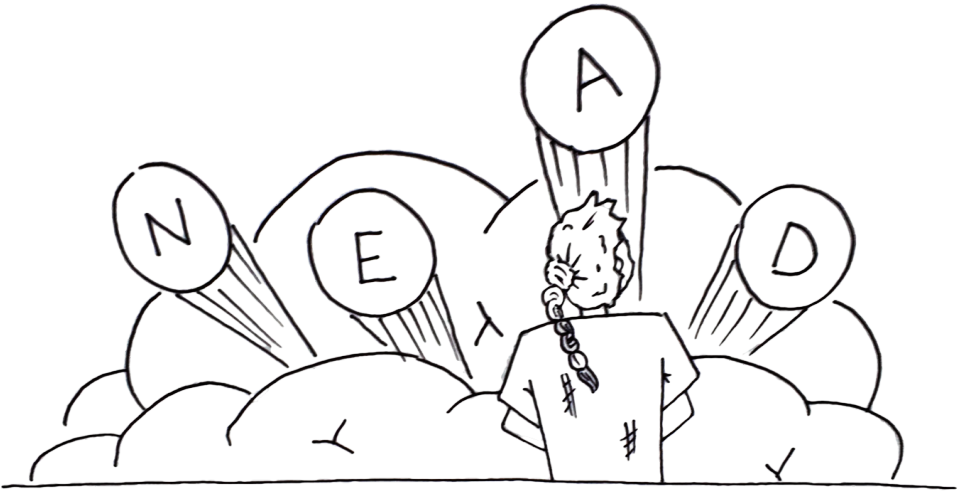


LIVING WITH
**NEUROLOGICAL
SYMPTOMS**
IN CHILDHOOD



**A SELF-HELP RESOURCE PACK FOR
YOUNG PEOPLE, PARENTS AND
PROFESSIONALS ABOUT NON-
EPILEPTIC ATTACK DISORDERS**

JACK GARLOVSKY & CHERYL NEWTON

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This book is a digital and print version of the information contained on the NEUROkid website (www.neurokid.co.uk). For the most up-to-date information please visit NEUROkid online where you can download worksheets, exercises and be kept informed of any new guidance in managing neurological symptoms.

This book has been made to provide young people diagnosed with Non-Epileptic Attack Disorder and their families with more information about the disorder. The information provided is not about other non-epileptic attacks explained by obvious medical causes.

Please do not attempt to diagnose yourself or others as the diagnosis of non-epileptic attack disorder can be difficult and depends on having experience and knowledge of different neurological problems.

You should consult your medical doctor if you have questions regarding symptoms that you are experiencing.

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LIVING WITH NEUROLOGICAL SYMPTOMS (INCLUDING NON-EPILEPTIC ATTACK DISORDER)

Non-epileptic attack disorder or NEAD is a condition that affects some children, teenagers and adults. It involves having seizures, with and without warnings and has lots of different names.

Doctors and other health professionals generally refer to these types of seizures as non-epileptic attack disorder (NEAD), non-epileptic seizures, dissociative seizures, pseudo-seizures, psychogenic seizures (PNES), somatisation, psychosomatic or functional seizures. Unfortunately this can be confusing, but the different names all refer to similar symptoms.

When people have non-epileptic attacks they experience sudden changes in their behaviour and ability to control their body. They are not intentionally having seizures.

This book has been made to provide young people, families, friends and carers with information about NEAD and ways to help living with the condition. There are chapters on understanding NEAD, managing symptoms, getting help and support for families and schools. At the back of the book there are some useful resources to help manage symptoms.

If you would like more information you should contact your GP or medical doctor for advice. You should not attempt to diagnose NEAD using the information here.

1.

UNDERSTANDING NEAD & SYMPTOMS



Non-epileptic attack disorder (NEAD) has a lot of different names. They can be called non-epileptic seizures, dissociative seizures, pseudo-seizures, psychogenic seizures (PNES), somatisation, psychosomatic and functional seizures. Unfortunately this can be confusing, but the different names all refer to similar symptoms experienced by young people.

WHAT IS NON-EPILEPTIC ATTACK DISORDER?

