

Information for patients

Taking control of your non-epileptic seizures



Diagnosed with non-epileptic seizures?

Some tips which may help

How can you help yourself if you suffer from non-epileptic seizures? People often feel quite confused and helpless when they are diagnosed with non-epileptic seizures. They are told that they can't be treated with medication and may assume that there is nothing they can do. However, there are many things you can do that may help you to take control of your seizures and your life. Perhaps your friends and family can help as well. This booklet describes some approaches that many people find helpful. It may well take time to learn some of the techniques and to feel the benefits from them, so be patient and keep on trying.

Things you can do

1. Sensory grounding

Do you get a warning before your attacks start? If so something called 'sensory grounding' may well allow you to fight off your seizures, or to delay the seizure until you are somewhere safe or more private. There are a number of ways of doing 'sensory grounding' but the one described below has been found to be helpful by many people.

- It is helpful to practice this 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. Then 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.
- Many people who have non-epileptic seizures also have anxiety and panic attacks. Sensory grounding can be a good way to take control of these too.

This is what you do:

1. Feel something rough or textured, with your fingers and thumbs. Really focus on what this feels like as you rub it harder or softer, or in different directions. As you do this also put your feet flat on the floor and notice how solid the ground feels under your feet. If you are sitting down notice how solid the chair is underneath you.
2. Look around you and really focus on the things you can see. Describe them to yourself in detail.
3. Listen and see what sounds you can hear, e.g. people talking, birds singing, traffic noise etc
4. Remind yourself where you are, what day of the week it is, what year it is, who you are with etc.
5. Remind yourself that you are safe.

2. Relaxation

Many people find that their non-epileptic seizures are more likely to happen when they are tense. If you are tense you may find yourself squeezing your hands together or fiddling with things. You may tap your hands or feet, grind your teeth or hunch your shoulders. You may often feel

'wound up' or be easily startled. In this case some kind of regular relaxation may be helpful.

- There are many relaxation CD's available, which describe how to tense and relax your different muscle groups. Some CDs use soothing music, whale song etc. to help people relax.
- Choose whatever works for you, or maybe just stop everything, listen to your favourite 'flop-out' music and give yourself time to unwind.
- You may find it helpful to put your relaxation CD onto an iPod or MP3 player if you have one so that you can use it wherever you like.

3. Abdominal breathing

Many people with non-epileptic seizures or anxiety attacks find that their breathing becomes difficult or quick and shallow before a seizure. This is called hyperventilation. It can make you feel strange and light-headed and more likely to have a seizure. Abdominal breathing is a way of controlling your breathing. It can help you to fight off a seizure and feel more calm. Practice this at home and then use it whenever you start to think that you are going into a seizure, or if you start to feel anxious or panicky.

This is what you do:

1. Sit comfortably with one hand on your abdomen below the navel.
2. Slowly breathe in through your nose, and as you breathe in feel your stomach expand beneath your hand.
3. Pause for a count of 3.

4. Slowly breathe out through you nose and as you do so think "Relax".
5. Rest for a moment.
6. Repeat for 20 breaths or until you feel back in control.

4. Time out on the spot

This is another good technique to use when you feel stressed or anxious. You can use it anywhere or anytime, and no-one else needs to know you are doing it. Just take a few minutes out of the stressful situation to go to the relaxing place in your mind.

This is what you do:

Think about a place you have been where you felt happy and relaxed. It might be somewhere you have been on holiday or a special place in your home. It should be somewhere where you have felt calm and at peace. Imagine yourself in that place. Picture it clearly and think about what you can see there, what you can hear, how it smells, how it feels to be there. Get the image fixed in your mind so that you can call it up whenever you like.

Now, when you are feeling stressed, imagine yourself opening a door which takes you to this place. In your mind picture yourself stepping into this place and soak up the atmosphere, feel the relaxation wash over you. You just need to do this for a few moments, and then return to where you were or what you were doing before.

5. Understand your triggers

- See if you can start to understand your seizures and what causes them. A good way to do this is to keep a seizure/emotions diary. Write down each time you have a seizure, when it happened and also what had been going on in your life that day. Particularly make note of things that might have made you feel emotional in any way.
- Also notice 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 were you talking 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.

6. Don't be over-cautious - look for solutions not for problems

Attacks can be frightening, and some people react to this by stopping many of their normal activities. So people may stop work and stay in the house most of the time. They may never go anywhere alone, stop using buses and trains and avoid being with people because they are worried about having an attack. If you do this you are likely to get bored, feel frustrated, lonely, depressed, and to focus all your attention on your illness. This can make your stress levels go up, affect your self-confidence and 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 interesting your life is, the better you will feel. 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 plan things to look forward to. This way life becomes meaningful again.

7. Don't let yourself become isolated

Many people with non-epileptic seizures feel embarrassed or ashamed of their attacks. They often don't know how to explain to people what is happening to them. As a result they may stop seeing friends, avoid going to places where there are people around, or even stop going out altogether. This too will make you feel lonely and depressed. It is much better for you to carry on seeing people and may well help your recovery.

- So try to be bold and don't let embarrassment stop you doing things.
- Explain to friends and family that you have non-epileptic seizures.
- Talk to them about your attacks and your worries about them, just as you might with any other medical condition.
- Give them any information you may have about the condition (including this leaflet).

