

Information Sheet

PSYCHOGENIC NON-EPILEPTIC SEIZURES (PNES) FOR MENTAL HEALTH PROFESSIONALS

A Definition of Psychogenic Non-epileptic Seizures

Psychogenic nonepileptic seizures (PNES) are episodes involving involuntary movements, alterations in consciousness, or both, without changes on an electroencephalogram (EEG, a test to record electrical activity of the brain). PNES may present with stiffening, jerking, flailing, or writhing movements of part or all of the body, and may be associated with an inability to speak or respond to others during the seizure. This may last seconds to minutes, or more rarely up to several hours. PNES are caused by psychological factors such as high levels of stress and as such are a psychiatric disorder. Importantly, it is no longer necessary to identify an underlying psychological cause to make the diagnosis of PNES, as these factors may not become apparent until extensive psychotherapy is completed. PNES are commonly diagnosed in epilepsy monitoring units. Alternative labels for PNES include “pseudoseizures” (now in disuse), dissociative seizures, and “nonepileptic attack disorder” (NEAD).

PNES constitute a category of conversion disorder or functional neurological symptom disorder (FNSD) -- specifically FNSD with attacks or seizures -- within the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-V). Under the International Statistical Classification of Diseases and Related Health Problems (ICD)-10, PNES are coded as F44.5, a subtype of conversion and dissociative disorders. A history of psychological trauma is frequently identified in these patients; with one-third fulfilling criteria for post-traumatic stress disorder (F43.1). The vast majority of PNES are outside of patients’ conscious control and seriously disrupt patients’ lives.

How is the diagnosis of PNES made and confirmed?

PNES are diagnosed by neurologists (usually epilepsy specialists) using clinical history, and ideally, simultaneous EEG and video recording of the episodes. While semiology (how a seizure looks) may be highly suggestive of PNES, video EEG, usually performed in a specialized inpatient epilepsy monitoring unit, is the gold standard for diagnosis. The diagnosis is made with a high level of certainty when the typical episode is recorded simultaneously on video and EEG, and the study does not show epileptiform brain wave activity before, during, and after the captured episode.

There are infrequent exceptions, where certain epileptic seizures, such as those coming from the frontal lobe or a very small area of the brain, (often with preserved awareness), may occur without changes on EEG.

If there remains continued uncertainty regarding the seizure diagnosis, changes in how the episodes look, or persistent concerns that the patient also has epilepsy, then referral back to the neurologist for repeat video EEG recording may be indicated.

Recommendations for managing a seizure in the psychotherapist's office

It should be noted that patients will not necessarily have a psychogenic episode in the therapist's office and if one does occur, these typically do not last longer than a few minutes.

Upon meeting the patient, the therapist should obtain a detailed description of the patient's episodes and jointly develop a plan for how to respond to PNES in the office. Obtain a patient's emergency contact information, too.

Some suggested questions: What do your episodes look like? How long do they typically last and how soon before you return to baseline? Do you have a "warning" before an episode occurs (e.g. feeling hot or sounds appear to be distant)? Should you sit on the floor or away from furniture? Is there anything I can do that might be helpful to you during the episode?

Should an episode occur in the office: Do not leave patient alone or have patient leave the office until recovered. Many patients can hear during the episode, so for most adult patients, you can continue speaking in a calm voice until the episode resolves. For children, it is usually best not to speak until the episode has resolved.

Unless the patient sustains an injury, the episode is notably different than typical episodes, or the patient is not responsive for an extended time, avoid calling emergency services. Most psychogenic episodes resolve on their own and often the therapy sessions can continue. If the patient typically experiences prolonged episodes, it might be useful to ask the patient to come to the appointment with a caregiver.

Recommendations for seizure management in daily life (e.g. work and school settings)

It is important for school and work staff to respond consistently to PNES. In most schools, the school nurse has the primary responsibility of responding to the episodes and/or training other school staff on the response plan. Clear and direct communication with the school is necessary. In the work setting, management of the episodes will depend on the individual's willingness to disclose the diagnosis to their manager. A plan for who will respond to the episode and then monitor the individual should be developed.

