**Homework in Preparation for Week 2**

## Practice Breathing Meditation Exercise

1. ***Complete “Developing Awareness and Understanding of Triggers” Exercise Below in Preparation for the Next Group***
2. ***Complete Seizure and Doctor’s Appointment Diary - Remember to Log Seizure Free When None Occur***
3. ***Breathing Meditation Exercise***

Try utilizing the “Breathing Mindfulness” exercise we practiced today (or another mindfulness technique you prefer).

Breathing exercise – below is a guide to start your own breathing relaxation meditation

* 1. Also note that you can download mindfulness and breathing exercises (apps) on your phone and follow those. An example of one app is “Headspace”.
* Start by placing both feet on the floor to ground yourself.
* You can either have your palms placed lightly in your lap or rest them on your legs palms up to create a feeling of openness or palms down to help ground yourself in the present moment.
* Start by just noticing your natural breath. Is it slow? Is it fast, shallow or deep? Do not attempt to change your breath or judge its qualities. Notice what is going on in your body and be with that sensation as it is at this moment, not trying to change anything.
* Next, inhale deeply through your nose, filling up your lungs and expanding your belly.

Hold **gently** and then **slowly** exhale, releasing your breath back out through your nose until your lungs are completely empty. Repeat this as many times as needed to bring relaxation and a release of tension. During breathing you may either close your eyes or keep them open. If you would like to keep them open, focus on a non-moving object or look down towards the floor.

* Each time your mind wanders gently bring it back to the present moment and your breath, without frustration or judgment. Like all things, mindful breathing takes practice.

It is okay if you start to think about other things. Meditation and breathing are not about clearing your mind. They are about recognizing and accepting your thoughts and each time gently bringing yourself back to the breath. As you get better at your breathing practice you can increase the time taken to inhale, hold, and exhale breath.

1

## B. Developing Awareness and Understanding of Triggers

What causes seizures? This question, for many patients, is central to the task of *taking control!* If we understand the cause of a seizure, we can develop a strategy to stop a seizure. In the world of science and medicine though, proving cause is among the most difficult things to do. When something *seems* to be related to something else, does that mean it caused it? For example, if you put the correct key in a locked door and turn it, the door opens; the wrong key will not open (or trigger the opening) of the door. In this example, the key is the trigger which allows the door to open, but really, it sets off a mechanism by which the door can be opened. The key is only the initiation of the opening of the door, it must be placed in the keyhole, turned by some mechanism and then the door must be pushed or pulled open. So, what do triggers, and keys have to do with causing seizures? In this first exercise of the 6 Week Group curriculum, you will begin to develop an awareness and observation of triggers. The word “trigger” in this context refers to something that appears to lead to a seizure.

Let us ask the question again in a different way, does a trigger cause a seizure? To answer such a question, medical science will have to move closer to understanding what causes non-epileptic seizures. The human brain is complex! How else could wo[man]-kind have been able to learn that the moon was in orbit, create a rocket and send people to a place that is 238,855 miles away? Even the simplest movement, like your knee jerking in response to the reflex hammer is a network of connections in the brain and spinal column. This small, involuntary action of knee jerking takes place only through a vast and complex network of connections. The brain picks up a signal, processes it (makes sense of it) and produces a reaction in the body. It is believed that triggers are processed in specific ways by the brain and in turn result in seizures. As in the door example though we don’t truly think of triggers as causes.

Triggers probably exist for all people with NES and some may need to be discovered. There are common triggers; many people describe that bright lights trigger (lead to) a seizure. But often what may be a trigger for you, has a very different effect on someone else. The focus of this week’s exercise is to help you become aware of your personal triggers and how they relate to your seizures. By doing so, you will find that you can intervene to reduce your non-epileptic seizures.

SJ has a very stressful job which does not allow reliable break time. Getting through the day had become a challenge because midafternoon, she realizes that she has been on her feet all day and has had no more than a few cups of coffee and a snack from the vending machine. During the first week of her NES group, she told everyone to forgive her in advance because she always felt irritable in the afternoon and had trouble tolerating being around others, often losing patience and becoming verbally abrupt. On most workdays, she would arrive home and have a seizure before her husband arrived home, preventing her from being able to make dinner. One of the group members joked, “It sounds like you are just getting ‘hangry’ late in the day. Why don’t you try keeping nutritious snacks in your locker?” SJ thought that seemed too simplistic to be useful, but tried it anyway, reporting the next week that her seizures were down 50% and she actually felt she had more energy at work!

