

***Mental Health and Epilepsy***  
**CURE Epilepsy Webinar**  
**(Transcript)**

Laura Lubbers:	00:00	Welcome everyone to today's webinar. I'm Laura Lubbers and I'm the Chief Scientific Officer of CURE Epilepsy. And I want to thank you for joining us today. Today's webinar is entitled Mental Health & Epilepsy: Improving Quality of Life, and it's intended for everyone, including people with epilepsy and caregivers. Mental health is among the many issues that can affect both children and adults living with epilepsy. While some people may experience few mental health issues, others may suffer the debilitating problems of anxiety, depression, or mood disorders. It is imperative that clinicians address and treat these psychiatric symptoms early in each individual's journey with epilepsy to reduce the negative consequences they might have on long-term quality of life. In fact, many clinicians and patients agree that treating anxiety and depression may help improve the quality of life for people with epilepsy, even more than reducing seizures.
Laura Lubbers:	01:01	This is the fourth webinar of CURE Epilepsy's 2022 leaders in research webinar series, where we highlight some of the critical research that's being done on epilepsy. Today's webinar, like all of our webinars, is being recorded for later viewing on the CURE Epilepsy website. You can also download transcripts of all of our webinars for reading. For over 20 years, CURE Epilepsy has raised millions of dollars to fund epilepsy research that supports our mission, which is to find a cure for epilepsy by promoting and funding patient-focused research. CURE Epilepsy provides grants that support novel research projects, and that advance the search for cures and more effective treatments. To date, we've raised over \$85 million to fund over 270 research projects from investigators around the world.
Laura Lubbers:	01:53	In Today's webinar, we'll discuss the prevalence of anxiety and depression among people with epilepsy. Viewers will learn how anxiety and depression impact people with epilepsy in different ways. And that neurologists often have multiple tools at their disposal to help alleviate these psychiatric symptoms.
Laura Lubbers:	02:11	In some cases, the treatment of these symptoms may influence the treatment of seizures themselves. This webinar is presented by Dr. Heidi Munger-Clary, an Associate Professor and the Epilepsy Fellowship Director at Wake Forest School of Medicine. Dr. Munger-Clary is an adult epileptologist whose research focuses on anxiety and depression and epilepsy. The overarching goal of her work is to develop and test strategies to use in the clinic to close the gaps in screening treatment and impact of these comorbidities. She is chair of the American

Epilepsy Psychosocial comorbidity, special interest group. She's chair of the American Academy of Neurology, Epilepsy Quality Measurement Work Group, and co-chair of the Integrated Mental Health Care Pathways Task Force of the international league against epilepsy's psychiatry commission. Very busy person.

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| Laura Lubbers:      | 03:09 | Before Dr. Munger-Clary begins, I'd like to encourage everyone to ask questions. You may submit your questions anytime during the presentation, by typing them into the Q&A tab located on your Zoom panel and click send. We'll do our best to get through as many questions as we can. We do want this webinar to be as interactive and informative as possible. However, to respect everyone's privacy, we ask that you keep your questions general and not specific to a loved one's epilepsy. So, with that, I'll turn it over to Dr. Munger-Clary.  |
| Dr. Heidi Munge...: | 03:42 | Thank you so much. I'm delighted to be here today to speak about this important topic. One of the things that we'll be doing is trying to introduce the topic in a way that can make you think about different approaches, to thinking about anxiety, depression, and other mental health symptoms in epilepsy, in a way that can help enhance life. And let's see. I'm figuring out the best way for me to advance my slides. Let's see. For some reason, the slides do not seem to... Aha. We got it. Thank you for your patience.  |
| Dr. Heidi Munge...: | 04:27 | So what we'll cover today are a few different topics. First, introducing some of the importance of mental health and epilepsy, and then thinking about how we can categorize symptoms related to mental health that affect people with epilepsy in a way that helps us determine what types of treatment approaches to address the symptoms might be most appropriate. And this is really important, both for patients and for neurologists and epilepsy caregivers to think about because the way that we examine the symptoms and their timing can really help lead us to the next steps to improve symptoms. And we'll talk about how to treat symptoms and some resources for patients and families. Let's see. |
| Dr. Heidi Munge...: | 05:27 | The technical challenge I have in advancing my slides is that the arrows are blocked by my menu bar. Here we go. My menu bar is blocking it. I apologize for this technical issue, what I'm going to do, if it's okay, is I'm going to ask for the slides to be advanced because the arrows are being blocked and that's the only way that's working. So, thanks for the patience with that.  |