When people have non-epileptic attacks they experience sudden changes in their perceptions (the things they see, hear, and feel) and in their ability to control their body. Other people may notice changes in behaviour or the ways the person acts.

A list of ways this may look can be seen on the next page.

fainting or blacking out
thrashing body
falling asleep
dizziness
shaking body
stomach pains
headaches
feeling distant
blurred vision
body weakness
tiredness
difficulty speaking
looking blank or
becoming unresponsive
memory problems

HOW ARE THEY DIFFERENT FROM EPILEPTIC SEIZURES?

Non-epileptic attacks may look like epileptic seizures but there are important differences.

The brain normally works by sending electrical messages along nerve fibres to carry out tasks. In epileptic seizures the brain produces abnormal electrical messages. These abnormal messages cause the changes in people's experience and behaviour during epileptic seizures. Although non-epileptic attacks look similar to epileptic seizures they have a different cause and there are no abnormal electrical signals.

WHY DO THEY HAPPEN?

Non-epileptic attacks are the brain's response to potentially threatening triggers inside or outside the body. Inside triggers include thoughts, memories, emotions or sensations. Outside triggers include difficult situations but also objects, scenes, sounds or smells which remind the brain of a difficult moment in the past. Sometimes this happens when people feel stressed. However, they can also happen to people who feel calm and relaxed. In most cases people do not know why they have them.

Some young people and their family find it difficult to believe that something as frightening as a non-epileptic attack is not caused by a process that would show up on a brain scan. However, it is well known that emotions can produce physical reactions in the body. For example, everyone has blushed in embarrassment or felt their heart thump in their chest before an exam. Non-epileptic attack disorder may be a way of your body telling you that something is too stressful or difficult to manage.

Some children have both epileptic and non-epileptic seizures. Your medical doctor will have told you which type you have.

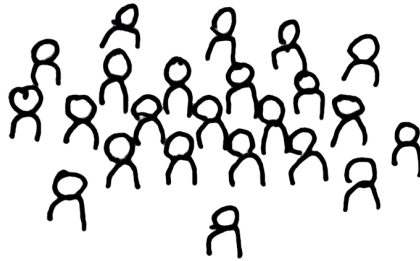
WHY AM I HAVING THEM?

There is no single cause of NEAD. You may have read or been told that non-epileptic attacks are caused by an upsetting experience in the past. However, many young people with NEAD have not experienced any major trauma before developing the symptoms. Sometimes NEAD occurs when young people are struggling to cope with their own or other people's expectations, or when they face difficult choices.

Studies have shown school worry/stress to be the biggest cause for non-epileptic attack disorder in children. However there are other factors that can sometimes be related. These may include: bullying; rejection; family disruptions; conflicts; loss of a family member or friend; significant injury/hospitalisation.

Sometimes the attacks seem to help people deal with their emotions and stress that are otherwise difficult to handle. Often children only have non-epileptic attacks in one place (e.g. school). This can make looking for triggers easier and help to find ways to manage or stop them happening.

DO OTHER PEOPLE HAVE NON-EPILEPTIC ATTACKS?



Yes. In adults we know that for every 1000,000 people, between 15 and 30 have non-epileptic attack disorder. Nearly half of all people brought into hospital with suspected epilepsy turn out to have non-epileptic attack disorder. However, we are not sure how common non-epileptic attack disorder is for young people, but it is likely to be similar to adults.

CAN THEY GET BETTER?

Yes. Children with non-epileptic attack disorder can recover fully and lead normal lives. Children with NEAD are more likely to become seizure free compared to adults with this problem.

Non-epileptic attacks often get a lot better when the diagnosis has been explained, and when young people and their families have had a chance to think about what might have caused the attacks. However, some young people may need extra help to get better.

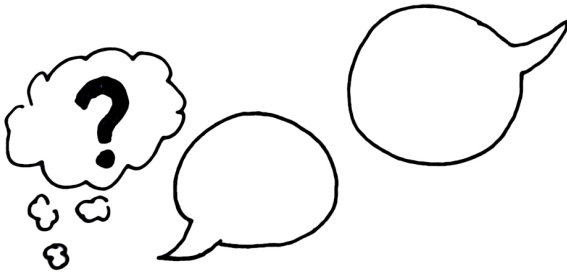
WHAT IS THE TREATMENT?