In both settings, the individual with PNES needs to accept responsibility for self-monitoring and identifying when feeling overwhelmed or when an episode is coming on. Short breaks during the day to use relaxation strategies may be necessary. The response plan will need to be modified based upon the environment and the comfort level of those responding to the episode.

Key principles are: the PNES will resolve on their own without intervention, advise those around the individual to resume normal activities without interacting with the individual, minimize attention to the episode, do not encourage avoidance of certain activities in response to the episodes, and do not call EMS unless the individual is injured or the episode is significantly different and is not stopping. After an episode, the individual should return to work or class as soon as possible to reinstate normalcy and minimize

disruption to daily activity. If they cannot return to work or class, they should have an emergency contact who can transport them home.

Some patients may have both epileptic seizures and PNES combined. It is important to differentiate between the two since the two are managed differently. PNES do not need treatment with seizure rescue medications.

Treatment approaches that can be used for patients diagnosed with PNES

A number of psychotherapy modalities have been reported as useful/ effective in PNES.

Cognitive Behavioral therapy (CBT): PNES are understood as a cluster of physical symptoms sustained by maladaptive thoughts, emotions and behaviors, which can be further reinforced by those around the individual (family, friends, school staff, etc.). The symptoms themselves become an avoidance strategy. Managing PNES and the underlying comorbid psychopathology, such as anxiety or depression, often requires the therapist help the patient identify and correct responses to emotional triggers, avoidance behaviors and unhelpful thoughts.

Prolonged exposure therapy (PE): might be used with patients dually diagnosed with PNES and PTSD. PE is an evidence-based cognitive behavioral treatment for PTSD. PE is designed to help patients emotionally process traumatic experiences by confronting distressing memories and situations in a safe context. Psychogenic seizures can act as a distress-avoidance mechanism; in PE, the patient learns that avoidance through PNES is not effective.

Mindfulness-based therapies are skills-based manualized psychotherapies (i.e. dialectical-behavioral therapy, acceptance and commitment therapy, mindfulness-based stress reduction) that have as common feature the practice of mindfulness. PNES are hypothesized to be automatic complex behaviors that feel outside of the patient's control, reinforcing a pattern of avoidance of unpleasant experiences. By increasing attention and cultivating an accepting and non-judgmental attitude, patients will be more at ease with those avoided experiences, will be less likely to automatically go into PNES and will feel they have more choice over their behaviors. This eventually leads to lower frequency of episodes.

Psychodynamic approach: PNES represents a suppression or repression of negative emotions, of which the person is largely unaware because this mechanism is unconscious. Management of strong emotional states is impaired for a variety of reasons. Physical symptoms allow the person to express/communicate these emotions, thus treatment must focus on helping the person gain awareness of emotion and develop methods for expressing them consciously and verbally.

Helping Parents/Caregivers Manage PNES:

Caregivers for persons with PNES play an important role in helping persons with PNES to manage these events. It is recommended that caregivers understand the diagnosis and that these symptoms are not being intentionally produced and should also know how to explain the diagnosis to others as well as how to handle an episode.

It is recommended that caregivers understand who is part of the treatment team (e.g. mental health professionals, neurologist) and what the course of treatment may include. The psychotherapist provides treatment and often manages the majority of the questions from caregivers. The neurologist may remain on the treatment team to answer follow-up medical questions, manage weaning of anti-epileptic medications if needed, and manage epileptic seizures if co-occurring epilepsy is present.

It is recommended that caregivers understand how to respond to PNES and be able to follow the plan consistently. They can encourage the person with PNES to develop an awareness of bodily cues that PNES is imminent and encourage them to use the strategies they have learned to calm themselves. Caregivers should also encourage and assist with the maintenance of healthy routines in the home (e.g. bedtimes, meal times and involvement in activities). They may be able to help the person with PNES to understand the stressors and barriers at home that might contribute to continued PNES and provide strategies to deal with these stressors in a healthy way.

It is recommended that caregivers help facilitate implementation of plans to return to normal activities and resume as much independence as possible. Return to school, work and social activities are important. In the case of children, parents and caregivers are also an important link to school staff, in terms of providing medical reports which document the diagnosis and provide recommendations for accommodations and services.

