had been used in a 6 month period between 1-50 times. 63% of parents felt that having an ISEP prevented delay in treatment while 61% of corresponding caregivers believed it prevented delay in treatment.

97% of parents and 92% of caregivers believed it prevented emergency department visits or calls.

### **CONCLUSION**

These findings support our hypothesis. Parents and caregivers both report the ISEP as very helpful. This simple written plan not only improved the care of the child with seizures, but also decreased the anxiety related to seizures. There were no significant differences between parents and caregivers. In addition, there was a decrease in the economic burden by preventing ED visits. Additional benefits cited included parent sense of empowerment, consistency of care, greater freedom to travel, and useful tool for training multiple caregivers.

[Epilepsia 44 Suppl. 9:135 \(Abst. 1.389\), 2003](#)

## INTRODUCTION

Parents of 60 children ages 2-16 years seen for an outpatient visit in a 5 week period of time were asked to complete a brief survey regarding their child's Individual Seizure Emergency Plan (ISEP).



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### Individual Seizure Emergency Plan

Date \_\_\_\_\_

Dear \_\_\_\_\_

\_\_\_\_\_ is a patient of the Minnesota Epilepsy Group.

\_\_\_\_\_ seizures type(s) are as follows:

\_\_\_\_\_ Absence-staring and decrease in responsiveness.

\_\_\_\_\_ Simple partial seizures \_\_\_\_\_

\_\_\_\_\_ Complex partial seizures \_\_\_\_\_

\_\_\_\_\_ Generalized tonic-clonic seizures \_\_\_\_\_

\_\_\_\_\_ Tonic seizures \_\_\_\_\_

\_\_\_\_\_ Drop (atonic) seizures \_\_\_\_\_

\_\_\_\_\_ Other \_\_\_\_\_

If \_\_\_\_\_ has a \_\_\_\_\_, please do the following:

1. Provide first aid. Keep safe. Do not restrain. Place in a side-lying position for a generalized tonic-clonic seizure. Time the seizure.
2. For a \_\_\_\_\_ seizure lasting longer than \_\_\_\_\_ minutes or for more than \_\_\_\_\_ seizure within \_\_\_\_\_ administer \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

• Call 911 \_\_\_\_\_

3. Notify \_\_\_\_\_ for \_\_\_\_\_

Phone # (H) \_\_\_\_\_ (W) \_\_\_\_\_

Beeper/cell phone # \_\_\_\_\_

Call our office at (651) 241-5290 with any questions or concerns you may have.

Sincerely,

PHYSICIAN'S SIGNATURE: \_\_\_\_\_ Date: \_\_\_\_\_

Print Name: \_\_\_\_\_ Phone: (651) 241-5290

R.N. Name: \_\_\_\_\_

Expert evaluation, treatment, consultation, research and support services for people with intractable epilepsy.

## **METHODS**

The writers asked parents of 60 children, ages 2-16 years seen for an outpatient visit in a 5 week period, to complete a brief survey regarding their child's ISEP. Parents were also asked to give a mail-in survey to caregiver. The survey asked if their child had an ISEP. If so, they were asked to rate on a 1-10 scale (1=not helpful, 10=extremely helpful) the helpfulness of the ISEP, and also rate its effect on their anxiety about caring for a child with seizures. If the ISEP had been used, they were asked if they believed that it prevented delay in treatment and/or Emergency Department visits or calls.

Caregivers using the plan included other family members, nannies, school nurses, and staff, daycare providers, homecare, and group home staff.

## **RESULTS**

60 surveys were distributed. 70% of the parents responded. Of these, 78% had an ISEP. 30% of corresponding caregivers responded. 85% of parent responders rated the ISEP from moderately helpful to extremely helpful, with 45% of parents rating it extremely helpful. 77% of caregivers rated helpfulness between very helpful and extremely helpful, with 61% of caregivers rating the ISEP as extremely helpful.

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42% of the parents stated the ISEP had been used in a 6 month period between 1-50 times. 63% of parents felt that having an ISEP prevented delay in treatment, while 61% of corresponding caregivers believed it prevented delay in treatment.

97% of parents and 92% of caregivers believed it prevented emergency department visits or calls.

## **CONCLUSION**

These findings support our hypothesis. Parents and caregivers both report the ISEP as very helpful. This simple written plan not only improved the care of the child with seizures, but also decreased the anxiety related to seizures. There were no significant differences between parents and caregivers. In addition, there was a decrease in the economic burden by preventing ED visits. Additional benefits cited included parent sense of empowerment, consistency of care, greater freedom to travel, and useful tool for training multiple caregivers.

## **Parent and Caregiver Comments Regarding Benefit of Having an Individual Seizure Emergency Plan (ISEP)**

- One parent that never had needed to use their ISEP reflected, “we never needed to use the ISEP, just knowing we have the medication and how to use it decreased our anxiety and stress level so much.”
- “Yes, it helps me feel in control of what is happening, and to be able to treat my daughter right away, instead of waiting for more seizures to occur.”
- “We spent her early life in the emergency room receiving medications with horrible side effects.”
- A caregiver reported, “the individual seizure plan helps in writing the individual emergency plan for school personnel and to direct nursing or delegated nursing care ..... of great value.”
- “When new caregivers or staff come it is nice to have a consistent plan.”
- “We have a plan for potential problems that may arise, have all medical information at my fingertips. If there is a substitute nurse she has a very clear understanding of what to do.”

