

PART ONE

# Self-Management in Epilepsy Care: Putting Teen and Families in the Center

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## Introduction/Summary

Epilepsy is one of the most common chronic neurological problems in childhood and adolescence. Unfortunately, it is also one of the most misunderstood conditions. Epilepsy can interfere with the physical, emotional and social functioning of youth of all ages, particularly if seizures are uncontrolled. Teenagers living with epilepsy face unique challenges as they make the transition from childhood to adulthood and shift away from depending on others to learning how to take care of themselves. Treating seizures effectively and preventing unexpected consequences requires a collaborative effort between health care providers, caregivers, families, and the teenager with epilepsy. The first in a year-long series on epilepsy and adolescents, "Self-Management in Epilepsy Care: Putting Teens and Families in the Center," explores how the self-management process may be used to help teens learn to care for themselves, and work with caregivers as 'co-managers' and facilitators of their epilepsy care.

## What are seizures and epilepsy?

Epilepsy is simply the term used to describe recurring seizures that are not provoked or caused by a specific illness. For example, seizures that occur only with a fever are not considered a form of epilepsy. However, if a person later develops seizures that can occur without fevers, then that person would be considered to have a form of epilepsy. This term is often used interchangeably with seizure disorders. A seizure is a symptom of a neurological disorder and is the result of abnormal electrical activity in the brain that occurs suddenly and unpredictably, interfering with normal brain activity and causing a seizure to occur. During a seizure, behavioral

changes occur, for example, altered awareness, thinking, talking, moving, feeling or perceptions. Exactly what happens depends on the area of brain affected. Generalized forms of seizures tend to predominate in childhood, yet partial seizures, or seizures beginning in one area of the brain, tend to increase in adolescence and early adult years.

Seizures can occur at any age, but epilepsy tends to start most often in children and older

adolescents. Physical, social and emotional problems can occur that affect a child's growth and development in critical ways, such as interfering with self-competence, physical function, peer relationships, independence, and school competence. (4) These problems may occur for many reasons. Epilepsy can disrupt the way some of the brain cells function, while the frequency of seizures can affect this even more. The underlying cause of epilepsy and side effects of treatment may contribute to the problems that teens experience, as well as the challenges of coping with a chronic, unpredictable health problem. It is important to understand that epilepsy is not a 'one size fits all' problem. Seizures and the associated problems can look and feel different from one person to the next. Some teens may have very few problems and manage well without additional help. For others, seizures may be only part of the picture. Other neurological problems may be present, or the seizure frequency or severity such that specialized help from health care professionals, families, schools, and community resources is needed. People of all ages with uncontrolled seizures tend to experience the greatest difficulties, yet psychosocial problems may occur even in youth with well-controlled epilepsy.

## Managing epilepsy requires...

- Information – a 'working knowledge' of epilepsy
- Skills and strategies – the 'how to'
- Resources and supports

adults. There are over 300,000 youth aged 14 years or less in the United States with epilepsy. While some forms of epilepsy may be short-lived and easy to control with medications, approximately 25% of people who develop seizures will have seizures that are not controlled (also called refractory or intractable epilepsy). (1) Research in recent years (2, 3) has suggested that epilepsy can become a much more serious disorder than commonly thought, with 40% of people continuing to have seizures after only the second medication tried. More than half of people with epilepsy may require medications for years, possibly throughout their life.

## What problems may occur for teens with seizures?

Seizures are not the only problem facing our

## Teen voices

How do teens view epilepsy? A survey of 19,441 teens in the general population who did not have seizures showed that the majority of teens did not understand and were not familiar with epilepsy. (5) Many misperceptions were found; 40% of respondents were not sure if teens with seizures were dangerous and 75% believed that teens with epilepsy

were more likely to be bullied or teased than other children. These plain facts highlight some of the social problems that teens may face as they learn to manage life with seizures.

