Functional Neurological Disorders
Recovery Workbook

A collaborative program developed by the
Department of Neurology
&
Department of Psychiatry
University of Colorado
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Creating a support plan:

The FND clinic providers are unable to provide urgent or emergent mental health or medical services. If you are experiencing a mental health emergency, please call 911 or go to your nearest hospital emergency room. If you are experiencing a crisis you may also contact Colorado Crisis Services at 1-844-493-8255 or text "TALK" to 38255

Support Plan:

1) Who has helped me in the past when I am having a seizure? What do I need in order to feel supported when having a seizure?

2) Who helps me when I am sick? Where do I turn for help when I am in pain?

3) What do I do when I'm feeling depressed or overwhelmed? What do I do to cope? Do I have anyone or anywhere that I turn to?

4) If things get so bad that I am feeling hopeless or are having thoughts of wanting to hurt myself or end my life, where do I turn to for help? What has helped me in the past?

Introduction:

Welcome to the Functional Neurological Symptoms Disorder Clinic (FND)! We have been treating patients with FND since 2014. At this time, we mainly treat patients with Non-Epileptic Seizures (NES), a common type of FND. This workbook is designed for use by each individual to keep track of symptoms and steps to recovery. It is also intended to answer many common questions about FND.

The FND clinic is a time limited program with the expectation of an average 6 months of treatment. We are unable to perform chronic ongoing care after the clinic discharge at 6 months. It is important to have a good working relationship with your primary care physician to help them understand your FND in order to create a smooth transition out of FND clinic once treatment is complete. Our clinic has limited ability to complete and fill out paperwork. We make an exception for transportation paperwork if it relates to transportation for your treatment in the FND clinic. The best person to complete any paperwork needs for disability or other needs is your primary care physician.

Patients complete assessments before enrolling in the FND clinic. All patients will see a neurologist and a behavioral health provider, followed by decisions about the best treatment pathway, which is most often group treatment. The group treatment takes two main forms: cognitive behavioral therapy (CBT) based psychological-education and multi-modal psychotherapy. Our goal is to improve your symptoms in order to return you back to your community providers with the tools you need to continue your recovery. <u>Completing the NES program takes approximately 6 months</u>. During this time, you will be assisted to establish ongoing-care for transfer to community providers. This may include establishing a primary care physician, individual therapist and a mental health medication provider if needed.

Please bring your workbook (including diaries if you are asked by the neurologist to track your events) to each of your individual and group appointments and be prepared to discuss what you have written.

Accurate Assessment:
A neurologist makes the diagnosis of FND, in the case of NES using an EEG. The clinic team completes further screening to assess for common needs in patients with FND which can include other physical health problems, or co-existing mental health problems like depression, anxiety or post-traumatic stress disorder, for example.

Current coping skills, and any challenges with family relationship patterns are also explored as part of a complete assessment.

State of the art treatment:

Our neurologists and psychiatrists have worked with the national experts in FND treatment to establish the FND program to provide the best care available for patients. It is an innovative treatment approach that is among the first of its kind in the United States.

Treatment consists of group psychoeducational CBT sessions that provide psychological support and education about FND. If needed, a patient may receive individual treatment with neurology, individual treatment with psychiatry, treatment with physical and occupational therapy, and a family assessment and treatment. Mental-health and neurology intake appointments last from 60 - 90 minutes and follow-up appointments are 20 – 30 minutes.

Is mental health treatment necessary?

Some people believe that treatment by a psychiatrist or other mental health provider is a sign of being "crazy" or otherwise mentally incompetent. This is not the case. The co-existence of mental health issues is very high in patients with an FND diagnosis. We believe in taking care of the ***whole*** patient which means that we must address physical and mental health needs. It makes sense to seek treatment from a professional most able to help you with treatment which is specifically directed at your particular diagnosis. Psychological influences can best be identified with the help of those with special training in this area: psychiatrists, psychologists, or clinical social workers. As with all other medical conditions, sometimes the exact cause remains unknown; even so we can concentrate on the most important goal: reducing or eliminating symptoms.

