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## Treatment advice for Dissociative Attacks (Non-epileptic attacks/seizures)

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If you haven't read them yet, have a look at the sections on **Seizures/ Attacks** at <a href="https://www.neurosymptoms.org">www.neurosymptoms.org</a> before you read on:

# Step 1 - You must understand and believe the diagnosis!

It is essential to gain an understanding of what Dissociative attacks are (and what they are not). The key elements are

- Due to a trance like state in the brain, not an abnormal electrical storm as seen in Epilepsy
- They are not due to a brain disease but they do not mean you are going mad or 'losing it' either. They don't fall neatly in to any category
- Do not result in serious physical injury (although can cause bumps and bruises)
- Can be slowly improved by a process of self-help and learning techniques to avoid them in the majority of cases.

Its essential that you feel the doctor has looked in to your case properly and come to the correct diagnosis.

If you feel angry with your doctor you need to spend longer trying to understand why they have made this diagnosis. It could be that they have explained it badly to you or are actually not sympathetic. Or it could be that they are sympathetic and you have been oversensitive in the way that you understood it.

#### If:

- You don't think the diagnosis is right because the doctors haven't been careful enough
- You think the doctors have been careful but you can't accept that there isn't some kind of neurological disease there or
- you can't help feeling that everyone is blaming you for the attacks

Go back to the beginning!

Treatment will not work while you feel so unhappy with the diagnosis. Talk to your doctors, read more about the condition on the website, maybe read through some patient stories or have a look at the NEAD trust website (www.neadtrust.co.uk)

If you are moderately confident that this is the right diagnosis then read on....

# Step 2 – Learning to recognise warning symptoms

The majority of patients with dissociative seizures have a warning before their attacks - not every time, and often its brief just lasting a few seconds.

Some patients have a warning but are unable to recall it after the attack. Sometimes a friend or relative will be aware of a warning even if the patient isn't

Some patients never have a warning and never become aware of it.

But learning to recognise the warning symptoms can be a key factor in learning to gain control of these attacks

During the attack you are losing control of your body. The aim of treatment is to find strategies to help you regain control.

A really important study of patients with dissociative seizures from London recently showed what kind of symptoms they can have in this warning phase (see table below). The authors compared patients with dissociative seizures to patients having epileptic seizures. They showed that symptoms of chest pain, heart racing, shortness of breath, sweating, numbness or tingling or a feeling of 'going crazy' were very common before attacks in patients with dissociative seizures.

These are all symptoms of 'fight or flight' when you have an adrenaline rush. They are also seen during panic attacks. They are symptoms of your nervous system being on "red alert".

	Dissociative Attacks (25 patients)	Epilepsy (19 patients)
Chest Pain	44%	5%
Pounding Heart	60%	26%
Shortness of Breath or	64%	32%
Smothering		
Sweating	64%	32%
Numbness or Tingling	68%	37%
Feeling that you are going crazy or 'losing it'	44%	16%

Table 1. Patients with dissociative seizures often have symptoms that suggest they are going in to a state of "red alert" prior to the attack (from Laura Goldstein and John Mellers and .lctal symptoms of avoidance behaviour and dissociation in patients with dissociative seizures. Journal of Neurology, Neurosurgery, and Psychiatry 2006;77:616-621)

The same study also showed that patients with dissociative seizures were much more likely to develop a fear of going out alone, or being somewhere where there are crowds, or where escape might be difficult. Often this happens because patients fear the embarrassment or fuss that might be caused by an attack.

Patients with dissociative seizures also sometimes feel concerned about the consequences of an attack. "Perhaps after one of these attacks I might not come round?", "Perhaps I might be left disabled, or 'out of control' in some way".

Sometimes the dissociative seizure is your body's way of "getting rid" of the horrible feelings you have during the warning phase. Its not that you are deliberately blacking out but the blackout does at least bring the warning symptoms to an end and sometimes this is how a pattern of blackouts gets established.

So, you might ask, how does all this help?

If you can learn to recognise your warning symptoms, even if they only last a few seconds, you may, over time, be able to learn how to control them sufficiently to avert an attack and regain control of the situation.

## **Step 3 – Learning to Avert Attacks**

What can you do to try to intervene when you get warning symptoms

# 1. Don't be alarmed! - are you having alarming thoughts when you get these symptoms?

These may be some of the thoughts you are having -

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"will I injure myself?"
"am I 'losing it?"
"will this be really embarrassing?"
"Is this epilepsy?"
"Might I die during an attack?"
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There are answers to all these questions which are not as bad as you think

but serious injury doesn't happen. Part of you is aware during the attack, but you cannot remember it afterwards. This part of you will prevent really serious injury happening to you (or others, for example a baby)
"am I 'losing it?"No, you are losing control temporarily but you are not going crazy or mad
"will this be really embarrassing?"Perhaps a bit, but is it really worth avoiding all the things you like to do because of that?
"Is this epilepsy?"No - if you're not sure why not then ask your doctor
"Might I die during an attack?"No - this has never happened

"will I injure myself?" ......Possibly, bruises and bumps are common

### 2. Try to distract yourself

The warning symptoms may 'rush over you' and it may be hard to focus on anything else but try to. In those few seconds before an attack your thoughts may be overwhelmed by the physical sensations you are feeling.