In our experience people describe seizures that fall into a few main categories. Most people describe and can relate to a **physical** trigger like flashing or bright lights. More of our patients

2

though, describe an **internal** trigger, like stress as the main thing which seems to be related to their non-epileptic seizures. Nearly as often, patients tell us that **external** factors, for example, loud arguments at home or at work seem to trigger seizures. This categorization of physical, internal and external triggers is used in the workbook written by Reiter et al.[[1]](https://olucdenver-my.sharepoint.com/personal/abbie_pennetti_cuanschutz_edu/Documents/Telehealth%20Materials/Word%20Doc%20Folder%20of%20Week%20by%20Week%20Homework/Homework%20in%20Preparation%20for%20Week%202%20(in%20process)ed.LAS%5b12677%5d.docx#_ftn1) For the purposes of learning your triggers, we will divide these into internal and external (sometimes physical) triggers

**What is an external trigger?** External triggers are people, places and things that appear to be linked to having a seizure. In epileptic seizures, external physical triggers are actually quite rare. For instance, only about 3% of patients with epilepsy have seizures which are triggered by flashing lights. It is far more common for patients to tell us that sleep deprivation, alcohol or drug use, and illness seems to be the physical trigger for their seizures. Other external triggers are stressful life circumstances like a loud home environment, a relationship that is caught up in argumentativeness or even physically violent. Take for example the story of TL.

TL had a 3-year history of NES. Her seizures were violent and would end with injury and exhaustion. TL had been in 6-week NES clinic group meetings for 3 weeks and was recounting details of things that were within reasonable control. “Every time the phone rings, I jump.” she said. Another group member suggested, “why don’t you change the sound of your phone alert?” TL went on to describe a bad seizure on the day previous just after receiving a phone call from her mother. While documenting the seizure in the seizure log, it suddenly became crystal clear, a phone call from her mother was reliably followed by a seizure. TL went on to describe what had transpired during the phone call and realized that the physical signal of the phone ring was connected to the fractured relationship with her mom, who was highly critical and belittling. It was the feelings of worthlessness this created in TL and not the phone ring that led to seizures.

In this example, a physical trigger (phone ringing) was leading to an event (talking with her mother) which was creating a sense of worthlessness (an internal negative state) in the patient and leading to a seizure.

**What is an internal trigger?** Internal triggers are thoughts and feelings, most often negative and/or stressful, that seem associated with having a seizure. In the story above, it was not actually the external trigger of the phone ringing, but the feeling of worthlessness induced by talking to her mom, that TL felt was really linked with the seizures. NES patients commonly describe internal factors as triggering for seizures. These are often feelings of sadness or anger, for example. It is also common to hear that a bad mood, anxiety or feelings of guilt or low self-esteem trigger seizures. Sometimes external triggers lead to these internal negative states (as the Reiter manual calls them) and are triggering for seizures. 1

To begin this journey of understanding your seizures through self-observation of triggers and the

**internal states** that they provoke, it is helpful to be able to first identify your triggers. If you have

**1** Taking Control of Your Seizures: Workbook. Joel Reiter, Donna Andrews, Charlotte Reiter, W Curt LaFrance. Oxford University Press, 2015.

3

been keeping the seizure diary we have recommended, you have already taken the first step of the journey, by simply logging your seizures and what you may have observed as being a trigger. Before you begin the exercises below, we want to be purposeful in acknowledging the difficulty of this journey. Many people with NES, express feelings of powerlessness that having seizures produces in their lives. It is common for people to blame themselves for their seizures especially when they begin to explore the process of taking control. Seizures happen, as part of life circumstances, situations and environments, both internal and external, producing stress. It is this, that we want to work to bring into control. As a result of working in these sessions, seizures begin to come under better control. This program is an opportunity to take small steps to begin to gain some control and to have a positive impact on seizures. We understand that there are obstacles that can stand in the way for each person.

What are some of the obstacles you face in identifying your triggers? You may begin by using some of the triggers you have logged in your seizure diary or write others down here.

For example: “I don’t remember anything once I have a seizure, so how can I identify a trigger?”