What is the prognosis?

With active participation with prescribed treatment, the prognosis is positive. Properly directed treatment can improve the symptoms of FND in as many as 80% of patients. Keep in mind that treatments are not a quick fix, and take time. A common challenge happens when patients struggle to accept the diagnosis and as a result do not attend their appointments. Illness which requires treatment will not get better without it. In the case of FND beginning treatment as soon as possible is very important. It is known that the sooner appropriate treatment begins, the better the chances of a full recovery.

Memory Problems?

Many patients with FND have significant difficulty with their memory. This is in part, due to the work of processing memories, emotions and thoughts which are related to FND. The brainpower needed for this processing leaves less space and brain energy for other functioning. At the severe end of the spectrum, this processing leads to a problem called dissociation. Dissociation is common in patients with FND and can be one of the reasons for problems with the working memory for everyday life. Often, addressing the emotions, etc. which are consuming the brains capacity to function well, can help this problem.

Here are some other tips and resources for improving working memory:

1. Get adequate sleep, nourishment and exercise.
2. Avoid multitasking so that you can focus your attention.
3. Explain new information to yourself in your own words. Use rewording and summaries to help remember complicated information.
4. Use memory aid strategies (e.g., using the word BAT to remember to buy bananas, apples and tea).
5. Use memory strategies that work for you. If visualizing things helps, use that technique.
6. Elaborate the details of the memory (e.g. Try to remember someone's name by remembering that their name is the same or similar to someone else).
7. Write things down. Some patients find a day planner to be useful.

What about marijuana?

Marijuana use in patients with FND is common for multiple reasons. Marijuana has not been studied in patients with FND and therefore we don’t have information on the safety of marijuana for FND and want you to be aware of the potential adverse effects associated with use.

There is good evidence that long-term use of marijuana can have negative effects on memory and ability to learn. This already tends to be a difficulty experienced by patients with FND. Marijuana is also associated with poor psychiatric outcomes including a higher risk of anxiety, depression and psychosis. Marijuana can decrease the effectiveness of prescribed psychiatric medications making treatment of conditions more difficult. Marijuana may also be used as an avoidance strategy to escape emotional pain. In the FND program our goal is the opposite, to get patients to start facing difficulties that have been previously avoided. Greater frequency of cannabis use increases the likelihood of developing problem cannabis use.

Marijuana has a specific withdrawal phenomenon that can lead to discomfort if stopped abruptly. These withdrawal symptoms are similar to the withdrawal symptoms from other substances of abuse like anxiety, moodiness, irritability, restlessness, insomnia, sweating, and abdominal pain. These symptoms are worse in the first week of stopping and generally improve quickly but can last for up to 6 weeks. The best way to avoid withdrawal if wanting to stop or cut back on your marijuana use is to decrease your marijuana use by 20% each day. In the FND clinic, we do not recommend or prescribe marijuana to treat FND or any psychiatric co-morbidities. Cannabis can also have health consequences with the most recognized being cyclical vomiting (Cannabis Hyperemesis Syndrome). In some studies, cessation of cannabis use has led to resolution of these symptoms.

More information on the use of marijuana can be found at The National Academies of Science Report on Cannabis and Cannabinoids which can be found here:
http://nationalacademies.org/hmd/Reports/2017/health-effects-of-cannabis-and-cannabinoids.aspx

Additional Questions:

Please go to www.nestreatmentucd.org

Frequently Asked Questions:

What is FND and specifically NES?

These are events that look like an epileptic seizure, but do not have changes on the EEG that we see with epilepsy. There is controversy about what causes NES and other FND. Current thinking points to over-expressed connections between brain regions which are created in people with a history of trauma, anxiety and depression to name a few processes involved in making these brain connections. Stress, psychological conflict, or the forgotten past are some of the triggers reported by patients. The answer to the question of “what is NES” is complicated and will be discussed in treatment.

How do we diagnose NES?