Dr. Heidi Munge...:	05:58	<p>So why are we talking about mental health and epilepsy? Mental health problems are really common among people with epilepsy. When we look at lifetime diagnoses of a psychiatric condition, one-third of people with epilepsy will experience this over their lifetime. And at any one given time up to a quarter of people with epilepsy may have a current psychiatric diagnosis. In addition to this, up to 50% of people may have high symptom scores when symptoms are measured in clinic visits or may experience other kinds of mental health symptoms related to treatment at different times in the course of their epilepsy. And the overall risk is increased two to five times the general population in terms of the number of people with epilepsy affected by mental health problems compared to the general population. So, it's really more pertinent for people with epilepsy than the general population, and the most common disorders include depression and anxiety. We'll move on to the next slide.</p>
Dr. Heidi Munge...:	07:10	<p>So epilepsy and mental health have what's called a bidirectional relation. And what this means is that we found from epidemiologic studies, that there is a dual relationship between mental health and epilepsy. For example, people may have increased chances of anxiety, depression, or other mental health problems, even before seizures start. And likewise, after the onset of epilepsy, there can be an increased risk of developing anxiety, depression, or other mental health problems. Why is this the case? Well, there's research looking into this question, but most likely it reflects in part a common underlying cause to some mental health problems and epilepsy, and this is complex, but for some individuals, there's evidence that there may be some genetic links that connect the two types of conditions. There may be relationships to neurotransmitter function in the brain and even relationships to hormonal brain functions, such as the hypothalamic-pituitary axis. In recognizing the importance of mental health to epilepsy, the most recent update of the definition of epilepsy in the past 10 years includes not only recurrent seizures, but also psychosocial consequences of epilepsy, including mental health.</p>
Dr. Heidi Munge...:	08:44	<p>So epilepsy and mental health have a lot of impacts on the lives of people with epilepsy. One of the most important things that has been identified in the past couple of decades is that symptoms like anxiety or depression are really impactful on quality of life and epilepsy. Multiple studies have demonstrated that anxiety and depression are bigger, independent predictors of poor quality of life among people with epilepsy, more than seizure frequency. And so, when we think about the everyday care of people with epilepsy, those clinic encounters often really</p>

focus on seizure frequency and seizure treatment, but examining and tackling anxiety and depression may actually help improve people's lives to a greater extent. We've also seen multiple research studies demonstrating the other impacts of mental health problems on people with epilepsy. There have been links between mental health problems and more severe epilepsy, increased healthcare costs, and increased need for intensity of treatment, such as hospitalizations.

Dr. Heidi Munge...: 10:01

People who have mental health problems and epilepsy are more likely to experience side effects of medications. Also, people with, for example, anxiety or depression and epilepsy often report worsened cognition compared to those who don't have these symptoms. And anxiety and depression and other psychiatric conditions are associated with increased mortality, both from suicide and other causes. So, it's really important that we address mental health and epilepsy. And so now what we're going to go on to talk about are some of the different causes of mental health problems in epilepsy, and some helpful categories to think about what sort of treatment approach might be most appropriate. So, we're going to think about four main categories of symptom types when we think about mental health and epilepsy. Some of these are directly related to epilepsy and its treatment, and others are more similar to general mental health problems that we see in the general population.

Dr. Heidi Munge...: 11:09

So if we look over here at this circle diagram, we'll talk about each of these categories. And first over on the left and the top are some more epilepsy-related types that we'll talk about first. Iatrogenic is a word that means caused by treatment. And there are some mental health problems that are directly caused by the treatments that we provide as epilepsy providers. And it's really important to be aware of these so that we can tackle the prevention and management of these symptoms. Peri-ictal up on the top of the circle are symptoms of mental health issues that are related to the timing of seizures and have a unique epilepsy-oriented treatment approach. There are also symptoms that happen over in the circle diagram. You can see them on the bottom and on the right, which happen in between seizures or no relationship to seizure timing, and maybe approached similar to general population management for depression, anxiety, or other things, although, some of these symptoms are actually specific to epilepsy.

Dr. Heidi Munge...: 12:22

So when we think about these different categories of symptoms, we think about their importance because the management approach varies depending upon which category

of symptom we're facing. So, this is why it's useful to think about these categories. When we think about the iatrogenic causes, which we'll talk about on the next few slides, the cause is changes in seizure treatment. And oftentimes the approach is to change the seizure treatment and reverse that problem which arose. When we think about the other two categories here to our right, peri-ictal mental health problems and interictal mental health problems, these are problems that are not directly related to epilepsy treatment itself, but it's important to think about what is the relationship of the symptoms related to the timing of seizures, because there are different treatment approaches related to that.

- Dr. Heidi Munge...: 13:23 In the middle here where you see the peri-ictal types of symptoms, this means that the symptoms are related to seizure timing. They happen around the time of seizures and the best treatment is to prevent it by controlling seizures. When it comes to interictal symptoms, and I should mention that ictal means seizure, so that's why that is in both of these terms. Interictal mental health symptoms, such as anxiety and depression occur independent of the timing of seizures. It means between seizures. And sometimes these are related to epilepsy, but in other situations, this may be similar to mental health problems that occur for people without epilepsy. So that's why we're going to talk about these different categories separately, because they have different approaches for clinicians to try to help alleviate symptoms.
- Dr. Heidi Munge...: 14:15 And we'll move on to the next slide. So we're going to dive into the epilepsy treatment-related symptoms first. These are the most directly addressed by neurologists. So there are some seizure medications that directly may cause symptoms of anxiety, depression, or other behavioral problems.
- Dr. Heidi Munge...: 14:33 And sometimes epilepsy surgery may also lead to symptoms. So, we'll talk about those in more detail on the next few slides, what some of the examples of these types of effects could be. Sometimes epilepsy treatment may have an indirect effect on mental health. For example, the effects of testing in an EMU may have an emotional impact afterwards. And at times some of the seizure medications that we prescribe may interact with medications, such as antidepressants used for mood. And we need to be aware of this so that we can respond and optimize treatment. So we'll move on to that next slide and talk about some of the seizure medication-related mental health impacts.
- Dr. Heidi Munge...: 15:18 Now, most people don't necessarily have anxiety or depression symptoms caused by the medications here on the list. However,