Non-epileptic attacks are something that the brain has learned to do – a bit like sticking your arms out to stop you from falling on your face when you have tripped up. There are no tablets to stop non-epileptic attacks. However, you can learn to spot situations which are likely to cause the attacks.

You can also learn to spot the first symptoms of a non-epileptic attack giving you more time to stop the attack from happening. Some people can learn to control attacks by changing their breathing or by concentrating on something outside their body. People can also improve by addressing some of the causes of stress in their lives.

All of these things can help the brain to “unlearn” non-epileptic attacks. You can learn these techniques during a course of psychological treatment. Several forms of psychological treatment may help, including Cognitive Behavioural Therapy (CBT) or psycho-education. If non-epileptic attacks are occurring together with other problems such as anxiety, depression or eating disorder, psychological treatment for these problems can also help reduce the attacks.

It is important to remember that psychological treatment is not a quick-fix and can take time to work. Just like physiotherapy, psychotherapy often involves practicing things – starting with something that is easy and aiming for things which are more difficult. Most children who receive psychological treatment for NEAD report improvements of their attacks and quality of life.



2.

GETTING HELP & LIVING WITH NEAD



If you have not yet had a diagnosis of non-epileptic attack disorder, but feel you may have non-epileptic attacks you should speak to your doctor to request further investigation.

If you have a diagnosis, the information in this book can help you to understand and find ways to manage the symptoms that you may be experiencing.

GETTING A DIAGNOSIS

If you/your child do(es) not have a diagnosis of non-epileptic attack disorder and are concerned that you or your child may have non-epileptic attacks you should discuss this with your GP, paediatrician or neurologist and request further assessment.

Assessment involves understanding the symptoms that are experienced by a medical professional and using assessment methods to establish if the symptoms are non-epileptic.

Please do not attempt to diagnose yourself or others as the diagnosis of non-epileptic attack disorder can be difficult and depends on having experience and knowledge of different neurological problems. However, having a diagnosis can help

to understand why you have the symptoms and identify ways to get the appropriate help.

WHO CAN HELP ME?

As we learned on the symptoms chapter, non-epileptic attacks are often a way of our bodies managing high levels of stress, worries and anxiety. There are people who can help you to learn new ways to manage stress and anxiety and hopefully reduce attacks. If you have not already been referred to a specialist who helps people in this way you should ask your doctor if they can request an appointment with someone in your local area.

The following professionals may have been trained to work with difficulties related to symptoms that people with non-epileptic attacks have. They often work in special teams called Child & Adolescent Mental Health Services (CAMHS) or some hospitals. More information about these qualified people and local services can be found on the NHS website (www.nhs.uk).

- Clinical Psychologists
- Psychiatrists
- Psychotherapists
- Occupational Therapists
- Physiotherapists
- Clinical Social Workers



Teachers, parents/carers and other adults may be able to help too. You can point them to the NEUROkid website (www.neurokid.co.uk) or give them a copy of this book to help them learn about your symptoms. There is a chapter just for them!

WHAT CAN I DO NOW?

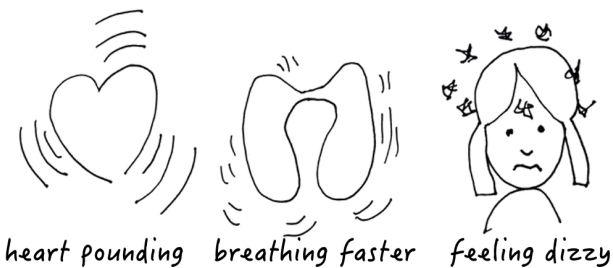
While doctors and other qualified people can help you to manage anxiety, stress and your attacks, there are some things that may help you now. Managing high levels of stress and anxiety has been found to be helpful in lots of young people and adults. If you are having significant difficulty you should speak to your doctor or GP about talking to someone about the feelings or symptoms you may be having.

