



Stress Management

In our increasingly fast-paced and demanding society, stressful situations have become a familiar and expected part of life. Experiencing mild stress for short periods is, in fact, considered beneficial; it can increase our motivation, energy, and efficiency.

Harmful effects of stress emerge mainly when stress responses are triggered too readily, too frequently, or go on for too long. We are then apt to experience detrimental effects on our psychological functioning and on our physical health. We may find ourselves living in a chronic state of tension, which erodes our ability to meet the everyday demands of living.

For all of us, managing stress has become an increasing priority. Because living with epilepsy comes with its own challenges, understanding and managing stress for those with epilepsy can be particularly important.

What Makes a Situation Stressful?

The experience of stress and what we consider a stressful situation are based fundamentally on how we *interpret* changes or events in our lives. If we perceive that we will have difficulty coping with changes that in some way seem to pose a threat to our security and psychological equilibrium, then we will feel stressed. Essentially we feel we are out of our comfort zone and that we don't have enough control of the situation – we feel we are in danger!

There are many everyday events that most of us will perceive as stressful. Some relate to the particular circumstances of our living and social environments (e.g. financial pressures, pace of life, high density living conditions, traffic, poverty, crime, and unemployment). Others relate to demands of the workplace or academic settings, while still others arise in conflicts with people. These can all provide potent sources of day-to-day tension.

Other types of situations occur much less frequently, although they are inevitable parts of life. These are the "major life stressors" and include serious injury or illness, death of a close family member, or major life changes such as retirement or an ending of an important relationship. One may be surprised that positive life events such as births, starting of school, or marriage can also be stressful. It is also of interest that it does not need traumatic situations or big stressors to impact a person; a lot of times multiple, small life events that do not change or resolve themselves can accumulate insidiously to affect us. A small life event at the end of a series may be the one that "breaks the camel's back".

Because stress is based on the meaning we give events, it is very much an individual experience. For some even major disruptions can be experienced as only mildly stressful, while for others relatively minor events can result in high levels of stress. Negative thoughts about our own efficacy and worth, unrealistic expectations, or being generally worried or unhappy will all make it more difficult to cope with challenging circumstances. On the other hand, a strong sense of self-esteem and efficacy can act to counter the effects of disturbing events.

Particular Stresses for People with Epilepsy

People with epilepsy, particularly those with incompletely controlled or newly diagnosed epilepsy, face a number of other types of challenges. A major worry lies in the uncertainty and fear around seizures – the individual's sense of control and safety are felt to be compromised. There may be concern as well about possible negative judgments of others if they witness a seizure or know about the diagnosis. As a consequence the individual may restrict his or her activities at work and in social interactions and also avoid disclosing that they have epilepsy. All of these strategies may unwittingly add to stress.

Living with epilepsy can mean numerous medical visits, medication changes, and having to maintain medication regimes. In some situations medication may have a negative impact on functioning, further eroding the person's sense of confidence and ability. Various types of limitations – in driving, employment, and school – may contribute to added external stresses as well as diminishing a sense of autonomy and efficacy. Negative societal perceptions of epilepsy (stigma) may also act to undermine and isolate the individual – even for those with uncomplicated epilepsy in whom seizures are completely controlled.

The Responses to Stress

When stressed we feel there is a risk of physical or psychological harm. There is a well-known, rapid, automatic response in such situations: the "fight or flight" response. "Stress hormones" such as adrenalin and cortisol are secreted; the body undergoes a number of changes intended to optimize our response to the threat. The agitation, fear, tension, anger, and other strong emotions associated with day to day hassles (arguing with a driver in the next car, for example) as well as bodily sensations such as a pounding heart beat, rapid, shallow breathing, trembling, sweating, stomach, and upset are rooted in the "fight or flight" response.