The most conclusive test to distinguish epilepsy from NES is video EEG monitoring, most often done in an Epilepsy Monitoring Unit (EMU), leading to near 100% certainty in the diagnosis. In order to capture one or two typical episodes/events on both videotape and EEG simultaneously can take 3-5 days. Sometimes this study is done while in the hospital or Emergency Department for recurrent seizures. In this case the study is done outside the EMU and again, with video-EEG monitoring.

Patients with NES as their FND diagnosis ask “Why was I told I have epilepsy?”

Most patients (about 80%) with NES have been treated with antiepileptic drugs for several years before a correct diagnosis is made. It is common for patients to initially be given the wrong diagnosis. Not all physicians have access to EEG-video monitoring, which must be performed by a neurologist who specializes in epilepsy (epileptologist). Because epileptic seizures are potentially more physically harmful than NES, physicians, when in doubt, will treat for the more serious condition. If seizures continue despite medications, the diagnosis of epilepsy comes into question. Before this happens, doctors often try changing treatment, which delays the correct diagnosis. After failure of treatment, patients may finally be sent to an epilepsy center, where the diagnosis is usually made. Unfortunately, this sometimes takes > 5 years to occur. A small portion of patients have both epilepsy and non-epileptic seizures but this is less common. If you have both types, it is very important that you and your family learn to distinguish the two types because the treatment for each is very different.

What about driving?

Many people with NES have stopped driving, because their seizures affect the ability to remain alert or in control of a car. There is no Colorado law that regulates driving in patients with epilepsy or NES, and neurologists will advise against driving to a patient who loses consciousness or physical control during seizures. This is true of any FND which disrupts consciousness or motor control. The decision as to whether you should be driving has to be made individually with both your psychiatrist and your neurologist. If your FND, including NES spells involve loss of awareness then YOU SHOULD NOT BE DRIVING. Generally speaking, patients should be free of events for at least 3 to 6 months before resuming driving.

Research in our clinic:

Most research on FND, including NES has been descriptive, meaning research has focused on describing specific NES symptoms and how they are related to other medical and psychological problems (also called co-morbidities). In the past ten years treatment research has been done by a nationally known clinician-scientist, Dr. Curt LaFrance among others. Dr. LaFrance has focused on treatment and treatment results (efficacy). Large, long-term studies are still rare. At the University of Colorado, we have developed a treatment clinic for NES based upon the few published papers by Dr. LaFrance and others showing treatment success. In order to further the science regarding FND treatment our group is systematically studying NES, a subtype of FND, starting with the patient perspective. We believe that beginning our research at the point when a patient is given the diagnosis is an important aspect of treatment. Our plan is to add to the generalizable (useful to all) knowledge about NES. We are honored and fortunate to have a population of patients with NES to invite to participate.

Patients will be invited to participate in this research to further our knowledge which involves reading and signing a consent form, filling out observation logs during each week of treatment, and completing a large packet of questionnaires assessing many other aspects of care.

Basic timeline for participation in the clinic:

Neurological Testing

- May include EEG, EMG, MRI, Tilt-Table, etc.
- Verify FND diagnosis
- Rule out any other neurological disorders
- Referral to FND clinic

Intake with Neurologist

- Discuss the pathology and mechanism of the FND diagnosis
- Discuss how the diagnosis is made, review testing
- Discuss the differential diagnosis if appropriate
- Fill out baseline questionnaires

Intake with a behavioral health specialist

- Discuss diagnosis and behavioral health comorbidities
- Discuss group therapy
- Begin to establish outside therapy and psychiatric care if needed

6 Week Group

- 6 week group treatment sessions with clinicians and fellow FND patients
- Please see 6 week group agenda in your entry packet

3 Month Psychiatry Follow Up

- Discuss how things are going
- Discuss any barriers to care and/or recovery
- Discuss progress toward obtaining outside therapist when needed
- Fill out questionnaires

12 Week Group

- 12-week group therapy session with clinicians and fellow NES patients
- See 12-week group therapy agenda in entry packet