3.

MANAGING STRESS, ANXIETY & OTHER SYMPTOMS



Everyone can get anxious or experience feelings of panic from time to time. This is a normal part of life. More stressful situations like exams, public speaking and going to a hospital appointment can make our bodies and minds show signs of feeling anxious. This might involve your heart pounding or beating very quickly; breathing getting quicker and more shallow; feeling sweaty and hot; getting dizzy and blushing.



These feelings are caused by our bodies going into a "fight, flight, freeze or flop" mode. As humans our bodies have evolved over time to help us survive dangerous and life-threatening situations (like being chased by a tiger!). When our body thinks that we are in a dangerous place (like before an exam), it releases chemicals like adrenalin and cortisol to

help us get ready to react to what might happen. These chemicals help our body to fight or flight (run away) from the danger. Some people also freeze or flop (faint) when their body thinks that they are in danger.

One way of trying to reduce these feelings is to use techniques to get back in control back of the feelings by slowing our breathing down. This then has a knock on effect to slow our heart rate down and then stop the extra chemicals being made. People have found the following techniques to be helpful in reducing anxiety and their non-epileptic attacks.

HELPFUL STRATEGIES

SENSORY GROUNDING

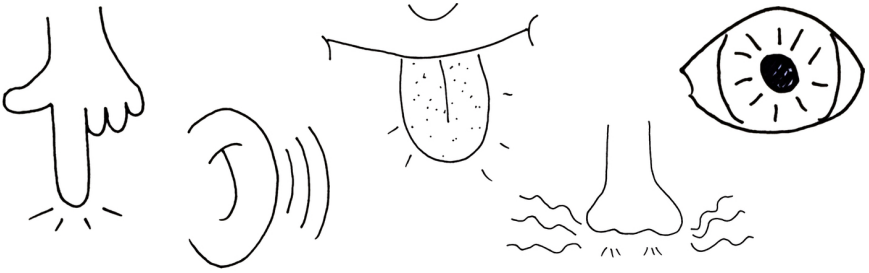
If you get a warning before your attacks you can try something called 'sensory grounding' to try and stop or delay the attack from happening. Sensory grounding involves using your senses to draw your attention back to the present moment and away from the non-epileptic attack. The exercise below is one example of sensory grounding that young people have found useful. It is helpful to try and practise this when you are feeling well so that you can remember what to do when you feel an attack starting.

Sensory techniques can help you to ground in reality using the 5 senses. By changing the sensory input in any of the senses, we can, in a sense, “reboot” the brain and stop feelings of panic, intrusive memories, and other feelings.

To use sensory techniques, follow these important steps:

Focus on your surroundings. Take 3 slow, deep breaths.

Try doing an activity that changes your current experience in any of your 5 senses:



- **Touch.** Varying textures, such as beads, chain, blanket, corduroy clothes, pets (can actually calm and lower anxiety).
- **Hear.** Safe person's voice, music, loud noise, car horn, whistle, dog bark.
- **Look.** What do you see in the room? Name 5 things.
- **Smell.** Flowers, aromatherapy, sharp smells (certain foods), laundry detergent, candles, lotions, bubble bath (added bonus of touch).
- **Taste.** Drink something cold or hot, eat something sweet or sour, suck on ice.

If an activity in one sense does not work, try another. Sometimes it takes a few tries.

After time, you will learn the activities that work the best for you.

Remember, sensory techniques are not intended to stop you from feeling altogether. The goal is to help you stay grounded in the present.

You can find more information about sensory grounding as well as a practise sheet in our sensory grounding worksheet download.

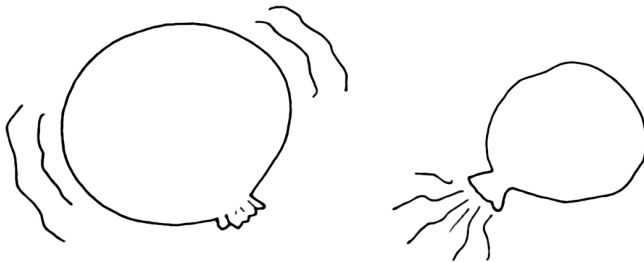
The sensory grounding exercise sheet can be found in Chapter 5.

