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AN EVALUATION OF THE USE OF CANNABIS IN EDS WITH CHRONIC PAIN

Webinar

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Ellen Lenox Smith

Video https://youtu.be/fVw38_2bjkA

[00:00:00]

[00:00:06] **Jessica Adelman:**

Hello and welcome to our webinar, and happy Ehlers-Danlos awareness month! My name is Jessica Adelman and I work in social media and communications for The Ehlers-Danlos Society. Today, we have Ellen Lenox Smith presenting on “An Evaluation of the Use of Cannabis in EDS and Chronic Pain.” This webinar is part of our ongoing series, “Living with EDS and HSD.”

A quick – Ellen Lenox Smith has emerged as a leading voice for patients in living with pain in Rhode Island. Ellen suffers from two conditions: Ehlers-Danlos Syndrome and Sarcoidosis. She turned to medical marijuana in 2007, in Rhode Island, when it was determined that there were no other options that she could metabolize. Since experiencing what a change

this has made in her life, she became committed to advocating for it across the country. Ellen is a Rhode Island ambassador, a co-director with her husband for cannabis advocacy and on the board of the US Pain Foundation, on the board of the Rhode – and on the board of the Rhode Island Patient Advocacy Coalition as secretary.

Thank you so much, Ellen, for being here today.

[00:01:08] **Ellen Lennox Smith:**

OK! Thank you! I hope you can all hear me. I appreciate the introduction and we're going to go forward, and in case anybody's never actually really seen a cannabis plant, I thought you'd might like to see a picture of an actual bud, and we will move forward from there and learn what use this product would have for our bodies.

[00:01:29] Slide 2

I first want to make sure you understand the disclaimer that these are my personal recommendations. You should talk to your doctors and your pharmacy staff at your dispensary if you're in a legal state as to what's going to be best for you, but I will today share what seems to have worked really well for me and for some of the patients that I actually grow cannabis for.

[00:01:48] Slide 3

So, for an introduction, I am a mother of four adult sons now. I have four grandchildren. I was diagnosed in 2006 with classical Ehlers-Danlos. Unfortunately, not diagnosed until the age of 54, which is, as you all know, inexcusable. I also, one year later, became diagnosed with sarcoidosis, with granulomas and enlarged lymph nodes in my chest, which was unfortunate to have two things coming here to have to face. I was a former middle school Social Studies teacher. I was a master swimmer, a high school swim coach, organic gardener, a reader, walked many miles, and today, I am a different person. I presently have had now, 24 surgeries. Right now, you can probably see the wires hanging here. This is a bone stimulator in the back of my neck, I just recently had another neck fusion four months ago. As was stated, I am co-director with my husband for cannabis advocacy for the US Pain Foundation. I was a former writer for the Pain News Network and today, currently write for National Pain Report and *1000 Watts* magazine.

[00:02:54] Slide 4

This is just a picture to show you a plant, and then the final product that will come out of a plant. That will be the magic, at least for me, to help me with dealing with my life in pain.

[00:03:07] Slide 5

So, why did I turn to cannabis? As many of you probably can relate to, I've been reactive to everything since birth. In fact, the doctor actually said to my mother, I seem to be allergic to my own body, but no one thought anything of it, and you just go on living your life. I found that any time I had to take medication, it always ended up making me more sick than just living with whatever was going wrong.

So, I was encouraged by a pain clinic doctor, to try cannabis. I, at that point, was not sleeping. I was desperate for some form of relief, facing another surgery out in Wisconsin at the time and I was still teaching, and I really just didn't know what to do. Everything else I tried just didn't seem to help. Eventually, a doctor in Wisconsin, before I flew out there, also asked me to have DNA drug sensitivity testing to confirm what would be compatible for my body. And this is about a year after starting cannabis that I actually had that test done, and interestingly enough, the testing done showed two, what are considered controversial things, that only came up that I can metabolize. One is ketamine, which I use when I am out of state, in an illegal state, and in a hospital, and the other one is cannabis, which I'm actually missing an enzyme for, but still have tremendous success with getting pain relief. So that is why I turn to it, and to be honest with you, I had tried it in college once. I did not like the sensation of lying in bed, feeling like I was in and out of sodium pentothal. It wasn't my idea of fun. So, that when the doctor suggested this, which had never once occurred to me, I literally sat there and laughed, and told him my parents would roll over in their graves listening to this conversation. OK.