Table 1

### Degree of Helpfulness:

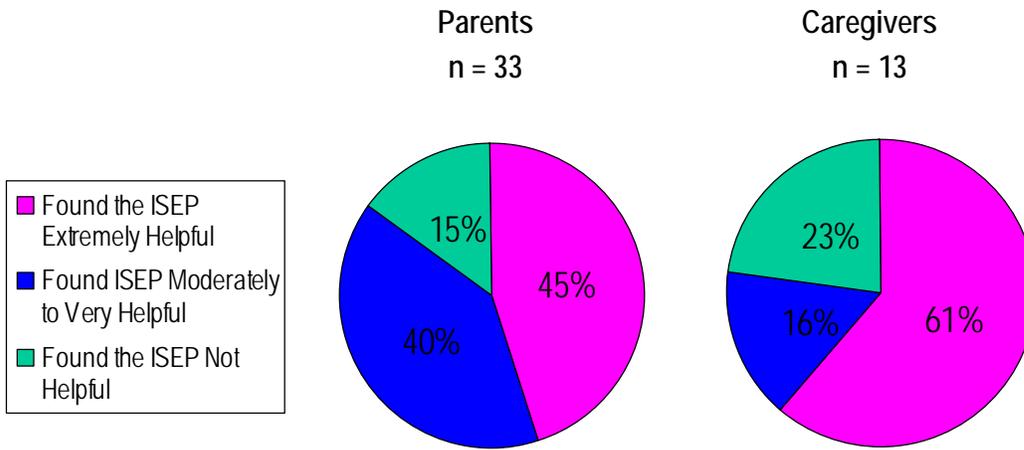


Table 2

### Effect on Anxiety in Caring for a Child with Seizures

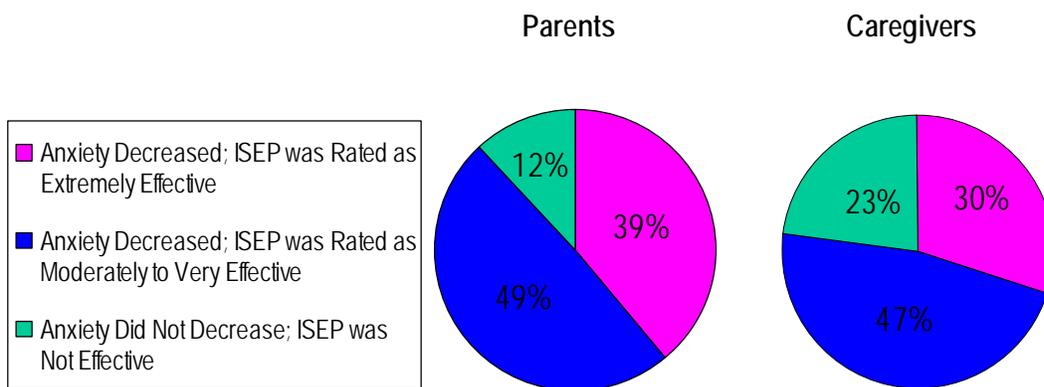


Table 3

### Delay in Treatment

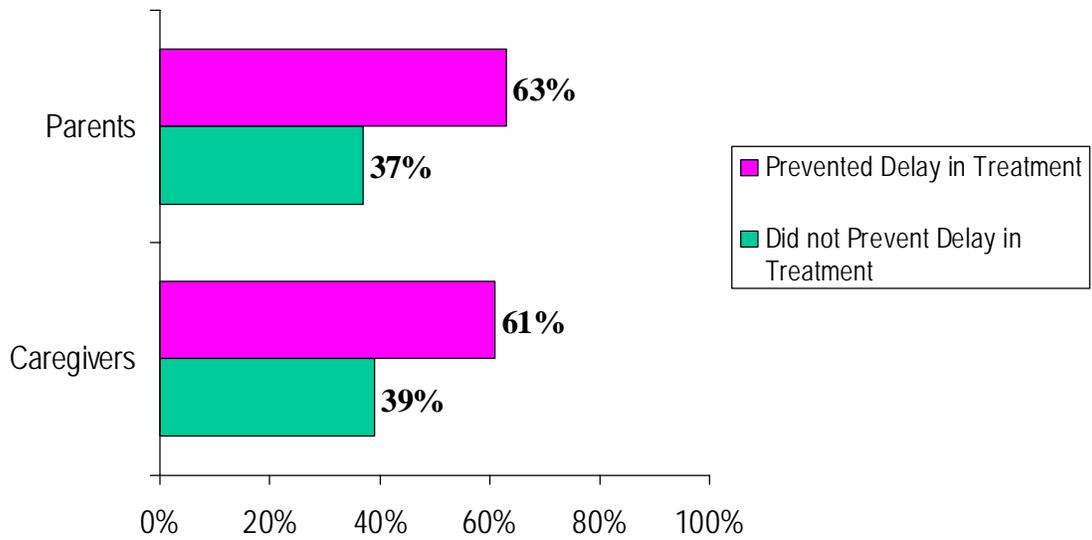


Table 4 Prevention of Emergency Department Visits or Calls