there's a subset of individuals who, when they're prescribed some of our most common anti-seizure medications, such as Levetiracetam, may develop symptoms of depression, anxiety, or other types of mental health problems.

Dr. Heidi Munge...: 15:44

Although it's a small subset of individuals who develop these types of side effects, they can be quite impactful. And the good news is that modifying treatment either by reducing the dose or switching to a different medication can alleviate symptoms if the seizure medication is causing the side effects. If you look at these boxes over to the right side of the slide, they list medications that are often associated in some patients with symptoms of depression at the top, anxiety, or some other types of behavioral symptoms. And as I mentioned, not everyone experiences these kinds of side effects. It's actually a pretty small minority of patients. But when it does happen, it can really be improved by changing the medications. And some individuals are at a bit higher risk for these types of effects. Those patients who have already had some mental health struggles with anxiety or depression, for example, or people with a family history of psychiatric problems might be at somewhat higher risk for anxiety or depression or other symptoms caused by anti-seizure medications.

Dr. Heidi Munge...: 16:59

We'll move on to the next slide and see some medications that actually can improve anxiety or depression. They're listed here. In the top box. Lamotrigine often does help with depression for some people with epilepsy. And the medications listed below Lamotrigine may help with depression or anxiety. The bottom box includes medications that help anxiety for some patients. So, these medications may be a good choice for someone who has anxiety or depression. And likewise, if one of these medications is removed from someone's treatment plan, sometimes mental health problems may arise. So, it's really important to be aware of whether or not any symptoms are changing with changes in seizure medication treatment so that your neurologist can work with you to help improve your symptoms and prevent any problems from the seizure treatment itself.

Dr. Heidi Munge...: 17:58

Now we'll move on to epilepsy surgery. So resective surgeries or other surgeries such as laser ablation can have a wide variety of potential psychiatric effects. Now actually, most people who have a surgery such as this have improvement in mood or anxiety over time after the surgery, but some individuals experience a variety of different psychiatric symptoms after surgery. And those who already had some psychiatric conditions or family history might be at higher risk. So, this is something to

keep an eye out for so that your neurologist can respond and help treat if anything comes up after an epilepsy surgery.

- Dr. Heidi Munge...: 18:44 Now we'll move on to the next slide and talk about neurostimulation surgery treatments. So, it's been an exciting time in epilepsy treatment in the past few years because we have new additional stimulation devices available for treating people with epilepsy. And what we have found so far is that some individuals who received deep brain stimulation had some new or worsening psychiatric symptoms. There may be ways that this technique can be modified over time to prevent these types of reactions.
- Dr. Heidi Munge...: 19:20 But some individuals may work with their neurologists to select other types of neurostimulation that might be less likely to worsen mental health, such as responsive neurostimulation, which has not had any adverse psychiatric effects identified or vagal nerve stimulators, which are actually FDA approved to treat depression.
- Dr. Heidi Munge...: 19:41 We'll move on to the next slide and talk about some other ways that treatment might impact mental health. So sometimes after EMU testing, patients may develop seizure-related mental health symptoms, and we'll talk more about seizure-related symptoms on the next slide. And some seizure medications may reduce levels of antidepressants, specifically Carbamazepine, phenytoin, and phenobarbital. The way that can be managed is that antidepressant doses could be increased in response to try to help keep good mood treatment on board if seizure medicine may affect those medications.
- Dr. Heidi Munge...: 20:20 All right, so now we're going to switch gears and talk about the relationship that may exist between anxiety, depression, or other mental health symptoms and the timing of seizures, and how this helps us know how to manage these symptoms and prevent them.
- Dr. Heidi Munge...: 20:37 So, as I mentioned on the previous slide interictal symptoms may happen at any time, not related to the timing of a seizure. And then here on the far right, peri-ictal symptoms occur around the time of a seizure reliably. For example, some patients may experience preictal symptoms. Oftentimes anxiety is a common one that's seen in the preictal period reliably before seizures. Ictal symptoms, what that means is that there's an emotional symptom that's actually occurring during the seizure. It's the seizure itself. And one of the most common examples of this may be an ictal fear, meaning a seizure that's an intense fear sensation that comes on and off. And it's

important to be aware that some seizures may have emotional symptoms as their manifestation to ensure that these are accurately diagnosed as seizures and treated as seizures and not confused with a primary psychiatric condition that would be treated in a different way.

