



Syncope Trust And Reflex anoxic Seizures®

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Cognitive Behavioural Therapy for chronic health conditions



Working together with individuals, families and medical professionals to offer support and information on syncope and reflex anoxic seizures

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Registered Charity No. 1084898

Glossary of terms

Chronic illness A condition that is long lasting in its effects or constantly recurring

Counsellor A person trained to listen to people's problems and to help find ways of dealing with them

Deconditioning The loss of muscle tone and function due to chronic disease

National Institute for Health and Care Excellence (NICE) Provides national guidance and advice to improve health and social care

Physiology The way in which a part of the body functions

Postural Tachycardia Syndrome (PoTS) Defined as an increase in heart rate of over 30 beats per minute when standing upright but without a fall in blood pressure

Psychological A term used to describe a condition relating to or arising from the mind or emotions (brain)

Reflex Syncope One of the most common forms of syncope

Syncope A medical term for a blackout that is caused by a sudden lack of blood supply to the brain

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What is Cognitive Behavioural Therapy (CBT)?

Cognitive behavioural therapy (CBT) is a structured talking therapy that can help us to accept and adjust as best as we can to our condition. It is not a cure but it can help improve recovery, ability to function and quality of life.

Therapy can be particularly useful in helping us cope better with some of the very real and frightening symptoms of reflex syncope, postural tachycardia syndrome (PoTS) and related conditions (such as a racing heart, chest pain, and dizziness) in such a way that prevents any anxious responses to these sensations causing them to get worse. It can help us cope better with the unpredictability of an illness. It can address stress that illness places on relationships with others.

CBT can help if our mood is or has become low. When our mood is low we often have distorted negative thoughts about ourselves, the world and the future. With chronic illness, we are often facing a type of grief – a loss of a future that we had hoped for ourselves. We may have frustrations about the time before diagnosis when we were not believed, or misdiagnosed with conditions such as anxiety or panic disorder.

The CBT approach helps us understand that it is not the bare facts of a situation alone that causes how we end up feeling. Even when it comes to very genuine difficult life-events, it is the way that we have learnt to think and respond to a situation that affects how we eventually feel. Our ways of thinking can become such habits that they feel like 'the truth' but, with practise, we can choose to notice these unhelpful patterns and to change them to help us feel better.

In essence CBT aims to teach us to be a better friend to ourselves in terms of what we do and how we talk to ourselves.



Are you suggesting it is all in my head?

Experience suggests that a referral to seek psychological support is often easier to accept when it comes from a trusted healthcare provider who is involved in our care. Unfortunately many individuals prior to correct diagnosis have had symptoms misdiagnosed, often as 'all in their head' (e.g. 50-80% of patients). As a consequence, any suggestion by a medical professional to seek psychological support can be misinterpreted as a trivialisation and misunderstanding of the physical nature of an illness, leaving some of us reluctant to access this important form of support.

This is similar to patients with illnesses that are not caused by deconditioning, requiring input from physiotherapy services to prevent future deterioration and to adjust to the changes wrought by their illness. In the same way, patients with illnesses not begun by psychological processes can benefit enormously from psychological support going forward.

Some issues that could be addressed in CBT

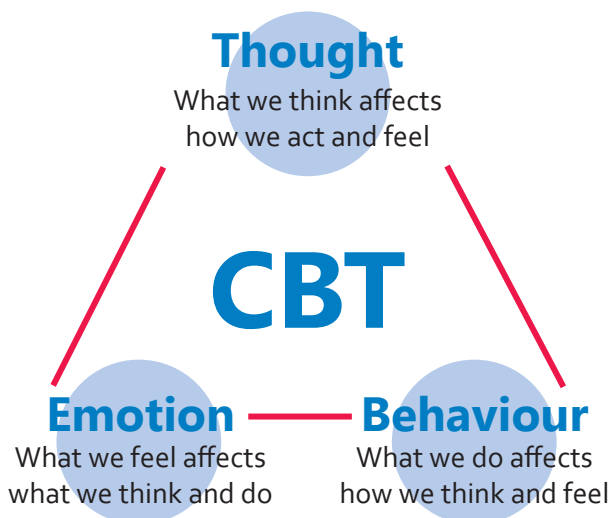
- Adjusting to the unpredictability of the illness
- Coping with scary physiological sensations
- Strategies for switching off fight/flight mode
- Managing pre-existing or associated anxiety or mood/adjustment disorders
- Grief associated with loss of health and life/relationship changes
- Activity pacing
- Sleep difficulties
- Relationship difficulties
- Self-esteem and self-compassion
- Shaking off an illness-identity
- Acceptance, values-based living, and living optimally

What can I expect from CBT?