ABDOMINAL BREATHING

We know that when our breathing gets faster, our heart beats more quickly and we are more likely to experience sensations that may result in an attack. Therefore, one way to reduce attacks is to get control of our breathing. Lots of people tend to breathe from their chests. However, breathing from the abdomen allows you to take deeper breaths and slow the heart rate down, often reducing (and eventually resolving) the uncomfortable feelings of panic. Try to do the following exercise if you find that your breathing can become fast and feel out of control when you have an attack.

Lie down on the floor and put your hands on your tummy.

Pretend that your tummy is a big balloon and that you want to fill it as full as you can.



Breathe in and see how big you can make your tummy. As you do, try counting slowly up to 10. You may need someone to help you at first.

Slowly let the air out of the balloon, counting back from 10. It may sound easy, but try not to let the air out too quickly.

Keep doing this, slowly breathing in and filling the balloon and then holding the air in for a moment. Then slowly letting the air out again.

The abdominal breathing exercise sheet can be found in Chapter 5.

OTHER THINGS THAT CAN HELP

There are many other things that people find helpful to reduce the amount of stress they have and the affect that stress has on them. It is important to think about the different aspects in your life that may contribute to your stress levels and feelings of anxiety. It may be helpful to think about the following:

Try and take the pressure off.

Take time out. It may feel like there isn't time to take a break because there is so much to do. However, if you are feeling that things are getting out of control, making a plan with breaks can make you feel back in control and the breaks allow you to clear your mind and have better focus on the task when you return.

Avoid medical treatment where possible.

Talk about feelings. We know that people's stress, anxiety and attacks reduce when people talk about their feelings rather than keeping the bottled up inside. Try and allocate some protected time with a friend or family member to talk about your feelings. With time, you will learn ways to let the feelings out and reduce the number of feelings you keep inside.

Learn to say no. It is ok to say no to things. It can feel difficult and stressful at the time, but try and think about the increased stress if you say yes to everything.

Don't be over cautious or become isolated. Lots of people become more cautious and remove themselves from social situations when they feel anxious as it feels like the feelings will go away at the time. However, they don't go away and often become worse the more isolated we become. Try and keep seeing people and doing things that you enjoy. The feelings of anxiety usually get less with time.

Learn triggers. As you get to learn if there are any triggers for your attacks, you can then learn which techniques work for you to control the attack or get yourself to a safe place.

Ask for help! - point your parents/carers/friends to this book or www.neurokid.co.uk and speak to people in school about getting support to work with the feelings you may be experiencing.

Find enjoyable things to do. Make sure you do something enjoyable in your week. Look at our list of things to do for ideas.

Some relaxation and activity ideas can be found in Chapter 5.

WEBSITES FOR HELP MANAGING STRESS & ANXIETY

- youngminds.org.uk - a website made for young people about ways to manage things like anxiety and stress.
- epicfriends.co.uk - a website for people looking for help with anxiety and stress by Sheffield Children's Hospital.
- [NHS website](#) - Learn about CAMHS and other services that can provide support in the NHS.

4.

INFORMATION FOR PARENTS, CARERS & PROFESSIONALS

WHAT ARE NON-EPILEPTIC ATTACKS?

When people have non-epileptic attacks they experience sudden changes in their behaviour and ability to control their body. Unlike epileptic seizures, the changes are not due to electrical activity in the brain. More information can be found on the symptoms page.

You may have read or been told that non-epileptic attacks are caused by a significant traumatic event in the past. However, the exact causes for non-epileptic attacks in children are not known. Most research indicates links between psychological distress and seizures, and not necessarily a traumatic event. Studies have shown school worry/stress to be the biggest cause for non-epileptic attack disorder in children.

WHY IS MY CHILD HAVING ATTACKS?

Non-epileptic attacks happen because of problems with managing thoughts, memories, emotions or sensations in the brain. Sometimes this might be due to stress or worries. However, they can also happen to people who seem calm and relaxed. In most cases people do not know why they have them.