If you can learn to focus o something else or distract yourself this may help. For example

- a. Count backwards from 100 to 0 in sevens, "100,93, 86, 79" or fours "100,96,92 etc"
- b. Pick up a magazine and start reading it
- c. Talk to someone
- d. Try playing a computer game on a mobile phone or some other device
- e. Try singing a favourite song

these are the kind of techniques that a psychologist can help you learn. They are also used to help people overcome panic attacks. Panic attacks and dissociative attacks are not one and the same thing. But they often have a lot in common, they are a bit like cousins

Another technique developed by researchers in Sheffield specifically for patients with dissociative seizures is called Sensory Grounding. (figure courtesy of Stephanie Howlett and Markus Reuber, University of Sheffield)

### Helpful procedure for dealing with threatened seizures or panic attacks

It is a good idea to practice this regularly when you are feeling OK so that when you really need it you will remember exactly what to do. Then as soon as you get a seizure warning or start to panic:

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

FIGURE 1. Sensory grounding approach.

### 3. Get other people to calm down

One problem can be that when you have an attack, people round about you become alarmed on your behalf. They may benefit from reading this website too. Even though you can't remember the attack, part of you is aware during the attack. If people around you are upset this will make you worse.

People around you should: Stay calm, supportive, make sure you have space around you, not put anything in your mouth, wait for the attack to settle and encourage you to get back up afterwards. You may even be able to carry on with what you were doing before, at work or at college for example.

# Things that indicate you are making progress with these techniques include:

- 1. You start to have more warnings. Often people have more warnings when the attacks first start. As they continue warnings may get shorter and shorted until they are not there at all. Sometimes people do get warnings which they forget as part of the attack. Relatives or friends may notice them going a bit blank or being unusually tired beforehand. As you learn more about the attacks it is possible to become aware of a warning phase that you had previously not known about.
- 1. You recognise the warning symptoms but are less alarmed by them. Understanding your diagnosis, understanding what dissociation is and what 'fight or flight' symptoms are can have the effect of reducing your overall alarm at the situation when it happens
- 2. Your warning symptoms are getting longer. This is one of the aims of treatment. The longer you can tolerate the warning symptoms without the blackout taking over, the close you are to eventually gaining control of them
- 3. You begin to avert some of the episodes. By learning to distract yourself or be less alarmed by the symptoms you may discover that you only have the warning symptom and not the blackout. If you can start to do this you are definitely making progress.
- 4. You have an attack when you remain conscious throughout. This can be frightening for patients who are usually unconscious or amnesic for an attack. But if this happens to you it shows that you are starting to get more awareness of the episodes and is a step in the right direction

# But I don't understand what sets my attacks off?!

Patients with dissociative seizures are often really puzzled by the apparently random nature of their attacks.

Often they are completely random but sometimes they are less random than you might think. The commonest situations in which dissociative seizures occur are

- 1. Sitting or lying at rest, not really doing very much. In this resting state, your body is much more vulnerable to going off into an attack. In this resting state your brain is not focusing or distracted by other things. Its easier to be aware of physical sensations like breathing, heart beat or dizziness
- 2. In crowded situations / places where escape is difficult. Even if you are not consciously thinking about it, some patients with dissociative seizures will be more likely to have an attack in situations where the consequences of the attack will be more marked. Often this is crowded places, because having an attack in a shopping centre or a cinema for example, is likely to be more embarrassing than having one at home. The more you anticipate the possibility of an attack and its adverse consequences the more likely it is to happen
- 3. **Triggered by thoughts and memories**. Some patients with dissociative seizures can come to realise that their attacks are actually triggered by unpleasant memories and thoughts
- 4. **In medical situations.** Patients often have attacks waiting to see the doctor or in the consulting room. This seems to be because of the anticipation of having to talk about the attacks with a doctors and simply thinking about them. Doctors sometimes think that patients are 'acting up' when they have them in these situations, not really understanding the usual reason for this.

When you are really feeling stressed, for example having an argument or rushing to get somewhere, your brain is often too distracted for the attack to take over. This is why dissociative seizures often don't occur when people are really stressed about something else.

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PLEASE NOTE: I cannot undertake to give advice to individual patients by email.

Sorry - I also do not carry out private practice. I hope this advice is of some help to you.