Another way to understand the teen experience is to read their stories. Teens from around the world have shared their experiences on Epilepsy.com, an online forum for the general public and people with epilepsy. The following are excerpts from teen stories posted on Epilepsy.com ([www.epilepsy.com](http://www.epilepsy.com)).

TEEN #1, AGE 18: "My medication had loads of side effects: I felt sick, I put on weight and I felt so drowsy all the time, which affected my schoolwork. I would often just get home from school at about quarter to four, flop down on the sofa and just sleep until about seven o'clock. Of course, this ended up just making the problem worse because it meant I couldn't sleep at night, so when I got up in the morning I would have a tonic clonic seizure due to lack of sleep...I can remember one time I had a tonic clonic seizure at school...Most of the other children were staring round at me. Some looked shocked, others very frightened. Most of the children were OK about my seizure once they had calmed down, but some were scared to play with me at break time in case it happened again. There were times, though, that I knew I was "different" to the other children and sometimes I felt singled out. I sometimes felt isolated, because I didn't know anybody else who had epilepsy who I could chat to about it. My school teacher, my family and most of my friends were very supportive towards me...but I feel that it is sometimes difficult for them to really understand what it is like if they haven't been through it themselves. ... I have to think about my health and safety as well..."

TEEN #2, AGE 14: "I've been diagnosed with epilepsy for about 3 years. I think that I had it for more years, months, maybe days. I was an energetic girl... I made everybody's day bright with just a simple hello. I wasn't afraid of nothing or to do anything. I had good grades in school— good enough to pass. Now I am a tired young girl, with little energy and grades that are barely passing."

TEEN #3, AGE 17: "I was in 8th grade when I first found out I had epilepsy. It was in the

middle of my science class. Since that day, my life has never been the same. I love cars and I love being able to drive. If I forget just once to take my medicine, my parents take away my car for a week because they're scared I'll have a seizure. Most of the kids think that epilepsy is a joke, or a disease. They don't think it's really anything to worry about. They don't understand how hard it really is to cope with the idea that if I have a tonic-clonic seizure, I won't be able to dance again. It's hard to make them understand. They all think I get special treatment because I have epilepsy, but it's not true. I just wish I could make them understand."

TEEN #4: "I remember just coming home from work, with a pounding headache, going for the computer to check my e-mail. However, my mind goes blank from there. The next thing I knew I was in an ambulance, with a female paramedic telling me to just lay down

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## Factors Influencing Self-management Care

- Confidence in one's abilities
- Satisfaction with care
- Communication with doctors and health care providers
- Support
- Emotional well-being or mood
- Stigma
- Feelings of control
- Individualized goals and treatment

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and rest, and my mom right beside me. My mom began to cry and started telling me how I had a seizure at home and she was thinking I was going to die and that she wouldn't have the chance to tell me she loved me one more time. A month later, I was officially diagnosed with epilepsy. I'll never be the same."

## What approaches and care are needed to help teens with seizures and their families?

Self-management is a term used to describe the way that people manage a chronic health problem such as epilepsy – what people actually do to manage their seizures and the way it affects their daily life. (6) Self-management does not mean that people treat themselves! Far from it – self-management requires teamwork between health care professionals, caregivers, families, and teens. Everyone works together as 'co-managers' centered around teens and families. It's important to also realize that family members may be 'hidden patients' with their own needs and concerns, while they fulfill their roles as caregivers and 'co-managers'. This approach means that no one is going to tell parents and their teens what to do, but will put the teen and their family in the center and recommend a plan of care that will help accomplish their goals.

## Teen-centered care – a team approach

To make self-management work, goals of treatment are best individualized to the teens and their family. These goals may include working towards 'no seizures and no side effects' in a manner that supports teen empowerment, yet also work towards improving the quality of life for teens and their families.