A good therapist should take time to help you understand how the treatment will work, address your questions and identify your goals. In terms of behavioural changes this might include working towards accepting your limitations, adjusting to the unpredictability of chronic illness, and helping you pace yourself to achieve the challenges of daily-living, whilst still maintaining activities which most help you feel positive and fulfilled.

A therapist should help you become aware how thoughts or cognitions about having a long-term illness or disability can influence your mood and even your symptoms.

Although there may not be many therapists who have experience working with PoTS and syncope, practitioners experienced in working with patients with other long-term health conditions should be able to adapt their approach usefully to your particular situation. A good clinician will take time to read relevant information to understand the condition more fully if you can provide it.



Finding a therapist

Your GP should be able to advise you how to access a suitable NHS therapist in your area. The British Association of Behavioural and Cognitive Psychotherapies (BABCP) keeps a list of accredited therapists and has a search facility on their website. Psychologists should be registered with the Health Care Professionals Council.

Successful therapy is a lot about finding a therapist you feel comfortable with. Therefore, it is reasonable to take time and therapist-shop (a little!) to seek out someone with whom you have confidence and with whom you feel you can establish a good working relationship.

Although everyone's needs are different, a good CBT therapist can support you in finding optimal ways to look after your mental and physical needs, getting you in the best shape to manage your condition most effectively.



But don't I need a real doctor helping me?!

Health providers are increasingly recognising that the separation that we attempt to make between mental and physical health is unhelpful. Recent NHS initiatives *No Health without Mental Health (2007)* and *Investing in emotional and psychological well-being for patients with long-term conditions (2011)* continue to prioritise and increase funding for psychological support for chronic and acute physical health conditions. Hopefully in the future physiological and psychological support will be routinely provided together.

We are yet to fully understand how trauma, inflammation, our genes, physiology, hormones, our gut microbiome, things that stress us, thoughts, expectations, social supports and other physiological and functional processes work together to determine our health outcomes and recovery. It is likely that there is a unique 'illness thumbprint' for everyone.

During the next decade ongoing research might hopefully bring us closer to some understanding. In the meantime it seems sensible to positively influence all the aspects of that complex process that are under our control.

Therefore, it makes sense to enlist the support of an experienced therapist to optimise our behaviours and thinking patterns, reduce our stress and prioritise rewarding relationships with those around us.

So, yes, you do need a real doctor helping as part of a team you can trust, so that you can take the lead in co-ordinating and managing your illness positively.

Evidence for the benefits of CBT

There is very little published in medical journals about the effectiveness of CBT for PoTS, syncope or reflex anoxic seizures (RAS). There are some case-reports, unpublished studies, and patient survey data that are suggestive of benefits to quality of life and functioning, and some good research being undertaken currently.

There is good and extensive evidence, however, on the effectiveness of CBT for other physical health conditions. The impact of chronic obstructive pulmonary disease (COPD) on quality of life has in research been equated with the impact of PoTS, and in both disorders patients have to manage unpleasant physical symptoms which can be easily confused with, and escalated by, anxiety. The benefit of CBT with this population has been well evidenced. CBT has proved efficacious in terms of quality of life, treatment adherence, mood and even disease progression in physical health conditions including cancers, multiple sclerosis and diabetes.

As evidence accrues that changing our thoughts can have a demonstrable influence on not just our brain-chemistry but also our physiology (and vice-versa), it seems increasingly sensible that improving our mental health can have an impact on our physical health.