Dr. Heidi Munge...: 21:45 And then finally, in the peri-ictal psychiatric symptom group, we have postictal symptoms. These occur after seizures. And typically, if someone experiences postictal psychiatric symptoms, there's a period of time after recovering from a seizure where things seem relatively normal and then symptoms may come on, anxiety, depression.

Dr. Heidi Munge...: 22:09 And we'll move on to the next slide. We'll talk about psychosis. This is a rare condition that sometimes happens after seizures or a cluster of seizures that it's useful to be aware of in case it occurs so that you can talk about a management plan with your neurologist. So a very small percentage of people may have clusters of seizures, recovery after the seizures, and then the occurrence of some real intense symptoms of paranoia, hallucinations, that may last a few days and may come on as much as almost a week after the seizures. This condition usually resolves on its own, but it does require supervision and may require treatment. And so, it's worth having some awareness that this type of condition can occur, but it can be managed and prevented in partnership with your neurologist.

Dr. Heidi Munge...: 23:10 So when thinking about the concept of peri-ictal symptoms, the thing to consider, and it's really important that this is a shared process of the neurologist and the patient together. Are there symptoms that only occur around the time of seizures? If so, that's something to talk with your epilepsy clinician about because it will help in treatment planning. Treatment is directed at seizures when it comes to symptoms that are in the peri-ictal period, only around the time of seizures.

Dr. Heidi Munge...: 23:43 Okay. Now we'll move on to the next category of mental health issues. The ones that happen without a relationship to seizures and not directly caused by epilepsy treatment. These are the interictal mental health issues. And the two most common general mental health disorders that we see in adults with epilepsy. They're also very common in children are depression [inaudible 00:24:08]. A few examples of some epilepsy-specific anxiety concepts.

Dr. Heidi Munge...: 24:22 And so we'll move on now and talk about some of the features of anxiety and depression. So, depression is characterized by at least one of two main features, and then some additional



features. This includes depressed mood, hopelessness, or a negative outlook for the future. And potentially loss of interest in usual activities. This comes along with other symptoms related to changes in sleep, eating, activity, energy thinking, or some other symptoms like feeling worthless, guilty, or thoughts of death. Those are the symptoms that occur in depression. Bipolar disorder is not as common as depression in people with epilepsy, but it is important to be aware of because it is a bit increased in prevalence for people with epilepsy compared to the general population. And the treatment approach differs for bipolar disorder as compared to depression. So bipolar disorder involves depression and a history of something called a manic episode.

Dr. Heidi Munge...: 25:32

And the reason why the distinction is important is that some of the first-line treatments for depression, the first-line antidepressant medications can worsen bipolar disorder and can cause manic symptoms. So what is a manic episode? Well, it involves some real intense symptoms over a period of time that are disruptive to people's life. And as you can see on the slide, here's a couple screening questions for mania. This can be some real high-intensity energy, feeling elated, so active, minimal sleep for days at a time that disrupt life, or it may involve some real intense irritability, arguments, altercations with other people that are not normal for someone's typical interactions. And so not that many people with epilepsy have mania, but it's really important to try to identify this if someone has depression so that the appropriate therapy is provided.

Dr. Heidi Munge...: 26:37

And individuals may be at risk for bipolar disorder if they have depression starting at a very young age in the early 18 years, or if there's a family history of bipolar disorder, or if they've tried antidepressants and symptoms like these screening questions arose during that time. Okay, now we'll move on to talk about two of the [inaudible 00:27:00]. Generalized anxiety disorder involves excessive and difficult to control anxiety or worry most days of the week for an extensive period of time, at least six months, and it causes distress. It includes other features as well, such as problems with sleep or irritability or muscle tension or restlessness. Now we'll talk about panic disorder, briefly introduce those symptoms. So, panic disorder is another anxiety disorder that's often seen in people with epilepsy, and it is characterized by recurrent unexpected panic attacks. And those are followed by at least one month of significant worry about the attacks. And what's a panic attack?

Dr. Heidi Munge...: 27:46

It's an intense fear or discomfort, which I recognize that sounds similar to this ictal fear that I was talking about on a previous

slide, and it can be tricky to distinguish. But in a panic attack, the symptoms of fear tend to come on a bit more gradually and to leave a bit more gradually than a seizure that has fear. For example, the symptoms build up slowly and peak in about 10 minutes and then come off. As opposed to a seizure, which is more like a sudden on off lasting, less than two minutes. Panic attacks involve not only this fear sensation, but then also these different thoughts, a variety of different bodily sensations, such as shortness of breath, tingling, dizziness, nausea, a combination of some... Not everyone experiences all of the things on this list, but a few of these different symptoms. Okay. So that's an introduction to a couple of the most common anxiety disorders and mood disorders that are worth understanding or hearing about the features people with epilepsy.