One challenge in the process of self-observation is illustrated in the example of TL. The first step she took was to log her seizures and triggers and to make the connection that the phone ringing seemed to be associated with having a seizure. By the time she woke up after a seizure, she had little to no memory of talking to her mother and the feelings (the negative internal state) that created. Her last memory was always of the phone ringing. To understand the meaning of the internal states that are associated with any trigger, a deeper dive is needed. All humans have experience with triggers leading to physical symptoms in the body. For example, people with migraine headaches will sometimes reliably get a headache if they eat aged cheese. In fact, lists of migraine food triggers are published and some people with headaches observe special diets to stop their migraines. For individuals with seizures, the brain is the part of the body that is affected by the triggers. Triggers often are accompanied by a recognizable negative internal state as in the case of RG below:

RG told the group after one session in the 6-week group, “I wake up depressed every Monday morning. There is no reason, in fact my weekends are always great, but every Monday I just want to crawl back under the covers and not get up.” He would often have a seizure and go back to bed, missing work. HIs boss was beginning to be suspicious that he was avoiding Mondays due to overdoing things on the weekend and was at risk of losing his job. The problem had been going on for the past 6 months. Someone in the group reminded him that he was in a new, relatively long-distance relationship that started 6 months ago, and his new partner only came for the weekends. Together, the group members put together that saying good-bye on Sunday night and the loneliness that followed was producing very restless sleep and a hung-over and depressed mood every Monday morning. RG developed a strategy, that he and his new partner would use FaceTime at noon on

4

Monday which he found gave him something to look forward to and lifted his spirits.

Due to the individuality of life experiences, triggers can be interpreted differently. Negative and stressful internal states are uncomfortable, and the body sometimes responds by producing a seizure for individuals with NES. When learning to recognize triggers, it is important to first understand and identify the negative internal state that is associate with or produce by the trigger. To fully benefit from understanding your triggers, you must become observant of your environment as well. This often requires considering what precedes a seizure or the trigger for a seizure. This is just as important as identifying your thoughts and feelings (the internal triggers).

Many triggers may not occur directly before a seizure, making it necessary sometimes to think backward from the seizure. Sometimes events and experiences may not produce an impact until quite some time has passed. Doing a little detective work, you can sometimes piece together what led to the trigger, or the internal negative state. Utilizing your seizure diary can give you some helpful clues. Pay attention to what happened, not only right before your seizure occurred, but in the days preceding. You may find you need to reflect on the broader things that have been happening in your life in the week or month as a whole. Let’s consider the example of RG. He thought of the new relationship only in its positive aspects and didn’t realize that this new intimacy was in stark contrast to his weekdays which he started to realize were intensely lonely. Asking yourself how you felt just prior to a seizure is another important part of the self-observation journey. You may find that these questions are very difficult to answer. If available, you can ask a friend or a loved one for their input as well. Even if you have trouble answering, try to make a commitment to yourself to be open minded and curious moving forward, you are the detective. You can ask yourself, “what was happening right before (or in the days preceding) my seizure?” Observation is a skill, and like any skill it takes work and practice to enhance and develop. Try using the questions below to begin this process.

Thinking about your personal journey in life, why might your triggers listed above be interpreted in such a way by your body that they produce a non-epileptic seizure?

Was it difficult or confusing to identify an internal (possibly negative) state that could be associated with your triggers?

5

How do I enhance my ability to become more aware of my triggers and the way my body interprets them? This is such an important question! Developing an awareness of our body’s signals and making sense of these connections can be a challenge. Many people with NES have learned to ignore or mistrust signals. One of the ways we have come to understand NES is that like many other symptoms, it can be a signal. Our bodies send us signals all the time, for example, our stomach will produce pain and noise when hungry as a means of calling our attention and focus to a need to eat. Like the example of SJ, lack of self-care was leading to not eating, producing irritability she recognized. In that example she ignored her hunger which was the signal her body was trying to send.

To take control over how seizures affect your life, you are encouraged to “tune in” to these signals. One of the ways to reduce anger and frustration is to identify how your attitude towards your brain and body are standing in the way of your recovery. If you have an angry relationship with your body and you blame your brain for the seizures, you are likely to miss the signal that your brain is trying to communicate. Throughout your time in the clinic you will be encouraged to shift your perspective to become inquisitive, to be the detective to discover what your brain is trying to communicate, to pay attention to the signals.