[00:04:48] Slide 6

So how is it that cannabis can be helpful with EDS for chronic pain? Number one, we all tend to be drug reactive with dealing with Ehlers-Danlos. We all tend to have issues with food sensitivities. And, studies have shown that there's little interaction with other medication with using cannabis. And studies show that there's little side effects to using cannabis. Although it won't cure us, it will provide us with a gentle calming to the body and give us restorative sleep, which is so important. I don't

think it matters what we have wrong with us, if we can't get any rest and sleep, then it's almost impossible emotionally to cope the next day and to feel like you're going to move forward and have hope. And evidence suggests it's a powerful antioxidant also to help support the immune system. So, these are all positive reasons to consider this, if you want to look for another option.

[00:05:40] Slide 7

So, should I assume that I'm going to get high using cannabis? Society has led us to believe that we get high like a recreational user, but remember, taking too much of any medication can cause reactions, so the dose does matter. You can use cannabis and get the high because you've taken too much, or you can use cannabis, be careful with your dose and instead, you're going to be a body in pain, and you're not taking too much, so what you get instead is pain relief, instead of what you're going to assume to be that stoned sensation. So, people generally, when they hear you use cannabis, assume you're just on a high, and you're not. Unless, as I said, you take too much.

There are night–daytime plants called sativa strains, and there's many different types of sativa strains. What they provide for you is pain relief, along with a stimulant feeling, so you can return to a more functional, productive day. At nighttime, you'd want to switch to an indica strain. It's going to provide pain relief also, but instead, it's going to be a calm sensation, a sedative sensation. That's going to relax and calm your body, and help you obtain quality sleep.

So, it's very important, if you get in to trying cannabis, understand: are you taking a daytime plant or a nighttime plant? I can't tell you how many times somebody doesn't pay attention to that, gets all upset and says, "Oh I took cannabis and I ended up being awake all night long," and then you find out that they took a daytime plant that has the stimulant, so it's very important to identify and find out from wherever you're going to be getting this product: is it for day or is it for night?

[00:07:22] Slide 8

And this is just a quick little picture to show you. We actually make our own topical. You can take the oil I use at night and ingest, and you can actually create it with some beeswax and some peppermint extract, and make a cream that you could rub onto you body, and it absorbs into the pores and helps with pain relief.

And I had one patient one time that was a representative, state representative that had horrible pain in her mouth for another condition, and she would suck on these little candies I would make with the oil, and that would help to relieve her pain. The only problem she had, I had to change it from lollipops to these little candies because everybody kept asking her for a lollipop, so we made these little candies instead, that she would pop in her mouth. So, there's going to be various ways to try this out.

[00:08:08] Slide 9

You can administer using it in oil form. My oil is actually one that I pour out of a bottle and measure it in a teaspoon. You can go to a center and they might have an oil very concentrated in a syringe, so just be careful and listen to the directions if you're gonna go for any of these products and pay attention to how you're supposed to take it.

You can vaporize. Well, I have sarcoidosis in the chest. If I smoke anything, it would be fatal. So that was never an option, so the doctor, the pulmonologist, was actually 100% behind vaporizing. When you vaporize cannabis, it's going to be less of a smell than smoking, but when you blow out, it's going to look just like smoke, but it's not. It's just water vapor that's coming up. So, it's a very safe, quick way to administer.

There's pops, there's candies, there's tinctures, there's edibles, smoking it, or you can even choose the large fan leaves.