Dr. Heidi Munge...: 28:58

There are also some epilepsy-specific anxieties, and I'll briefly introduce a couple of those. Anticipatory anxiety of seizures is an excessive fear of having a seizure, that includes constant worry about having a seizure and concern about their possible consequences. And it's specific to the occurrence of seizures. That's the additional element that's different from some of the general anxiety disorders. And this may have some aspects of a dual treatment approach, which is why it's important to know about this type of condition where on the one hand you may be treating anxiety symptoms to help manage this, and you also may focus on certain strategies to help with seizures themselves. On the next slide, we'll talk about some other epilepsy-specific anxieties. Some individuals may experience phobia about seizures specifically, for example, behaviors that involve avoiding circumstances where seizures have occurred before, and this can be quite disruptive to people's lives. Or epileptic, social phobia, which may involve fear about being seen during a seizure and it interferes with normal life.

Dr. Heidi Munge...: 30:18

And these conditions may have some specific approaches related to the epilepsy or seizure occurrence themselves in addition to managing with anxiety approaches that would work for other types of anxiety as well. So now what we're going to do, now that we've introduced the concept of different types of mental health symptoms. We'll briefly go over some tools that neurologists, epilepsy, clinicians, and other physicians can use to identify depression or anxiety symptoms. And I'm going to introduce two brief depression screeners and anxiety screeners that you may see in clinical practice. The first is the NDDI-E, which is a six-question depression screener that was developed specifically for people with epilepsy. And it's the most well-validated instrument to detect depression and people with

epilepsy. You can see on the left side, the items that individuals are asked to rate over the past two weeks, and these are really core depression symptoms that are unlikely to be confused with side effects of medications or epilepsy-related symptoms.

Dr. Heidi Munge...: 31:32

So this is a very brief and easy-to-use tool that some neurologists may use in the clinic to identify depression. If we go to the next page, we can see the items that are part of another instrument called the PHQ-9. This is a depression screener that's often used in primary care, and it has been validated in epilepsy as well. It includes items that hit on the specific diagnostic criteria for depression. So, you may see your neurologist or other clinicians using these kinds of instruments in the clinic as well. The one downside to this instrument that some of us see and why we might favor the NDDI-E for some patients, is that there are some items like this one trouble concentrating on things that might not really be specific to depression for some people with epilepsy.

Dr. Heidi Munge...: 32:29

Now we'll talk about some anxiety screeners. So, this is the list of questions that are part of the Generalized Anxiety Disorder-7. This is an instrument that's been validated to detect anxiety, people with epilepsy and multiple languages, and can be a helpful tool to identify anxiety. It tends to focus on generalized anxiety and not some of the other types of anxiety that we talked about on the previous slides. And it wasn't designed specifically for people with epilepsy, although it can be very useful in epilepsy. If we go to the next slide, we'll see some of the questions from a new instrument called the brEASI, which is one of the two epilepsy-specific anxiety instruments that has been recently designed. And this may be very useful to neurologists over time, because in addition to including some general symptoms of anxiety, it has a little bit of information that might clue clinicians in about panic, for example.

Dr. Heidi Munge...: 33:38

If you look about halfway down the slide, you can see, I got sudden feelings of panic, unrelated to my seizures. It also touches on some potentially epilepsy-specific symptoms that people may experience such as, I avoided places where it would be difficult to get help if I had a seizure. So this instrument may be really helpful to start delving into the different types of anxieties that people experience so that we can really target treatment to the wide range of anxiety that some patients may experience. There's also a longer version of this called the EASI, which has a few more questions about epilepsy-specific anxieties, and may be useful to some of the epilepsy clinicians. And this leads right into our discussion of treatment, because understanding what types of symptoms patients are

experiencing and the relationship to seizures and treatment really is what informs our approach to try to help improve these symptoms and improve people's lives.

- Dr. Heidi Munge...: 34:41 So we'll go over from a broad perspective, what is the treatment approach for each of these categories? So, this epilepsy treatment-related symptoms, those iatrogenic symptoms, the approach is to try to reduce that offending agent. So if the medication is causing the symptoms, adjust the dose, eliminate it. Also, planning ahead and trying to select treatments together through a shared decision-making with your neurologist can help reduce the chances that these kinds of problems may arise from epilepsy treatment. Now, we'll talk about those peri-ictal symptoms. What do we do if someone has peri-ictal symptoms?
- Dr. Heidi Munge...: 35:26 Well, the main treatment approach is to adjust seizure treatment and really try to get better seizure control. This can be challenging for people who have medication-resistant seizures. So, considering all the range of seizure treatment options can be helpful. And sometimes rescue medications for clusters can be helpful if someone has had post-ictal psychosis, watching out for warning signs of that, and sometimes coming up with an action medication plan and family supervision if someone has had post-ictal psychosis in the past, they develop it again. Those kinds of action plans can really help to manage and reduce the impact.
- Dr. Heidi Munge...: 36:07 Okay. So now when we think about interictal anxiety and depression, what kinds of treatment options are out there? There's a wide variety of options, and there are some barriers and challenges that we face for some of the specialty referrals. We'll talk about all of this in the next few slides. But there are some self-directed things that patients can do with a little bit of information, and sometimes that's a really appealing option. Medication treatment is an option and that's becoming more and more available in neurology clinics and non-psychiatry type settings. Then there's referrals for mental health specialty care. And there's a whole array of self-management programs that have been studied in recent years. And they're available at some epilepsy centers and through some community organizations. So, we'll dive in a little bit more into some of the self-directed management options that are out there.
- Dr. Heidi Munge...: 37:03 So there's a lot of education materials out on the web for helping to optimize all sorts of different things that can help mental health. Also, your neurologist or clinician may have some targeted education that they can provide to you at your