The 5 Elements approach to managing your condition

water

Achieving adequate **hydration** (water and salt) nutrition

fire

Passions and interests: relationships, inner-strengths and value based living

earth

Physical: stretching and exercise, grounding exercises and mindful living, core-strength, counter-manoeuvres

air

Calm: sleep/wake cycle, breathing, managing unhelpful thoughts, ways to switch off, fight/flight

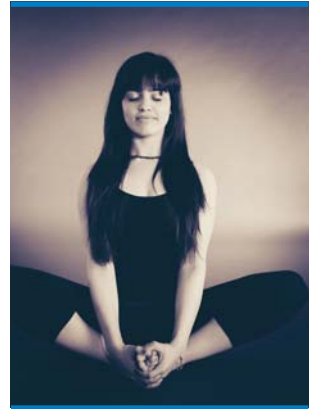
chemistry

Pharmacological support if needed

What about other therapies?

Although CBT has been most extensively researched and is recommended by NICE guidelines as the first choice psychological therapy for many physical health conditions, other types of treatment can also be beneficial. To a certain extent therapy approach is a matter of individual preference.

Many CBT practitioners also incorporate 'third-wave' therapies such as mindfulness-based CBT, Acceptance and Commitment therapies and Compassion-focused approaches. As they are new, evidence about their effectiveness is limited. However it is clear that meditation and mindfulness (being fully present, in the moment, with acceptance), can have a profound effect not just on stress-management and energy-levels but also on physiological processes including blood pressure, heart-rate, blood sugar regulation and even a measurable effect at the cellular level in cancer patients.



Cognitive behaviour therapy (CBT) is the psychological approach whose effectiveness has been most clearly established in research trials, and for this reason it is recommended as the treatment of choice by NICE for a wide range of physical health conditions. Some more recent variants of CBT, especially those which incorporate ideas of mindfulness and acceptance are increasingly being advocated. More traditionally associated with eastern philosophies, these have been demonstrated to have direct impacts on our physiology, as well as patient-reported quality of life.

Mindfulness based CBT (MBCBT) was originally developed to support an individual's long-term recovery from depression. Mindfulness is defined as paying attention to what is happening in the present moment (in the mind, body and external environment) with an attitude of curiosity and kindness.

Meditation is one technique to practise this type of attention, in order to use it in day-to-day life. For patients with PoTS and syncope it can be useful to help notice calmly, and respond helpfully, to symptoms. In emphasising that we can always 'deal' with things as they come up in the present moment, MBCBT can also help to resist getting drawn into unhelpful and distressing thoughts about the future, or 'if things get worse than they are now'.

Acceptance and Commitment Therapy (ACT) places great emphasis on the need to accept those difficulties and hardships which are out of our control, and which are an inevitable part of life. This does not mean giving up. Rather the approach feels that only when we accept, can we stop throwing energy uselessly at what we cannot change. Then instead we can consciously choose to direct our precious and limited time and energy to things which will improve our quality of life, and give us purpose and meaning. It is easy to see how these skills can be very useful in adjusting to long-term health issues.

There are many other therapeutic approaches which may be of help to people experiencing PoTS and syncope. You are probably now only too aware that there is rarely a 'one size fits all' with any aspect of varied conditions such as PoTS and syncope! We are all individuals and will vary in what language suits us and what we find helpful. Some people may prefer psychodynamic approaches which explore the effect of early childhood on the adult's responses. Perhaps most important is finding a therapist and approach which you can have confidence in. That is perhaps the essential factor to help to navigate as well as possible the inevitable fears, difficulties and adjustments that PoTS and syncope symptoms lead to at times.

Introducing this support as early as possible following a diagnosis is likely to be a very important factor in preventing quality of life deterioration and associated 'secondary factors' which can otherwise follow, such as reactive depression, anxiety, and avoidance-related physical deconditioning.

Will CBT work for me?

To reap the full benefit of therapy generally requires a patient to be committed to engaging fully in sessions and tasks between sessions, to have some hope or confidence in the approach and, guided by their therapist, be able to gain good insight into the consequences of their thinking styles and behavioural patterns.

It can be very hard-work making all the necessary life-changes to live with a chronic illness. It can help to know that after all their hard work, and adjusting to what they cannot do, while focusing on what they can do, many patients will report enjoying happy and fulfilling lives.

As with many long-term health conditions, although we would never wish them upon ourselves or others, a positive outcome can be a new appreciation for the things that really matter to us and an opportunity to re-establish priorities and live life thereafter to our full potential.



STARS

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Please remember that this publication provides general guidelines only. Individuals should always discuss their condition with a healthcare professional.

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