Let me go back to the edibles for one second. I think you need to be very, very careful with Ehlers-Danlos and the fact that we already are reactive to foods, and if you haven't identified what those foods are, and then you go eat a nice cookie that somebody hands you with cannabis in it, number one, you don't know how much food you're getting- how much of the medication you're getting into you. You're not going to notice anything when you eat and swallow it down immediately, so what tends to happen, is people will suddenly eat the entire cookie and then an hour later, they can't get off the couch, and that's not how this is meant to be. This is meant to offer pain relief and give you some quality of life, not to just get you so you're a blob on the couch, so you have to be very careful with edibles.

Juicing the large fan leaves...If you happen to be fortunate like me and you're in a state that's going to allow you to grow or you have a friend that grows and they're throwing those big fan leaves away, which many people do, you want to see if you can get a hold of those. I have a Lexen juicer. A doctor out in California, Dr. William Courtney, I met at a conference,

and he told me about this. He said, “Don’t you juice your leaves?” And I didn’t know what he was talking about. He sent me home with an article. I called his office in California the next day, they literally sent me a juicer and I started using those leaves. I had just had leg surgery. I had had the surgery a year before on my left leg, with a cadaver tendon to hold my fibula in place. I had just returned back from Wisconsin, had the same surgery on my right leg, met him, came home and started juicing, and within three months, I was totally healed with the bones. From juicing those leaves and sipping that juice down. It had taken me 10 months the year before for the exact same surgery.

So, in the, in the large fan leaves, is what you’re going to hear a lot: you hear a lot right now about CBD, and those leaves are filled with CBD, no THC, so you’re not going to get any high from drinking that juice, but it will help with healing, which there was no question that’s what did it for me. It’s amazing.

[00:11:09] Slide 10:

So, how is it I take my medicine? As I said, due to sarcoidosis in the chest, I’m unable to smoke anything. I had to immediately convert my product into an oil and- and strangely enough, I ended up sleeping for the first time in years. I took a teaspoon of that oil, warned my husband that I had taken it, assumed that I was just going to be just gone and out of it, and instead I went to bed and the next thing I knew, I woke up, and it was shocking. I literally slept the entire night on my first trial of taking some of this oil. You take it at nighttime it activates, and I love it this way, because it activates while you’re sleeping.

[00:11:52] Slide 11

When you take it this way, it’s much safer for your lungs to not be smoking the medicine. It’s easier to store and travel with. I have traveled across the country with a bottle of this oil in a medical bottle, in my bag of medicines in my checked-in suitcase, and I’ve never had any problem with being checked about it at all. I’ve never seen anybody ever open a bottle of medication on somebody at an airport. For many, achieving their true dose can mean less need of medication during the day, for it keeps the body calm into the next day.

We have found that using more than one type of an indica plant helps to create a tremendous (inaudible) of a sleeping oil. So, if you can get the— even the clippings from the Indica plant—remember that picture I showed

you at the beginning, when they take the bud and they clip all the green around it, so it's just a bud that's left the dry out, all those clippings are loaded with CBD and THC. Everything you need that's in that bud, is also in that clipping, and many times people will throw those clippings away. So if you have somebody you know that's growing are you grow, don't throw those clippings; that's what we tend to use to make our oils and we have learned that's, that instead of just using one strain of an Indica plant for making a nighttime oil, we try to put three or four strains in it together, and that way each plant has something a little bit different to offer, and that way you get the combination which is very helpful.

[00:13:22] Slide 12

Tips for using oil. Remember when you're ingesting this medicine, that you have to allow time for it to be absorbed before you're gonna get your pain relief. It's not like you take something and you instantly are gonna feel it when you ingest it down. So, when you first take it this way, it could take up to a full hour to begin to feel a change and say—actually I met one person recently, took them three hours the first time they ever tried cannabis and that's extremely unusual, but you just don't know how your body is going to be. Eventually it will probably take less time for it to activate, so it's important that you want to figure out what time you want that needed relief to let's say, go to bed, and then I'd go back one hour from that time, take my medicine—I always mix it with a little yogurt, applesauce, or something—you never want to just take a teaspoon of oil on an empty stomach or you're going to end up with a nice stomachache.