- Tell them what will happen if you have a seizure, and what you would like them to do.
- Use the techniques in this leaflet, such as sensory grounding, abdominal breathing or time out on the spot to help if you feel a bit anxious.
- Make contact with other people non-epileptic seizures through the NEAD Trust (contact details at the back of this leaflet). Find out how they tackle things.
- Try to think about other things and not dwell on your worries about having a seizure.
- Go out, see people and enjoy yourself.

8. Avoid medical treatment where possible

Although non-epileptic seizures are unpleasant and alarming, 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 and creates a lot of drama. It may result in you mistakenly getting treatment for epilepsy which will not do you any good.

- It is helpful to explain in advance to friends, family and workmates 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 causes an injury or does not stop at all.
- Some people find it helpful to wear a card around their neck or alert bracelet explaining their condition and giving contact details for partners or family members. If you would like a card, ask your consultant or psychotherapist and we can provide one for you.

9. Learn to delegate and 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 people who have non-epileptic seizures seem to spend all their time looking after others but ignore their own needs for rest, space, enjoyment, support, exercise and a 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 around 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.
- You deserve it as much as anyone else.

10. Talk about your feelings

Many people who have non-epileptic seizures have a tendency to push away or 'bottle up' difficult feelings. They may have been brought up feeling that it was weak or bad to experience emotions, so they never allow themselves to have them. Whatever difficult things 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. They don't want to 'burden' other people. Others bottle things up for as long as they can, and then explode in an uncontrollable outburst.

However, it is by talking about difficult emotions and experiences and sharing them with others that we deal with our feelings. Talking about what is wrong can help us to realise that we are not alone. It can make emotions feel less frightening and more manageable. When we try to lock things away in boxes and throw away the key, they tend to cause other problems. These may include non-epileptic attacks or other physical symptoms, or 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. This could be in a diary, by writing poetry or just plain writing.
- Telephone help-lines may also be a good way to unload.
- Your thoughts and symptoms may seem strange and frightening. This is not unusual for people with NES. Tell your doctor or psychotherapist about them as it may be very helpful for your treatment.

Things others may be able to do for you...

Your friends and family often feel confused and anxious themselves when their loved one is diagnosed with non-epileptic seizures. They may feel helpless and not know what to do. However, there are many ways that they can help you recover. Here are some of the helpful things they can do.

1. During an attack

It is helpful if your seizures are dealt with in as low-key a way as possible. It is more upsetting and embarrassing for you if each one becomes a major drama.

Your friends and family should:

- Stay calm and try to keep other people from panicking.
- Keep you safe from injury by removing any dangerous objects.
- Move or guide you to a safe place.
- Protect your head by placing some soft clothing underneath it.
- Not try to hold you down or restrict your movements. This can be frightening for you and may cause injuries.
- Speak to you calmly, explaining where you are, what is happening and reassuring you that you are safe. You may be able to hear and feel what other people are doing during an attack and being spoken to calmly may help to make the attack shorter.
- Encourage you to control your breathing using the abdominal breathing technique we have already described in this leaflet.

- Encourage you calmly to try and come out of the seizure.
- Observe exactly what happens in the attacks or if possible video some. Afterwards they should write down what they have observed so that they do not forget any of the details. This can help your doctor with the diagnosis.
- They should not call an ambulance unless you have injured yourself or the attack goes on for a long time. They should also try to stop other people from calling an ambulance.
- If an ambulance is called, explain to the ambulance crew that the seizures are non-epileptic. This helps them to understand how to treat you.

2. Help you to become more independent

Understandably your family may feel anxious about your safety and discourage you from doing things that they feel put you at risk. However, as we have seen, stopping doing things can have a bad effect on your life and actually make your symptoms worse. Your loved ones can help by:

- Encouraging you to do more.
- Not doing things for you that you can do for yourself
- Helping you to find ways of starting to do things that you have been avoiding, e.g. going shopping, travelling on trains and buses.

Although they may find this worrying to start with it is a really important role they can take.

3. Accepting your feelings

The people close to you may also try to protect you by stopping you from getting upset. They may think that this will cause a seizure, or they may just find it hard to see you upset. In fact seizures are often linked to feelings that are not expressed. So if you need to talk about your feelings or have a good cry the best thing that friends and family can do is to:

- Listen, encourage you to talk and try to understand
- Let you cry if you need to
- Give you a cuddle if you want one
- Not rush to find solutions or make it all better
- Take your feelings seriously
- Be patient with you. Some things that seem trivial to them may be very important for you.

4. Take some of the pressures off you

If you are one of those people who are constantly on the go, doing things for other people and never taking time for yourself your family can help by:

- Sharing the household tasks
- Encouraging you to take time off for yourself
- Helping you to plan some enjoyable leisure activities

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

Some helpful contacts

The **NEAD Trust** is a support group for people with non-epileptic seizures and their families and friends. It is run by people who have non-epileptic seizures with the aim of raising awareness of this condition and supporting sufferers and their families. They have an online forum and hold regular coffee mornings in Sheffield. You can contact them on:

www.neadtrust.co.uk

The Samaritans offer confidential support 24 hours a day to people who are going through a crisis or feeling suicidal. You can ring them on:

08457 90 90 90 or contact them by email on **jo@samaritans.org**

CRUSE offer bereavement counselling.
Daytime Helpline 0844 477 9400

Alcoholics Anonymous offer support for people with problematic drinking and their families.
National Helpline: 0845 769 7555

National Domestic Violence Helpline: 0808 2000 247

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