visits. For example, in my health system, I'm able to provide different handouts about different lifestyles and wellness and healthy habits that can really help people with anxiety and depression, relaxation, exercises, different things that folks can do on their own at home that might already start to make an impact. There are apps available for relaxation for other types of techniques. For example, there's an app called Headspace, that a lot of the psychiatrists I know are really like to use with their patients. Exercise, relaxation, mindfulness, yoga, sleep, and healthy living and social support can all be some things that can start to help tackle these symptoms.

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| Dr. Heidi Munge...: | 38:09 | Now, in terms of things to discuss with your doctor more directly, or that would be a direct action for your doctor to do, antidepressant medications are really helpful for a lot of people with anxiety or depression and epilepsy. There's referrals to different types of mental healthcare. Some centers may have specialty relaxation training or complementary alternative medicine options. Now the options available in your own local environment are going to vary. And so it's important to ask about what might be available, cause there may be some unique options available in your environment.  |
| Dr. Heidi Munge...: | 38:48 | We'll go on to the next slide. I think an exciting development in the epilepsy field is that neurologists are becoming more and more willing over the years to start treating patients with antidepressants. And this is a list of different commonly used antidepressants that are helpful for depression or anxiety disorders.  |
| Dr. Heidi Munge...: | 39:12 | And all those highlighted in yellow here are ones that are very appropriate for potential prescribing by a neurologist or non-psychiatry provider. And so, I think it's a potentially exciting time where neurologists and patients may start to meet at the middle. Now, what do patients want? We recently in our center did a survey of within our own patient practice, individuals who had screened positive for anxiety or depression. And we asked whether or not treatment of these symptoms was a priority. And the vast majority of patients said, yes, it was. And we also asked about different treatment options to see what kinds of treatment approaches were preferred in our practice. We specifically asked people to say whether they would want a medication prescribed in the neurology clinic to manage their symptoms or being referred to a psychiatrist. These were the two most common approaches that neurologists had reported to us in a prior survey. |

Dr. Heidi Munge...:	40:17	We found in our practice that the patients seemed to want to have medications prescribed in the neurology clinic, although, there were different preferences across different patients. If we look at the next slide, we can see a variety of different kinds of treatment options with all these blue bars showing treatment options that patients said that they would be likely to want to try. There were many options that were patients felt they would be willing to try. And two of the most common or most favored options were medication prescribed in the neurology clinic and wellness activities. But lots of other things were potential options as well, including counseling and medication prescribed by a primary care provider or complementary alternative therapies. So there are lots of different options and each patient may have different preferences. Now, what do providers prefer? Or what are they willing to do?
Dr. Heidi Munge...:	41:18	What are the provider level considerations in this area? This summarizes some results of a survey of leading epileptologists in the US a few years back. And the good news is that most of these neurologists were willing to prescribe medications for depression. And oftentimes referrals were also things that neurologists would want to do. There were some challenges accessing psychiatrists and counseling services for patients. And that's one of the challenges that we face as a whole, and that the field is working to try to come together and enhance the options available to patients.
Dr. Heidi Munge...:	41:58	If we look at the next slide, this is a survey that was done more recently among international epilepsy providers. And similarly, there are challenges accessing mental health specialty care, even though that's something that we would like to offer to patients more often. Even internationally, however, prescribing medication is a consideration that clinicians are doing.
Dr. Heidi Munge...:	42:25	So we do have a few different options, some of which the neurologists can do directly. And what is the international community doing to try to address the barriers to mental health specialists? Well, one solution to this potential challenge is to try to integrate models of care, where there's a mental health specialty presence, but not as intense as a referral out to a specialty clinic. This is something called integrated care that we can see on the next slide what a definition of integrated care is. So, this is an idea to partly blend some mental health services along with the seizure care services. And oftentimes this may involve less time total from that mental health specialty provider and be more feasible to overcome the barriers. And so integrated care models may treat both mental and physical needs of people with seizures and better meet that aim to

improve patient outcomes by addressing mental health problems together with seizures.