Many individuals find it intensely distressing to turn their attention to their body’s sensations and their thoughts and feelings. “Tuning out” these triggers can be a coping mechanism that the brain and body use to relieve distress and pain. Unfortunately, when we “tune out” our thoughts, emotions and experiences the signals go unanswered. The “tuning out” process is often an adaptive process that, for many, began with early life experiences and is often reinforced with experiences in adulthood. In early childhood, some children receive the message that their emotional needs are unimportant. Some of these individuals have experienced emotional or physical abuse when trying to express pain, fear, anger, or sadness to a parental figure. These individuals then learn that having and expressing these emotions is unacceptable. As adults, when these emotions are experienced, a person may feel guilty, shameful, or feel nothing at all.

For example, the child in the above description may experience the following cycle: Sadness ⇒ expressing sadness to parent ⇒ neglect or punishment instead of help or comfort ⇒ the child learns to stop sharing ⇒ ignoring feelings becomes a pattern

When that child becomes an adult, the following cycle may persist:

Sadness ⇒ tuning out feelings ⇒ feelings become bigger and harder to ignore ⇒

hiding feelings from others ⇒ shame for having feelings ⇒ seizure

The example above demonstrates how our past experiences shape how we interpret triggers

in our environment. The individual in this example, learned to tune out feelings because it was unacceptable and unhelpful and even punishable to experience them as a child. As an adult this pattern naturally gets repeated. Many share that “tuning in’ to emotions and thoughts leaves them feeling shameful and angry with themselves. Developing an awareness of your triggers must be accompanied by developing a deeper understanding of how this awareness is making you feel. By understanding how it feels to become more observant of your emotions and thoughts, you will be able to start to explore the hurdles that stand in your way.

6

Am I compassionate towards myself? Do I accept my emotions and feelings?

Is it difficult to “tune in” to your emotions and thoughts? How does it feel to do this exercise? Where do these feelings come from?

Accepting your emotions, thoughts and feelings is a part of enhancing observation skills. It will be important to be aware of the attitude you have towards yourself and if you practice compassion and patience with your body. Anger and frustration with your seizures is a normal part of this process. Understandably, they are causing significant distress and for many, pain and suffering and ultimately, seizures. It can therefore be exceedingly difficult to have patience with your body. Developing kindness and compassion for yourself starts with recognizing your self talk and creating a new narrative that you can share with yourself when you find anger and frustration bubbling towards the surface.

Do you find yourself getting angry and frustrated with your emotions and thoughts? Do you notice any negative self-talk that you experience when angry?

Identifying your patterns of self-talk is the first step to developing a new way of communicating with your body. One helpful exercise is to imagine a friend shared with you the emotions and feelings you have been listing above. Would you say to them, what you say to yourself?

Some of the triggers you may have identified are triggers that feel unavoidable. We would like you to begin the exploration process of whether you might be able to take steps to change your exposure to triggers, or if you can change how you are affected by them. For example, you may

7

be able to reduce your interactions with an unhealthy individual in your life. However, you will likely not be able to avoid an argument with your partner and the emotional experiences that follow. Recognize that avoiding all painful experiences and emotions is not a healthy goal and focus on how you can make changes to shift the effects triggers have in your life.

Utilizing the exercises below, you will be asked to identify triggers and to determine if you are able to change them or change how they impact you. Then explore if you want to change these triggers, and if not, why not? By exploring this model of change, you may find you are able to identify barriers to your progress.

To help with these exercises please list the triggers you identified earlier in the space below.

Next, identify whether you can directly change the triggers you listed above? For ex. Can you avoid arguments with your spouse, can you avoid loud noises in a crowded restaurant, can you avoid conflict between family members?

Next identify whether you can change how these triggers you listed above affect you and your quality of life?

Ask yourself, whether you want to change these triggers or how they affect you? Are you ready to make these changes?

8

How do you feel when you think about making these changes? What emotions are provoked during this exercise?

## C. Complete Seizure and Doctor’s Appointment Diary - Remember to Log Seizure Free When None Occur

[**[1]**](https://olucdenver-my.sharepoint.com/personal/abbie_pennetti_cuanschutz_edu/Documents/Telehealth%20Materials/Word%20Doc%20Folder%20of%20Week%20by%20Week%20Homework/Homework%20in%20Preparation%20for%20Week%202%20(in%20process)ed.LAS%5b12677%5d.docx#_ftnref1) *Taking Control of Your Seizures: Workbook*. Joel Reiter, Donna Andrews, Charlotte Reiter, W Curt LaFrance. Oxford University Press, 2015.

9