Prognosis for PNES

Studies have explored what happens with PNES patients after diagnosis. For a small subset of patients, PNES can stop or significantly reduce after the diagnosis is explained to them, particularly those who are diagnosed soon after onset. Another subset of patients improves over the course of short-term psychotherapy. A third subgroup of patients will continue to experience PNES over time. However, there are significant limitations to published long-term outcome studies, and few considered the type of treatment received.

Two prognostic factors have consistently been reported across the literature: acceptance of the diagnosis improves prognosis, and receiving disability benefits worsens prognosis. Psychotherapists can focus on these to maximize the chances of a positive outcome by 1) working with the patient in understanding the diagnosis and helping them accept treatment, and 2) by encouraging patients to re-enter work or school as soon as possible.

There is currently not enough evidence to suggest that any particular subgroup of patients with PNES will not benefit from treatment interventions. Therefore, all patients with PNES deserve to be offered a course of short-term treatment. Improvement is typically related to the patient's level of understanding of their condition, their level of participation in therapy, and the amount of practicing of skills learned in therapy.

Additional published resources for mental health professionals and their patients

Publications for Mental Health Professionals

Reference books on PNES:

- Psychogenic Nonepileptic Seizures: Toward the Integration of Care (2017). Dworetzky B & Baslet G (Eds.), Oxford University Press.
- Gates and Rowan's Nonepileptic Seizures (2018). LaFrance Jr WC & Schachter SC (Eds.), Oxford University Press.

Peer Reviewed Articles on PNES Interventions and Effectiveness

- Carlson and Perry (2017). Psychological interventions for psychogenic non-epileptic seizures: A meta-analysis. *Seizure* (45), 142-50.
- Baslet G, Seshadri A, Bermeo-Ovalle A, Willment K, Myers L. (2016). Psychogenic nonepileptic seizures: An updated Primer. *Psychosomatics* (1), 1-17.
- Myers L, Vaidya-Mathur U, Lancman M (2017). Prolonged exposure therapy for the treatment of patients diagnosed with psychogenic non-epileptic seizures (PNES) and post-traumatic stress disorder (PTSD). *Epilepsy Behav*, 2017 Jan;66:86-92. doi: 10.1016/j.yebeh.2016.10.019. Epub 2016 Dec 27.
- Myers L & Zandberg L (2017). Case Report: Prolonged Exposure Therapy for comorbid psychogenic non-epileptic seizures (PNES) and post-traumatic stress disorder (PTSD). *Clinical Case Studies*.
- LaFrance WC, Jr., Reuber M, Goldstein LH (2013). Management of psychogenic nonepileptic seizures. *Epilepsia*. 54 Suppl 1:53-67.
- LaFrance WC, Jr., Baird GL, Barry JJ, Blum AS, Frank Webb A, Keitner GI, et al. (2014). Multicenter pilot treatment trial for psychogenic nonepileptic seizures: a randomized clinical trial. *JAMA Psychiatry*. 71(9):997-1005.

Guides for conducting therapy:

- Treating Nonepileptic Seizures-Therapist Guide, (2015) by LaFrance C and Wincze J, Oxford University Press
- Pediatric Psychogenic Non-Epileptic Seizures: A Treatment Guide 1st ed. (2017) By Caplan R, Doss, J, Plioplys S, Jones J. Springer Press.

Publications for Patients

- Overcoming Functional Neurological Symptoms: A Five Areas Approach (2011) By Williams C, Kent C, Carson A, Sharpe M, And Cavanagh J. Hodder Arnold Publisher.
- Psychogenic Nonepileptic Seizures: A Guide (2014) By Myers L. Create Space Press. (Also Available in Spanish And Japanese)
- Reiter JM, Andrews D, Reiter C, LaFrance Jr WC (2015). Taking Control of Your Seizures: Workbook. Oxford University Press. (Also available in French)

Disclaimer: This information sheet is designed to serve as a quick reference resource for clinicians. It is not intended to establish a community standard of care, replace a clinician's medical judgment, or establish a protocol for all patients. The clinical conditions contemplated by this information sheet will not fit or work with all patients. Approaches not covered in this information sheet may be appropriate.