- Dr. Heidi Munge...: 43:32 And so, with this in mind, the international league against epilepsy has created a new task force to on integrated mental healthcare pathways. And the mission of this group is to try to move the field of epilepsy forward to address mental health via integrated care models. And some of the first efforts related to this are going to be trying to disseminate information about how centers have successfully created integrated care models and to really try over time to move the field forward so that there are more options available to patients.
- Dr. Heidi Munge...: 44:10 On the next slide, we'll talk briefly about some other resources. So, some epilepsy clinicians are not comfortable yet treating anxiety or depression. And so, the American Epilepsy Society has created some brief resources to try to help equip epilepsy clinicians with some tools to help starting to address more closely anxiety and depression for adults or children with epilepsy.
- Dr. Heidi Munge...: 44:39 So, this is a link to the website where there are these resources and on the next slide, is it just a little snapshot of what these brief information resources look like for clinicians.
- Dr. Heidi Munge...: 44:51 Finally, in terms of patients and families, this can be quite a challenging area to figure out how can you help your loved one, especially if things really come down to the worst type of scenario. What if someone's depression is so bad, they're thinking about harming themselves, we're in that emergency type situation. Now there are resources available to help. This national suicide prevention lifeline is available 24/7. And there are also resources for patients and families here. So, in addition to hopefully what are more robust resources that you'll be able to access through your own providers and clinicians, there are also these resources available in emergencies in a widespread manner for everyone.
- Dr. Heidi Munge...: 45:44 So that was a very quick whirlwind of a very complicated topic, but hopefully we'll have time for a good discussion at this point. Thank you so much for listening and thanks for the patience with the technical issue at the beginning.
- Laura Lubbers: 45:59 Thank you so much, Dr. Munger-Clary. This was an excellent review. Lots of great information and lots of great questions have come in that we can start to delve into. And one of the questions actually, it's come up a number of times. What are

recommendations for dealing with anxiety and depression in non-verbal children?

- Dr. Heidi Munge...: 46:22 Ah, okay, so this is a great, and this is a really challenging area because a lot of the work that we've been doing to try to address it has neglected this area. So, one of the things that needs to happen is we really do need a lot more focus and attention to this area. Now, one of the things that I have heard that can be very helpful in terms of tips from pediatric psychologists is really observing the behavior of the patient.
- Dr. Heidi Munge...: 47:00 Listening to the family, what is their intuition about how that person is doing? And then trying treatment approaches. I think it's a real challenging area. Opening a dialogue with the neurologist can be a starting point. But it may really be that for individuals like this, if there's a specialty clinic focused on neurobehavioral care or care of individuals with behavioral issues and developmental delay, that setting might address those patients' needs even in an even more robust way. I will say for myself being a neurologist in practice, really trying to address these kinds of topics in a better way over time, we at our center, we're lucky to have this excellent neuro behavioral clinic.
- Dr. Heidi Munge...: 47:58 And I do find that once I run out of some options for potentially optimizing the seizure medications for behavioral effects, thinking about maybe a very commonly prescribed medication, sometimes an SSRI is worth considering. But getting those patients to the specialized care, I think right now is the best thing to do because this is not an area that the neurologists are really well equipped to start managing themselves, but starting the dialogue and getting the referrals and finding those resources in the community that are appropriate, I think, is the most important thing for it right now.
- Laura Lubbers: 48:40 And that is wonderful advice. And I think this ties into the idea of evolving this integrated care methodology. Bringing this forward, I would encourage our listeners to download this presentation once it's available on our website and it will be, and share it and share the resources with your physician because a lot of this is new. Help them help you as well. Is that accurate?
- Dr. Heidi Munge...: 49:06 I think that's really important. And this is an area that there is work starting to be done with the professional advocacy organizations, as well as I understand it. I haven't seen it come out yet, but the AES I think is working on some resources. And there is a task force of within the psychiatry commission of the



ILAE, that's focused on intellectual disabilities as well, and trying to bring gr greater attention to this area. So, I think that's really important. There also is going to be a session on autism epilepsy at the AES in the upcoming year, which managing behavioral aspects of that sometimes crosses over into this question as well,

- Laura Lubbers: 49:52 Right. This is such a challenging area for families. And it's great to know that there are resources coming forward. Sure.
- Dr. Heidi Munge...: 49:59 Not enough.
- Laura Lubbers: 50:00 Not enough. And encourage your physicians, your care providers to learn more that there are materials coming, but we all need to be learning together. So, here's a question it's come up a number of times in a number of ways. Can you share more about the correlation between hormonal issues and seizures?
- Dr. Heidi Munge...: 50:21 Oh, okay. I'm trying to think about how to focus it in the mental health area, but one of the things we commonly see in day-to-day epilepsy practices that sometimes seizures are related to the menstrual cycle in terms of the timing of seizures. This may also impact behavioral symptoms as well. I'm trying to think about what the best way to focus this response would be. But if one of the questions is a concern about seizures and hormones, doing some careful tracking of hormonal cycle related changes, whether it be the menstrual cycle or even treatment changes that might affect hormones and seizure frequency can be helpful. In terms of the way I alluded to hormones within the brain, potentially being related to mental health issues, that's an area that's primarily in the research zone right now, and doesn't have a lot of everyday practical clinical implications yet from my perspective.
- Laura Lubbers: 51:34 Okay. Okay. Here's a different question around the transition in life related to teenagers. So do medical treatments for anxiety change for younger people, for teens compared to adults?
- Dr. Heidi Munge...: 51:50 So this is an excellent question. So, there is more of a potential concern about whether SSRI, the most commonly prescribed antidepressant category, whether might be higher risk for suicidality in teens than in the adult population. There is a bit more of a regulatory warning associated with these medications in the teen years. So having said that if, for example, a teen is seeing an adult-focused neurologist, or maybe a pediatrician, there might be a bit more reluctance to prescribe. And so there may be more of a recommendation for specialty care. Having said that, SSRIs are used very commonly in teenage people. But

I think the level of expertise to make sure that it's safe and that it's really the right thing to do is important.