6 Month Psychiatry Follow Up

- Discuss how things are going
- Fill out questionnaires
- Finalize any discharge needs to ensure a smooth transition to ongoing community care

****Keep in mind that each patient may have a slightly different experience of this timeline and individual factors that may lead to a different treatment approach.**

For scheduling questions:

You will need to be your own advocate for getting the most out of your treatment process. If you cannot make an appointment, please contact the clinic to cancel at **720-848-2087**

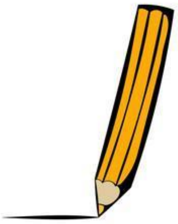
How to get the most out of the FND clinic?

Keep track of your appointments! It’s helpful!

My neurologist intake appointment: ____________________
My behavioral health intake appointment: _______________
My 3-month follow-up appointment: ____________________
My 6-month follow-up appointment: ____________________
6-week group starts: __________________________________
12-week group starts: _________________________________
One-year telephone follow-up: _________________________

Keep track of your scales! It helps your providers to know you better and personalize your experience!

Date of initial scales: __________________________
Date due for 3-month scales: ____________________
Date due for 6-months scales: ___________________



Please note:

If you are having trouble making it to appointments in general, please contact the Program Manager at 720-445-5345.

***For extra materials go to** www.nestreatmentucd.org

Transition out of the FND clinic:

My individual therapist is: ______________________________

My psychiatrist (if needed) is: ___________________________

My primary care physician is: ___________________________

What other support might I need for successful transition out of the FND clinic after 6 months?

1. Further support groups
2. Psychiatrist
3. Volunteer opportunities
4. Family assessment or therapy
5. Help from social work
6. Help with transportation
7. Help with employment
8. Primary care physician

Things to consider:

1. Make sure that if you were prescribed new medications that one of the above providers is willing to take over the responsibility for the medication when you are discharged from the FND clinic. In most cases, our team will be assisting to facilitate this.
2. In order to continue the improvements gained in our treatment clinic, it is vital that you have set up providers for transition well in advance of your discharge from the FND clinic.
3. It is recommended to find an individual therapist to work with during your treatment and to continue what you have learned in the FND clinic with this therapist. The FND mental health team are willing to speak with your individual provider to help coordinate your care. You can fill out a release of information with the medical assistants in the neurology clinic for this to take place.

Getting Started:

There will be a number of self-report questionnaires to assess how you are doing at the beginning of treatment. These will be repeated at 3 months and at the end of treatment. This will help you and your providers personalize your care and track your progress. You will receive a report of your answers on these questionnaires. Patients will be asked to complete an observation log documenting how often your symptoms occur each week. It is helpful to include as many observations as possible.

FND clinic team members and contacts:

Providers:

- Neurologist
- Psychiatrist
- Licensed Clinical Social Worker
- Psychologist
- Nurse Practitioner & Physician assistant with neurology

Program Manager:

- (720) 848-7824

Learners:

- Resident physicians trained in therapeutic techniques and learning about FND
- Fellow physicians specializing in the overlap between psychiatric and medical symptoms
- Clinicians in training

How to contact these providers?

My Health Connection which you can sign up for here
https://myhealthconnection.uchealth.org/register.aspx

Additional Questions:

Please go to www.nestreatmentucd.org

FND Clinic:

What we do:

- Analysis of tests performed
- Diagnosis of FND
- Discussion about this diagnosis in understandable terms
- Diagnosis and treatment of any co-existing psychiatric disorders during 6 months
- Support & brainstorming what you will need to be successful in the clinic and afterward

Group Treatment:

6-Week Group:

This group is intended to help you better understand your FND symptoms and what triggers may be associated with your events or symptoms. The goal is to assure that you have a "tool-kit" of skills to accomplish this. The 6-week group is structured and has an agenda with homework and observation logs for you to complete each week.

Questions to think about in preparation for the 6-Week Group:

1. What is your understanding of FND?
2. How do you explain your FND to your family?
3. What challenges do you have in communicating about your FND to your family?
4. What challenges has FND created in your life?