With persisting stress, multiple stressors, or after an extraordinary, crisis-like situation, stress symptoms may emerge. Physically, we may experience a variety of aches and pains, stomach discomforts, restlessness or difficulties sleeping, and fatigue. Emotionally, there may be ongoing feelings of tension, agitation, irritability, low temper threshold, and worry. Cognitively, we may find it more difficult to think clearly, to focus on a task, remember information and make good decisions. Our thought pattern may be negative, both about ourselves and others. Behaviourally, our eating, sleep, and sexual patterns may change; we may do more or less in all three areas. We may find social interactions irritating and withdraw, or try to occupy one's self with endless commitments. We may use alcohol as well as prescription and non-prescription drugs to try to relieve the feeling of stress.

If stress is unrelenting, we are at risk of developing a number of physical and mental health conditions: cardiovascular conditions such as high blood pressure and heart disease as well as disturbances in the gastrointestinal system have been well described. We are at risk for anxiety, insomnia, and mood disorders.

Seizures as Responses to Stress

While stress is not seen as a cause of the development of epilepsy, it is possible that stressful situations may increase the likelihood of having a seizure. In a number of studies in which people with epilepsy are asked to identify events that in their own perception seem to be related to an increase or worsening of seizures, stress is frequently cited as a precipitant. As well, there is work that indicates that with better stress management, seizures may diminish.

It is not clear how stress may come to increase seizure likelihood. It may be through indirect pathways such as the effects of stress on sleep and fatigue. We know that sleep deprivation can facilitate seizures. It may also be possible that changes in breathing associated with stress may precipitate seizures in some types of epilepsy. As well, individuals under stress may forget to take medication, or may use alcohol or other drugs that are known to facilitate seizures. There may also be more direct pathways: stress-related fear and anxiety may directly involve those brain regions from which seizures originate in some types of epilepsy. As well, the elevation of certain hormones like cortisol during stress may directly influence brain activity, lowering the threshold for seizures.

While the methods in most studies make it difficult to conclude definitively that stress can actually cause seizures, there does appear to be an association that is important for those with epilepsy to consider in managing seizures. This is particularly true because the occurrence of seizures and the associated fear and lack of self-control are in themselves a major contributor to stress.

Dealing with Stress

To effectively manage stress it is important to recognize that we are stressed, and moreover, to understand our own particular responses to stress. In many cases, particularly when stress is sudden or severe, the signs are obvious. When stress is recurring or longstanding, we may be less aware of it. Our experience of stress becomes so much a part of our lives that we may not realize that we are in fact stressed. In the above, some of the important signs that we are not effectively dealing with life changes are described: sleep changes, aches and pain, poor concentration and memory, or intolerable feelings of anxiety or discouragement. In addition, the Canadian Mental Health Association web site offers a brief questionnaire for helping us decide whether and to what extent we are living with stress:

http://www.cmha.ca/bins/content_page.asp?cid=4-42-216

But, once we recognize that we are living under the shadow of unnecessary, high levels, and repeated stress, what can we do?

1. Taking charge of the body

There are a number of relatively straightforward and constructive ways to obtain relief from stress symptoms, which involve exercise, relaxation, and breathing procedures. These are described in a number of publications. A good review can be found in:

www.helpguide.org/mental/stress_relief_meditation_yoga_relaxation.htm

Working out in a fitness center, running, doing yoga, meditation, and progressive muscle relaxation can all enhance our well-being, reduce the physical discomfort of stress and provide a sense of control and confidence in one's bodily functions. While they are straightforward, the catch in all these activities is that they have to be done regularly and over a period of several weeks for them to begin to have an effect. Subsequently they need to be incorporated into a regular routine. Also, as for anybody, the individual with epilepsy needs to evaluate which types of activities are most suitable and whether certain types or levels of exercise or other activities might be harmful. Some studies have indicated that meditation may facilitate seizures, although these conclusions have been disputed. Consulting with medical or other health professionals may be helpful.

2. Dealing with the stress of having epilepsy and seizures

Children and adults with epilepsy are more vulnerable to being victims of insensitive behaviours and attitudes. Children in school may experience teasing and bullying (with or without epilepsy) and people

at work may also face prejudices. Informing and educating people in positions of care at school, at work and in social groups can help advocate for people with epilepsy. With increasing respect and a change in attitude towards seizures by others, the fear of being teased and discriminated against will diminish. In turn, there would likely be less concern about the unpredictability of seizures and having seizures in front of others.