So, I would mix it with some food and you start with a very, very low dose to introduce this into your system. If you jump—you say to yourself, "Oh, I'm in such pain"—and you jump up to this high dose, you're not going to like the sensation. If you slowly introduce it into your body, and let your body adjust to this, you're going to find it's very gentle and very calming. So, I suggest with this: with this recipe for the oil, that you start with just a teas-, a quarter of a teaspoon, mix it with something and then see how you do.

[00:14:47] Slide 13

Now, you're going to take it one hour before you want to go to bed for the night. The goal is to eventually sleep through the night and not wake up groggy. So, each night you add a little bit more. A quarter teaspoon more until you have woken up and said, "My gosh! I just slept the whole night," and you're not groggy, then stop at that dose. If you're groggy, back it

down and don't go back up to that dose at that time. If that sensation does happen and you get groggy, don't panic. It will wear off throughout the morning and it tells you to be sure to not take that dose again, but instead decrease it a little bit. With the right dose you get to sleep and you do not wake up feeling groggy and that will be the goal for you.

[00:15:35] Slide 14

On top of this, with our condition, it's really important to remember that we always should be focusing on reducing inflammation. No matter what you are facing, inflammation causes more pain with EDS, and thus, that means more subluxations. If our body is inflamed, then things are going to slip even more quickly.

So, there are two things that were suggested to me that were extremely helpful. One was ALCAT or MRT Food Sensitivity Testing. Simple blood test. Unfortunately, here in Rhode Island we've had to pay out-of-pocket for it, but the information is priceless. It gives you a list of foods that you need to stay away from for a good three months and then slowly re-introduce, and that—if you can get those foods that—and it's normally wonderful food that's healthy for you, but at the time it's not compatible to your body. If you can eliminate those, those items for a little bit, it will help to calm the body down and, and it will be incredible change for you with inflammation of reducing.

Also, the DNA drug sensitivity testing. I happen to use a company called Genelex. They are very kind people. You can contact the office, they will walk you through the process. Any time a doctor's interested in starting a new a medication with me, I always first contact Genelex, have them look at my DNA results, and tell me if it's compatible or if I need to switch to something else. So, it's a wonderful tool to have and it's something we can do, there's so little things we can do to help control our lives. This something we can do.

[00:17:11] Slide 15

So, what do I do, how do I find out if I qualify in my state? This is a link that you can turn to and there's many others out there. This site lists qualifying conditions by states and, and also gives you more information about your rules and regulations within your state. You can also contact your Department of Health and to look, and normally that will be right online to get the form to fill out. Many states have programs, but you must have a certain condition to qualify for that program. Unfortunately, the list of

qualifying conditions can be very, very limited. Common, typical things they'll let right into a program is cancer, PTSD, AIDS and so on, and then what about us with Ehlers-Danlos? So, EDS will qualify under the title of chronic pain.

And I have to congratulate New Hampshire. They are so far the only state in the country that literally has Ehlers-Danlos as a qualifying condition. However, they already had chronic pain listed, they did this specifically to make awareness of the condition, because they knew people could get into the program, but they wanted to qualify what Ehlers-Danlos was and, and make people within the state more aware.

[00:18:29] Slide 16

States differ in their application processes, but you typically are required to have a doctor's note or medical record stating that you have one of the list of conditions that you can apply for. A doctor normally is not writing a script, they're just signing a form confirming that you have this condition, and then that would be sent in with the other application forms to the Department of Health. You want to approach a trusted doctor about signing this form, confirming that you have a qualifying condition, and if you're at a loss and your doctor says no, dispensaries can be very helpful and give tips on the application process, and sometimes refer you; here in Rhode Island, we work very hard to not only have doctors be allowed to sign-on, but we also have a couple places where you can take your medical records, get an appointment with the real doctor at this, this—we have one B&B Consultant and Canna Care and they also have the rights to sign a patient on if they qualify.

