

...About NEAD Trust

NEAD Trust is a support group for people who have Non Epileptic Attack Disorder and their families. The main purpose of NEAD Trust is to provide some much needed support to people with this condition and allow them to talk to others in the same situation.

The aims of NEAD Trust are:

- To relieve the suffering of people with this condition, through the provision of information, advice and support online, and social contact via our support groups.
- To raise awareness of this condition and what it means to the people who live with this illness every single day.

Our online community has a mix of sufferers, carers and families all of whom help and support each other, pass on advice and information from personal experiences on how to cope with this condition and the life changing effects of it.

www.neadtrust.co.uk
admin@neadtrust.co.uk

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Hints & Tips To Help Reduce Non Epileptic Seizures

How can you help yourself if you suffer from non-epileptic seizures? People often feel quite confused and helpless when they get a diagnosis of NEAD. They are told that it can't be treated with medication and may assume that there is nothing they can do about it. There are, however, a number of approaches that may help you to take control of your seizures and your life.

1. Sensory Grounding

If you are someone who gets a warning before your attacks start, a sensory grounding approach may well allow you either to fight it off, or at least delay it until you are somewhere safer or more private. There are a number of sensory grounding approaches but the one on this web-site (insert link please) has been used and found effective by many NEAD sufferers.

In addition to their non-epileptic episodes, many people with NEAD suffer from anxiety symptoms and panic attacks. Sensory grounding can also be a good way to take control of these.

- It is helpful to practice the technique when you are feeling OK so that you will remember it better when you need it.

- Also explain it to the people close to you, so that they can encourage you to use it if you forget in the heat of the moment.
- Many people find it helpful to carry something rough or textured around with them (e.g. a rough pebble, small nail file) in their pocket or bag to rub in the sensory grounding.

2. Relaxation

It seems that for many people, the more tense they are, the easier it is for non-epileptic seizures to be triggered. If you habitually squeeze your hands together, fiddle with things, tap your hands or feet, grind your teeth or hunch your shoulders, or if you often feel 'wound up' or are easily startled, that is an indication that you are tense. In that case some kind of regular relaxation may be helpful.

- There are many relaxation CD's available commercially, which may go through how to systematically tense and relax your different muscle groups, or may have soothing music, whale song etc.
- Choose whatever works for you, or maybe just stop everything, listen to your favourite 'flop-out' music and give yourself time to unwind.

3. Understand Your Triggers

See if you can start to understand your seizures and what triggers them. A good way to do this is to keep a seizure/emotions diary, where you write down each time you have a seizure when it happened and also what had been

going on in your life that day, particularly things that might have had an emotional impact.

- Also note whether you were feeling tired, ill, where you were at the time, what you were doing.
- If you were watching TV, what were you watching?
- If you were chatting with friends what was the conversation about?

That way you may start to understand triggers that you were not aware of. For some people the seizure comes straight after the trigger for others it could even be the following day.

4. **Don't Be Over Cautious – Look For Solutions Not Problems**

Attacks can be frightening, and some people react to this by stopping many of their normal activities and restricting their lives. In addition family and carers may be anxious about the welfare of a loved one and therefore discourage them from doing things.

If you do this you are likely to feel bored, frustrated, depressed, and to focus all your attention on your illness, so that your stress levels go up. This can put a strain on relationships. The longer you go without going out or doing much, the harder it becomes to start again, and the more depressing life becomes.

- It is better to try to carry on with your normal activities as much as possible.

- Gradually start to do things and become more independent again, finding ways of tackling problems.
- Don't put life on hold until after the attacks stop. The happier and more fulfilling your life is, the better you will feel, and this may well reduce the number of seizures you have.
- So plan outings, arrange treats for yourself, do things that are fun and interesting and have things to look forward to, so that life becomes meaningful again.

5. **Avoid Medical Treatment Where Possible**

Although non-epileptic attacks are unpleasant, and can feel alarming for the sufferer and people witnessing the episode, they are not in themselves dangerous and do not generally need medical treatment.

If you keep getting rushed into hospital this can interfere with you getting on with your life, creates a lot of drama, and may result in you getting treated inappropriately for epilepsy.

- It is helpful to explain in advance to friends, family, workmates or other people who may witness you having an episode, exactly what your attacks are and what they can do to help if you have one (this varies from person to person).
- In general it is not necessary to call an ambulance unless your attack results in an injury or goes on for a long time.
- Some people find it helpful to wear a card round their neck or alert bracelet explaining their condition and giving contact details for partners or family members.

6. Learn To Delegate & Say 'NO'

Are you one of those people who is always there looking after everyone else but no-one seems to look after you? Do people always bring you their problems but you feel you shouldn't 'burden' anyone with yours? Are you continually busy with all the demands and responsibilities you have and never seem to get a moment for yourself? Does it feel selfish if you think of saying 'no' when someone asks you for help, as if you would be letting them down?

Many NEAD sufferers spend all their time looking after others but ignore their own needs for rest, space, enjoyment, support, exercise and a general balanced life. As a result they become stressed, tired and even resentful, and have more seizures. If this applies to you think about your life.

- Do you really need to do everything you are doing?
- Do you have a partner or teenaged children who should be doing more round the house?
- Are there people who would like to give you support if only you asked?
- Are there chores you do that aren't really essential?
- Are there things you are doing that people really should and could do for themselves?

- Talk to your friends and family and see what they think, and try to make space for you - to rest, relax and do things you enjoy.

7. Talk About Your Feelings

Many NEAD sufferers have a tendency to push away or 'bottle up' difficult feelings. They may have been brought up feeling that it was weak or bad in some way to experience emotions, so they never allow themselves to have them. Whatever difficult experiences life throws at them they 'just get on with it'. They may feel that if they started crying they would never stop. Other people do experience strong emotions but only let them out when they are alone, so that they don't 'burden' other people. Others bottle things up for as long as they can, and then explode in an uncontrollable outburst.

However, it is by putting difficult emotions and things that have happened into words, sharing them with others, talking about what is wrong and realising that we are not alone that we gradually start to process our emotions and they become less frightening and more manageable.

When we try to lock things away in boxes and throw away the key, they have a habit of making their presence known, through non-epileptic attacks or other physical symptoms, or through psychological problems such as anxiety and depression.

- So try talking about your worries and feelings to people you can trust.

- If there is no-one available to talk to, writing feelings down can often help, for example in a diary, by writing poetry or just plain writing.
- Support groups and forums such as the NEAD Trust can be a good way of sharing your concerns with other people who understand what you are going through from their own experiences.
- Telephone helplines may also be a good way to unload.

So give it a try. Different things seem to work for different people, and you may well find other approaches that help as well. So use the ones that work for you and start to take control.



Written on behalf of NEAD Trust by
Stephanie Howlett
Specialist Psychotherapist
Dept of Neurology
Royal Hallamshire Hospital