It is also important for people with epilepsy to have accurate information about their epilepsy from professionals involved in their care and achieve a balanced understanding of their seizures and underlying condition. Individuals with epilepsy can sometimes have misperceptions of the severity and impact of their epilepsy. A general anxiety about epilepsy, due in part to negative attitudes and behaviours in society, may unnecessarily increase the sense of threat that their epilepsy presents. Even those with well-controlled epilepsy can come to believe that their lives are significantly affected by seizures, although objectively seizures may be under good control. The psychological attitudes people may have about their own epilepsy can have more of an effect on adjustment and well being than the epilepsy itself.

Besides talking to medical professionals, talking to others and reading about others who are living well with epilepsy can also be of help. Through a more balanced and realistic understanding, people with seizures may feel less anxious or threatened by their epilepsy. They can also come to have a more accepting and tolerant attitude towards themselves and being in a situation in which they may not have complete control. There are, of course, things to do that can increase the sense of control such as avoiding activities that may increase seizures and remembering to take seizure medications. As well, for some people it may be possible to use auras to prepare for seizures.

Because of the stigma of epilepsy, it is also not uncommon for people to keep their diagnosis hidden, particularly in the early stages after diagnosis. A person needs time to process the implication of sharing this condition with others. Keeping epilepsy a secret may defer facing the fear of disclosure, but at the same time it may heighten anxiety of a seizure happening and create a vicious cycle of stress and vulnerability to more seizures.

One may wonder what makes it so difficult to tell. Of course, there is the fear of being judged negatively. As well, learning to face epilepsy is a great inner challenge; it involves facing the pain of hearing the diagnosis, resenting the diagnosis and wishing it was untrue, the frustrations of limitations, the grieving and adjusting to the loss of health, and varying degrees of independence. Being ready to tell trustworthy others indicates one has gone through the difficult process of assimilating the fact that one has epilepsy as well as a myriad of difficult emotions. Once ready to tell, the burden of keeping the secret, the energy to cover up, and the fear of the unpredictability of seizure and its disclosure will be of lesser concern.

If one has a choice, no one would like to have epilepsy. However, once diagnosed with epilepsy, it is important to see oneself as a person with epilepsy rather than an epileptic person. One can still maintain self-respect, establish meaningful relations and develop personal interests. Just as no parent was born the best parent, or no student born to be the best student, a person with epilepsy has to learn to be a sensitive person learning from their seizures to develop confidence.

Some examples illustrate how this may occur. A person with epilepsy commented that all her siblings left home at age 18 and they led very independent and separate lives from their parents and her. As an adult, she realized it most probably was a reaction to her parents spending a lot more time and attention in caring for her that they moved out to search their own lives and attachment. With this knowledge, she went to all her siblings one by one to thank them for their generosity and acceptance for letting her take up most of the parenting time at the sacrifice of theirs. This broke the longstanding isolation of different family members and the adult siblings started to return home to be with the parents more often and share with her deeper relations. She describes it as “the family became normal again!”

A parent reported that keeping a child's epilepsy a secret meant they had to make excuses to opt out of family events when the activities involved the limitations for epilepsy. This created misunderstandings and tension. However, after the disclosure of the fact that one of her children had epilepsy, the misunderstandings dissipated and drew the extended family closer. More extended family members offered to baby sit her other children and she felt she no longer needed to keep a distance from them to maintain the secret.