Some children have both epileptic and non-epileptic seizures. Your medical doctor will have told you which type your child has.

WILL THEY GET BETTER?

Children with non-epileptic attacks can recover fully and lead normal lives. Non-epileptic attacks can often reduce significantly once the diagnosis has been given, but children often need some extra help in getting better. Children are also more likely to become seizure free compared to adults.

WHO CAN HELP MY CHILD?

There are people who can help your child to learn new ways to manage their stress, worries and anxiety and hopefully reduce or prevent more attacks. If your child has not already been referred to a specialist who helps people in this way you should ask their doctor if they can request an appointment with someone in your local area.

Health professionals such as clinical psychologists, psychotherapists, psychiatrists, occupational therapists and physiotherapists may have been trained to work with difficulties related to symptoms that people with non-epileptic attacks have. They often work in special teams called Child & Adolescent Mental Health Services (CAMHS) or some hospitals. More information about these qualified people and local services can be found on the NHS website.

WHAT CAN I DO?

While it may be difficult, acceptance of the diagnosis is key to helping your child get better. It is also important to recognise that the physical symptoms are real and your child is not deliberately making them happen.

Like epileptic seizures, non-epileptic attacks are frightening to see. However, it is best to try and keep calm and make

sure the child having the attack is safe from injuring themselves.

Remember that non-epileptic attacks do not cause any damage to the brain, even if they go on for several minutes.

Speak calmly to the child having the attack; non-epileptic attacks often stop more quickly if the child having is addressed in a calm and reassuring way. Your child may be able to tell you what is helpful to them.

You should only call an ambulance if you think that the seizure is epileptic. When a diagnosis of non-epileptic attack disorder (without epileptic seizures) has been made, it is not necessary to call an ambulance even if the seizure lasts more than five minutes. You may wish to ask your child's doctor about this.

WHAT CAN MY CHILD DO?

While doctors and other qualified people can help your child to manage anxiety, stress and attacks, there are some things that may help you and your child now. Managing high levels of stress and anxiety has been found to be helpful in lots of young people and adults. If your child is having significant difficulty you should speak to your doctor or GP about talking to someone about the feelings or symptoms they may be having. More information can be found on our strategies page.

GETTING HELP IN SCHOOL

If a diagnosis of NEAD has been made, it is important that school staff are aware of certain key information in order to understand the problem and best help the them. General information in the previous chapters can also be useful for

school staff, to allow them to provide optimal help for young people with NEAD.

They may look like epileptic seizures, but brain electrical activity is normal during a non-epileptic attack, in contrast to what happens during an epileptic seizure.

Non-epileptic attacks are often linked to emotions and may represent difficulties in expressing feelings and/or in dealing with stressful situations. In children with NEAD, scientific studies have indicated an important role for stress associated with school. Challenging life events can also trigger non-epileptic attacks. In some cases, a traumatic event in the past may also play a role.

When a non-epileptic attack occurs at school, and when the diagnosis of NEAD has already been made by healthcare professionals, it is usually unnecessary to call an ambulance.

During a non-epileptic attack at school, it is important for school staff to stay calm, remembering that even if the seizure may look quite dramatic, there is no risk of brain damage. Staff should remain with the child to reassure them and to make sure that there is no risk of injury.

After a non-epileptic attack has finished, it is important to allow the child to gradually recover in a quiet, calm place before returning to the classroom. Most of the time, it is not necessary for the parents or carers to take the child out of school.

The occurrence of a non-epileptic attacks can be a warning sign for the school to be particularly vigilant for any signs of school anxiety, for example related to academic pressure, social isolation or bullying.

The school should inform parents as soon as a diagnosis of NEAD is suspected or made.

USEFUL WEBSITES ABOUT NEAD

There are currently very few online resources for young people with non-epileptic attack disorder. However, there are several websites that have been made to help adults, with some listed below.

Remember that the websites related to adults and the symptoms and causes listed may be different for young people as there is much less known about non-epileptic attack disorder in children.

nonepilepticattacks.info

a website for adults with NEAD by our colleagues at Sheffield Teaching Hospitals

nonepilepticattackdisorder.co.uk

a community run website with information about NEAD by people with NEAD (adults)

neurosymptoms.org

a website (more specifically for adults) on management and adjustment to neurological symptoms including NEAD

5.