So, you know, just don't give up. If, if you can find a doctor that is—has a relationship with you and knows your condition, that is obviously the best way to go if you can, and there's also a difference in cost. If you go to your own doctor, you're just paying a co-pay to have them sign. If you go to one of these other places, like Canna Care or B&B Consultant, you have to pay for that doctor's time to sign the form. So, it's a lot cheaper if you can get your own personal doctor.

As a note, there's generally an out-of-pocket cost associated with being certified by a doctor and with registering with the state at this time. No insurers cover medical cannabis. The state of Hawaii right now does have a bill pending that would make it required that insurances would cover cannabis if this bill goes through. It would be very exciting and I believe it's

the country of Germany that is the only place in the world right now that has required insurance is to cover cannabis for their patients.

[00:20:32] Slide 17

So, you want to tell your story if you're trying to help advocate in your state. You'll find that telling your story is the key, so you want to try to find others who will also be able to help share their condition and how this medication's helping them, if you want to move your state forward on cannabis. Many of us already have a medical cannabis program, but we need to improve it. Not one program in, in the state, in any state is absolutely perfect yet, so it's a continual process. You want to share about your condition, how it affects your daily life, how using medical cannabis in the past has made a big difference. Now I say the past, because I want you to remember, if you're in an illegal state, and you're gonna go share your story about how cannabis suddenly has helped your life, you want to be very careful about how you do this. You do you not want to take a chance of being arrested, so you want to use terminology that, when you were in a legal state that you tried this and this is what it did for you, so you don't put yourself in a difficult situation.

And if you're able to attend a meeting, be sure that you want to dress like you're going to work, keep up the language clean, show them that you're not—that you're an everyday person just trying to live with major medical difficulties. You do not want to be perceived as a recreational drug user, which people initially assume, so they're so shocked when normal, everyday people walk into this room to testify and they realize they're just neighbors, friends and family.

[00:22:02] Slide 18

If they want you to come testify, your demeanor matters. Show them that you are their family, their neighbor, their friend, you're in need of safe pain relief. I know you're going to be on your best behavior for this and your goal is to educate. Prepare your speech before you arrive if you're going to go testify to help support your state. Find out what the time limit would be for you to speak. There's nothing worse than to have this nice preparation of a speech, and then two minutes is up and they say, "Sorry. You're all set. Thank you very much. Sit down, please," and you haven't even gotten to your points.

So, you really have to get organized. Consider putting your main points on a card to talk from, instead of just reading, so you have eye contact. It

really goes a long way to look to the representatives and senators that are sitting there, and have them listen to you, and look at you. You want to stay on point. Time is limited and you must respect this or they will shut you off to allow others for their timeslot too. You need to state- state your name. They want to know that you live in that state. You want to share your medical condition, a description of what it does to your daily living, and then share how cannabis has made life more tolerable in the past when you've tried it. Ask them to have a heart and to help you and all the others in your state. And I usually end with something along these lines, that "you never know what life might bring each of you next, I didn't ask to have to cope with this condition please show your compassion."

[00:23:33] Slide 19

Now, advocating for the right wording is important too. Along with sharing your story as to why this would help improve the quality of your life, you also need to discuss what the qualifying conditions are on the proposal. There is no way they're ever going to include every possible medical condition that's out there that causes pain, so therefore, if it's not in the wording in your state law, or you're working towards a bill to get one going, please work hard to try and get something along the lines of "severe, debilitating, chronic pain." That way, we fit in with Ehlers-Danlos, and if you don't get that wording in there, many people will never qualify. There was a time, in the state of Michigan, that a whole bunch of people never signed on to the program, they can't understand why. They had left out chronic pain. As soon as they added that wording into the qualifying condition so many more people were able to join in.