Managing epilepsy requires that everyone have a 'working knowledge' of seizures, but more importantly, that they know what to do to implement the plan of care! Caregivers and families need accurate information, the 'how to' skills and strategies, and the appropriate resources and support to make it all work. A psychosocial model of epilepsy self-management suggests that critical needs or components extend beyond seizures and medications to include management of safety, lifestyle, and information (7). In addition, teens with epilepsy must learn how epilepsy may affect their general health and what skills and resource they need to live independently.

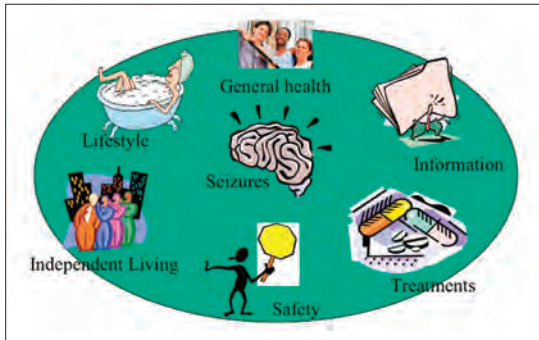
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## Self-Management Components

### Designing a treatment team



As a child enters adolescence, parents and other caregivers design their treatment in relation to the teen's current needs and anticipate the potential problems that may develop in the future. The team may begin with just the primary care provider or neurologist. If seizures are not easily diagnosed or controlled, specialists in epilepsy care will be needed. A nurse, or other appropriate health care professional, should be incorporated to provide necessary education, skill-building, and support. However, since life with epilepsy is more than just the seizures, caring for the teen with epilepsy may also require the expertise of neuropsychologists, psychiatrists, social workers, educators, and rehabilitation therapists. Other caregivers in the community may be called upon, depending on the teen's needs, such as a school nurse, guidance counselor, camp counselor, employment specialist, personal care attendants, or respite care workers.

Making this work involves figuring out what kind of decision-making process that families and teens prefer. For example, do they prefer that the doctor or other professional be the 'authority' and assume control? Or do the teen and parents work best when control and decision-making is a shared process? Understanding the roles and power of each person will help the team communicate more effectively.

### What factors may affect the success of epilepsy management?

There is no recipe for successful epilepsy care. However, research in epilepsy and other

chronic illnesses have suggested a number of very important factors to consider.<sup>(7, 8)</sup> A person's self-confidence (also called self-efficacy) has been shown repeatedly to influence how well a person manages and copes with chronic illness, including medication management for epilepsy. The ability to talk with the doctor, make shared decisions, and feel empowered are aspects of communication that may help a person move from asking questions to taking action. Being satisfied with their care and having support from others influences a person's self-confidence and ability to manage seizures. Likewise, a person's mood influences their confidence, as well as their feelings and reactions to stigma, a problem common for many teens with seizures. When mood problems such as these are present, a person's ability to manage their health may also be affected, thus emphasizing the need to identify and treat mood problems early. Lastly, tailoring goals and treatment empowers each person to be in charge, to be responsible, and to take action. Unfortunately many barriers to obtaining care exist, such as lack of health care resources, insurance, or transportation, as well as social and cultural barriers among different groups of people. Making epilepsy care work for teens will depend upon finding ways to overcome these barriers, while building on successful self-management approaches.

### Summary

The adolescent years are a time of many changes, conflicts, and growing independence. Teens living with seizures will face additional challenges that require good working relationships and communication between parents, health care providers and teens. The self-management approach can be used to facilitate this relationship and help families and caregivers organize their needs, implement plans, and teach teens how to manage their epilepsy.

Epilepsy.com is an online resource of the Epilepsy Therapy Development Project and strives to inform and empower people facing newly diagnosed seizures as well as people with persistent seizures. Next month, Epilepsy.com teams up with Exceptional

Parent and Dr. Orrin Devinsky to explore the difficult tasks of sorting out seizures from other medical conditions and understand the difference between uncomplicated and devastating forms of epilepsy. Resources to help families and caregivers work with the health care team and sort out seizures will be included. [EP](#)

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