WORKSHEETS

Sensory techniques can help you to ground in reality using the 5 senses. By changing the sensory input in any of the senses, we can, in a sense, “reboot” the brain and stop feelings of panic, intrusive memories, and other feelings.

To use sensory techniques, follow these important steps:

Focus on your surroundings. Take 3 slow, deep breaths

Try doing an activity that changes your current experience in any of your 5 senses:

1. **Sight** – What do you see in the room? Name 5 things.
2. **Taste** – Suck on candy, drink something cold or hot, eat something sweet or sour, suck on ice, gum
3. **Touch** – Varying textures, such as beads, chain, blanket, corduroy clothes, pets (can actually calm and lower anxiety), a safe person w/ permission
4. **Smell** – Flowers, aromatherapy, sharp smells (certain foods), laundry detergent, candles, lotions, bubble bath (added bonus of touch)
5. **Hear** – Safe person’s voice, music, loud noise, car horn, whistle, dog bark

If an activity in one sense does not work, try another. Sometimes it takes a few tries. After time, you will learn the activities that work the best for you.

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Lots of people tend to breathe from their chests. However, breathing from the abdomen (our belly) allows you to take deeper breaths and slow the heart rate down, often reducing (and eventually resolving) the uncomfortable feelings of panic.

Try to do the following exercise if you find that your breathing can become fast and feel out of control when you have an attack.

1. Lie down on the floor and put your hands on your tummy.
2. Pretend that your tummy is a big balloon and that you want to fill it as full as you can.
3. Breathe in and see how big you can make your tummy. As you do, try counting slowly up to 10 (you may need someone to help you at first).
4. Slowly let the air out of the balloon, counting back from 10. It may sound easy, but try not to let the air out too quickly.
5. Keep doing this, slowly breathing in and filling the balloon and then holding the air in for a moment. Then slowly letting the air out again.

Taking up a hobby – people who find school or college stressful often find having a hobby can help them switch their brains off from work pressures when they are back home. For example, if you are drawing or painting, you are thinking about what your fingers are doing rather than the essay that needs handing in next week. Often when you go back to the thing that you were finding stressful, you can then cope better having taken a break.

Aerobic Exercise – exercise where the heart rate is increased releases endorphins which make you feel good. Exercises could include going to the gym or sport such as football or netball but could also include cycling, skate boarding, surfing, riding a horse, swimming – think about the type of things you are interested in and build your exercise around that. (See our section on exercise below.)

Walking – walking also releases endorphins but can also help you to switch off from pressures as you take in the scenery around you and get into a steady rhythm – and can be a far more pleasant way to travel than on a stuffy tube or busy loud bus which in itself can be stressful. Getting fresh air also helps you to relax and sleep better.

Yoga – yoga, tai chi and pilates are designed around relaxation and breathing techniques which can all aid relaxation.

A warm bath – it sounds simple but a nice warm bath helps the muscles relax and encourages a general feeling of relaxation. Aromatherapy candles or bubble bath could also help your mind to relax and some people find listening to chilled music while you are having a soak helps. Watching a film or reading a book – escapism is a great way to switch off from reality for a while and help the mind to relax.

Meet a friend – leaving the stressful situation you are in and talking things over with a friend or even chatting about something completely different from what caused the stress can take your mind off things and aid relaxation.

ABOUT THE AUTHORS

Dr Jack Garlovsky is a Paediatric Clinical Neuropsychologist and works in the Psychology Department at Sheffield Children's NHS Foundation Trust.

Dr Cheryl Newton is a Consultant Clinical Neuropsychologist and works independently, having previously worked in the NHS.

We both work with children and young people with a range of conditions including non-epileptic attack disorder. We have experience working with young people and their families in adjustment and management of the condition and have provided the information on this book and on the NEUROkid website to help young people and their families understand more about non-epileptic attacks and learn ways to manage the condition.

If you have questions about the condition you should consult your medical doctor or professional that you are working with.