12-Week Group:

While almost every patient will complete the 6-week group, about 65% of patients will complete the 12-week group. Each patient's individual needs will be discussed with their care team to decide if the 12-week group will be needed or beneficial. This group is designed to help you understand more about the individual and psychological factors which co-exist and may be playing a role in your FND. This group is focused on discussing trauma and how it may contribute to FND and many other aspects of your life including your relationships, ability to ask for help, personality factors and your upbringing. We discuss the development and expression of emotions and how this may contribute to your FND. This group does not follow a set agenda but allows for content to be discussed that will be most helpful for the individual members.

Questions to think about to prepare for the 12-Week Group:

1. How do you connect your emotional and physical pain and why is that important?
2. What role has trauma played in the development of your FND?
3. What is FND trying to communicate to yourself or your family?
4. Why does your body manifest the symptoms of FND?
5. How do you communicate your needs to people in your support network including medical providers, therapists, friends and family members?

No show policy:

Due to the time limited nature of our clinic and the high demand for our treatment services, it is important that you make all efforts to attend your appointments as scheduled. It is critical that you are able to attend all treatment sessions in order to achieve the maximum therapeutic benefit. While we understand the need for some flexibility for emergencies, if you miss more than two of the 6-Week Group sessions you will be rescheduled for the next available 6-Week Group. Similar policies exist for both individual appointments and 12-Week Group models as well. Please contact the clinic if you are unable to make any appointments and speak to your provider if you are unable to continue with your treatment.

Chronic inability to attend sessions will result in transition out of NES clinic and to accessible resources for further care.

Family and your FND:

This worksheet is for you to complete with your family to discuss your needs and how they can best support you during your symptoms.

Creating your own response plan for your family members:

Important information to remember:

- FND symptoms **DO NOT** require treatment in the emergency department unless you have injured yourself.
- Remember these episodes are not purposeful or intentional.
- FND symptoms can be associated with an inability to recognize and cope with stress, anxiety, frustration or other strong emotions. The "overload" this produced can cause a physical response to these emotions.
- The best treatment in addition to the FND clinic sometimes includes individual psychotherapy. Goals are different for each patient but many commonalities include: decreasing body arousal by learning relaxation techniques, increasing awareness of emotions, changing dysfunctional beliefs, increasing communication of thoughts and emotions, and increasing social support.

How to respond consistently to minimize the impact of FND symptoms:

1. Create a description of the symptoms for everyone in contact with the person with NES. The goal is to recognize when an NES is happening. ***Remember,*** the person with NES may experience symptoms that are not outwardly obvious and witnesses may observe things that are unknown to the person with NES. Work together! Create a description to share with anyone who may have a chance to be helpful and supportive.

a. Symptoms that occur:

____
____
____
____
____

2. If your family member indicates they think they are going to have an increase in their symptoms, try to talk with them and also take note of what is happening (are they speaking, responding, nodding their head?) Note the time, date and symptoms you are witnessing. Things you can say are: "I am here. You are safe and I will help

to keep you safe." After brief reassurance it is best to stay close and lessen interactions, keeping the environment calm.

a. Other calming words for my family member to use during an increase in FND symptoms:

____
____
____
____

3. Ensure your family member is in a physical position that will maximize safety and minimize any potential injury during an increase in FND symptoms.

a. Discuss and document the best physical position to be in when having an increase in FND symptoms (e.g. Laying down, sitting up):

____

4. Make a list together of what support is helpful or not helpful to communicate this with everyone in the environment. This can be things like being held or not being touched, being spoken to, getting a cold compress, being in certain physical positions, etc. The following support is helpful to my family member when experiencing an increase in their symptoms:

____
____
____
____

a. The following support is not helpful to my family member when experiencing an increase in their symptoms:

____
____
____
____
____

Helpful Resources:

1. Overcoming Functional Neurological Symptoms: A Five Areas Approach
Author: Professor Christopher Williams

2. Taking Control of Your Seizures Workbook
Author: Joel M. Reiter

https://www.amazon.com/Taking-Control-Your-Seizures-Treatments/dp/019933501X

3. Gates and Rowan's Nonepileptic Seizures
Authors: Steven C. Schachter and W. Curt LaFrance Jr.

https://www.amazon.com/Nonepileptic-Seizures-Cambridge-Medicine-Hardcover/dp/052151763X

4. Psychogenic Non-Epileptic Seizures: A Guide
Author: Lorna Myers, PhD

https://www.amazon.com/Psychogenic-Non-epileptic-Seizures-Lorna-Myers/dp/1492881414/ref=sr_1_1?crid=10IA3IHKQ2TIV&keywords=nonepileptic+seizures+book&qid=1565796344&s=books&sprefix=non+epile%2Cstripbooks%2C199&sr=1-1

5. In Our Words: Personal Accounts of Living with Non-Epileptic Seizures
Author: Markus Reuber

https://www.amazon.com/Our-Words-Personal-Non-Epileptic-Brainstorms/dp/0190622776/ref=sr_1_1?keywords=in+our+words&qid=1565795805&s=books&sr=1-1

6. View from The Floor: Psychogenic Non-Epileptic Seizures: A Patient's Perspective
Author: Kate Berger and Lorna Myers (Foreward)

https://www.amazon.com/View-Floor-Psychogenic-Non-Epileptic-Perspective-ebook/dp/B0161NE9AQ

7. Lowering the Shield – Overcoming Psychogenic Nonepileptic Seizures
Author: John Dougherty
https://www.amazon.com/Lowering-Shield-Psychogenic-Nonepileptic-ebook/dp/B00BTMB38G#_

8. Your Memory: How It Works and How to Improve It
Author: Kenneth Higbee, PhD
https://www.amazon.com/Your-Memory-How-Works-Improve/dp/1569246297/ref=sr_1_3?crid=W8TRRICCWCYQ&keywords=your+memory+how+it+works+and+how+to+improve+it&qid=1565795920&s=books&sprefix=your+memory%2Cstripbooks%2C197&sr=1-3

9. The Memory Book: The Classic Guide to Improving Your Memory at Work, at School, and at Play
Author: Harry Lorayne
https://www.amazon.com/Memory-Book-Classic-Improving-School/dp/0345410025/ref=sr_1_1?crid=3BQ29LVMD75GR&keywords=the+memory+book+the+classic+guide+to+improving+your+memory+at+work&qid=1565795988&s=books&sprefix=the+memory+book+the+cl%2Cstripbooks%2C194&sr=1-1

10. Treating Memory Impairments: A Memory Book and Other Strategies
Author: Vicki S. Dohrmann
https://www.amazon.com/Treating-Memory-Impairments-Other-Strategies/dp/0761630414/ref=sr_1_1?keywords=treating+memory+impairments&qid=1565796192&s=books&sr=1-1

Online Resources:

1. https://fndhope.org/
2. nonepilepticseizures.com
3. https://www.neurosymptoms.org/
4. http://www.nonepilepticattackdisorder.org.uk/
5. Non-Epileptic Seizures Webinar: An Introduction for patients and loved ones. Dr. Lorna Myers https://www.youtube.com/watch?v=xYuDv-QFYu0
6. https://www.aafp.org/afp/2005/0901/p849.html
7. https://emedicine.medscape.com/article/1184694-overview

Community Resources:

Epilepsy Foundation
https://www.epilepsy.com/learn/types-seizures/nonepileptic-seizures-or-events
Help Guide - Trusted mental health and wellness
helpguide.org
National Center for PTSD
ptsd.va.gov
Anxiety and Depression Association of America
adaa.org
The Center for Trauma and Resilience
traumahealth.org
UCCS Veterans Health and Trauma Clinic
https://www.uccs.edu/healthcircle/veterans-health-and-trauma-clinic
National Alliance for Mental Illness
https://www.nami.org/find-support/nami-programs/nami-connection
Colorado Crisis Center
https://coloradocrisisservices.org/