3. Understanding our stressors, personality, and coping styles

In this final section, the "Five R's" describe some general ways to embark on the task of achieving a more comprehensive approach to stress management, one which involves an exploration and a taking charge of the external situations of our lives as well as our own attitudes, feelings, and habitual ways of responding.

i. Recognize our personality style and be mindful of the feelings that accompany our coping style. Being aware of whether we are perfectionist, overcritical, or worry too much can begin the process of changing stressful ways of thinking and habitual ways of dealing with situations. We can work on finding a balance of work, solving daily problems, relaxation, fun with self and others. Because it can be difficult to recognize how our own ways of thinking, acting and feeling can contribute to stress, it may be helpful at times to talk to others in our lives or mental health professionals.

ii. Reduce unnecessary stress by reviewing goals and priorities and becoming more flexible with expectations. If we find ourselves overstretched with many demands of roles and time, this may involve learning how to say "no", avoid people or environments that cause stress, or cut down the number of commitments.

iii. Reframe our understanding of our inner resources and external environment so that we can discern and accept those aspects we cannot change. This involves a willingness to compromise and to be realistic with our available capacity and time management skills. It also means acknowledging that we need not avoid all stressors, but can accept a certain level of discomfort. We may need to be content with small changes, realizing that it may be necessary to break down projects into smaller and more achievable targets. Acceptance implies that we can be open to seeking help and advice from others and to delegate responsibility.

iv. Revitalize ourselves by nurturing our body, emotional, and social life. Every cloud has a silver lining; be positive and try to see the cup of water as half full rather than half empty. Appreciate humor, learn to have fun and accept that we live in an imperfect world. Develop a healthy life style with a healthy diet, adequate sleep, and reduced caffeine and sugar. Avoid drugs, alcohol, and cigarettes. Share feelings with a person you can trust or a professional. Remind yourself to take breaks, set aside time for exercise and relaxation, and do something enjoyable even when you are experiencing a low mood, anger, or anxiety. Do not wait for your stress to subside before practicing all the above strategies.

v. Reach out to others for support. Having supportive connections with others is a key element in gaining perspective as well as in coping with stressful situations. People with more severe types of epilepsy with positive social support describe better coping with less stress than people with mild conditions of epilepsy but lacking in support. However, positive connections with family, friends, or workmates can sometimes be difficult to make or sustain. When we are feeling poorly or stressed, there may, in fact, be a tendency to avoid others.

It can be very helpful to make and then to sustain contact with an epilepsy support group. The benefits are well described in: www.epilepsy.com/epilepsy/support_groups

Contact staff at the BC Epilepsy Society about support groups available across BC. At their website at www.bcepilepsy.com/publications_and_resources/Chat_Rooms_and_Forums.aspx you'll find web-based support groups.

If there is a great deal of anxiety in social situations, talking to a mental health professional can be helpful. While many with epilepsy adjust well socially and emotionally, anxiety and depression occur more commonly in those with epilepsy; the rate of suicide is higher. It is important for those with epilepsy, their families and teachers at school to be aware of the risk and if the signs of depression or anxiety are present, to consult with mental health professional.

Conclusion

Reading the above "Five R's" may itself be anxiety provoking. It is important to take stress management step-by-step, control the bodily symptoms and gradually work on the internal attitudes and external environments. Achieving equilibrium means balancing external demands, one's expectations, as well as one's capabilities and capacity. When the demands and expectations do not match, adjustments and compromises will need to occur. Thus, flexibility will be the key ingredient in every step towards overcoming stress. After all, stress management needs a person's readiness, a commitment of the heart, mind, and body to learn, grow and be persistent and patient with the gradual learning curve. Learning to appreciate the small steps of changes and the tiny gains in coping is the essence that would lead to long-term gains of peace of mind and freedom in spirit!

To find out more about stress management generally and as well as stress-related issues for those with epilepsy, the following web sites are recommended:

www.bcepilepsy.com (BC Epilepsy Society)

www.helpguide.org (HelpGuide.org)

[www.epilepsyontario.org/client/EO/EOWeb.nsf/web/Wellness+&+Quality+of+Life+\(kit\)](http://www.epilepsyontario.org/client/EO/EOWeb.nsf/web/Wellness+&+Quality+of+Life+(kit)) (Epilepsy Ontario)

www.epilepsy.com/epilepsy/provoke_stress (Epilepsy.com)

www.cmha.ca/bins/content_page.asp?cid=2-28&lang=1 (Canadian Mental Health Association)

Approved for circulation February 2008 (jz/ah)

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