Dr. Heidi Munge...:	52:52	There's a lot of behavioral approaches, counseling, psychology-based approaches to anxiety management in children and in adolescents. And it seems that there's a greater emphasis on that when we look at the literature and think about what kinds of treatment recommendations are out there. There also seems to be more psychology resources in many pediatric centers than I have seen in some adult centers. So, to answer the question, the approach may be different, talk to the neurologist and other care providers to see what they recommend. And it may be that more of a specialty-focused approach is appropriate in the pediatric age group.
Laura Lubbers:	53:38	Okay. Okay. Can you explain that a little bit more, the specialty piece?
Dr. Heidi Munge...:	53:43	So it may be that a pediatric neurologist may be more likely to recommend a referral to a pediatric psychologist or a psychiatrist to manage anxiety in either the teenage age group or younger age groups than so then some adult neurologists who might take on the management themselves.
Laura Lubbers:	54:06	Okay.
Dr. Heidi Munge...:	54:07	This may be evolving over time. Talk to the neurologist and find out what their comfort level is. There are a lot of pediatric centers that have really robust psychology resources. So that's the potential silver lining to that question. There might be a resource there in a pediatric setting, more likely than an adult.
Laura Lubbers:	54:30	Okay. Okay. It's really important to have that relationship with your provider and work with them to find solutions. There was a question that came up about, does the person raise the issue or should they rely on the neurologist?
Dr. Heidi Munge...:	54:46	Ah, so this is a great question. We wish that the neurologist would always bring this up. But I think that you can really help yourself, your loved one, your family member. If you have concerns in this area and you bring it up, it's much more likely to be addressed. Some neurologists may address it as a routine. We know from survey data that sometimes they will only address if it's raised by the patient. So do not be afraid to raise your concerns. It can really help lead to it being addressed. So I think it's a great idea to bring it up as the patient.

Laura Lubbers:	55:28	Okay. Speaking on the patient, on behalf of the patient, somebody asked the question, how do you know when for somebody perhaps who's non-verbal, when you should change a medication or try something else?
Dr. Heidi Munge...:	55:41	Ah, so good question. And in terms of the question, if we're thinking about, is there a mental health side effect, a behavioral side effect from the medication, for example, observing behaviors and behavior changes as a medication has been added. For example, one of the medicines I listed as often good for anxiety, Clobazam, sometimes this causes agitation and behavioral problems, and it seems to be more common among intellectually disabled people. So if a new medicine is added, watching your loved one's behavior and seeing, is something changing that makes me concerned? Bring it up with the neurologist and see. And then if it is the medication, medication could be reduced or taken away, and then you'll find out if that was the cause.
Dr. Heidi Munge...:	56:37	Now, how do you tell if a medication specifically for mental health is working for your loved one? I think it would be similar to observing the behaviors that were the concern in the first place, and that led to prescribing that medication. Is that improving with the treatment? If it's not, then it's time to go back to the prescriber and think about what else could be tried to help.
Laura Lubbers:	57:04	Okay. Wonderful. Does it make sense for families to stay in touch with their provider more frequently as there's a medication change?
Dr. Heidi Munge...:	57:15	I do think it's a good idea, specifically, if you notice a change that is of concern. Sometimes people feel like they need to wait until the next visit to bring these kinds of issues. It's important to know what's the best way to work together with your neurologist. I do think though that most neurologists, if there's a problem with the medicine, would rather hear about it sooner to be able to respond than not. But check with your neurologist as well to see what their recommended approach would be.
Laura Lubbers:	57:55	Okay. Wonderful. Well, we are almost up on time. We have an enormous number of questions and comments that we have not gotten to. But we will take a look at what people have submitted and see if we can consolidate some of the topics and perhaps bring you or another recommended speaker back to address those issues. This was a wealth of information, very helpful.

Laura Lubbers:	58:19	So I want to thank you, Dr. Munger-Clary for your presentation and our audience for just such amazing engagement and support. If you have any other questions, please do submit them to via our e-mail address at <a href="mailto:research@CUREepilepsy.org">research@CUREepilepsy.org</a> . You can also check out our CURE Epilepsy website for more information about our programs and webinars. I also just want to briefly mention that we have another webinar coming up on June 14th, which is being presented in partnership with our friends at Wishes For Elliot and Partners Against Mortality in Epilepsy, or PAME. That webinar will discuss what we know about some unexpected death and epilepsy or suit up for rare epilepsies and provide strategies for mitigating the risk of suit up within this population.
Laura Lubbers:	59:07	So I want to thank you all again. Be well and see you soon.