[00:24:29] Slide 20

Wow. I got to the end already? That's amazing. I want to make sure I didn't miss anything. I guess I did. OK. So I want—I want to do, is take questions, and also, if you notice on this page here, I included my email address for you, so if anybody's interested in, in the oil and taking it at nighttime and letting it activate while you're sleeping and then to be honest with you, I'm 68 years old, I've had 24 surgeries and as soon as I went back on my oil, I don't need to take medication during the day. I—it's amazing to me, but the oil I take at night literally keeps my body calm all day long the next day and I'm still, to this day shocked that it's doing that for me. I don't know how many other people can have that same success, but I can't keep my mouth shut and not share this with you, because it's pretty

phenomenal to me that we can actually take something so simple at nighttime and be OK during the day, and I've been able to eliminate many other medications that I had taken, gabapentin, and other things that I took, that I just don't need anymore, with the calming of cannabis into my system. So, I don't know if we have any questions, but I would love to answer them if anybody has any.

[00:25:52] **Jessica Adelman:**

We do have some questions for you.

[00:25:54] **Ellen Lenox Smith:**

OK.

[00:25:54] **Jessica Adelman:**

OK. There is a couple on the questions about hemp CBD, that is available in legal states, can you tell us a little bit about that? It's uses and all of that?

[00:26:08] **Ellen Lenox Smith:**

Absolutely. An excellent question and it's—every, every person right now can go online and order CBD. If it's from hemp, hemp is not cannabis. So, there is nothing wrong with it, it's the same process that I get by taking those big fan leaves and juicing those. All I'm getting out of those leaves is CBD. And I'm not belittling that. It's wonderful, as I mentioned to you, CBD helped to heal my bone from surgery, from 10 months down to three months.

So, CBD is wonderful for the body, but if you're looking for pain relief, you might initially find CBD is, is helpful for your body, but I'm guessing in time it's not going to be enough. Do not be afraid of THC that's in the real cannabis plant. The THC is extremely necessary, as long as you don't take too much of it, you're not going to be high, your body [is] in pain, so if you take the dose it's appropriate for your body, you're going to get pain relief.

So, there's a Dr. Jordan Tischler, out of, I think he's out of Harvard, who has a recent podcast out talking about Ehlers-Danlos and using cannabis, and he mentioned that when the state opened up for CBD after hearing Dr Sanjay Gupta's, not recently, but the program he presented before, he opened up everybody's eyes across the country, that what are we doing? Why are we not helping these poor children's seizures? And many states quickly entered legislation and approved it to allow CBD within their states. What he did say, and it's very interesting, that he said within about six months many of those children that are getting relief with CBD drops,

which is from the hemp, eventually need to switch to the real cannabis and get some of that THC in there to continue to have that success.

So please don't let people scare you about THC. I've been using this since 2006. I am alive and having a fairly decent quality of life because of it, and I have THC in my body every day and it's not ever a time that I ever feel like, "Oh my goodness! Where is, where is my oil? I need to hurry up and take it!" It doesn't work that way. I don't have any craving for it, I just appreciate what it does to calm the body. OK?

[00:28:32] **Jessica Adelman:**

Thank you. There's a couple of questions about oil.

[00:28:37] **Ellen Lenox Smith:**

OK.

[00:28:38] **Jessica Adelman:**

One is, you make your oil yourself, how difficult is that? And one is, what oil base do you use?

[00:28:47] **Ellen Lenox Smith:**

OK.

[00:28:49] **Jessica Adelman:**

She said that some oil bases cause her nausea and indigestion.

[00:28:52] **Ellen Lenox Smith:**

OK. Absolutely. You can pick the oil base that you prefer. I happen to use extra virgin olive oil. Years ago started that. I have friends that make it with coconut oil. So, you can you can pick the oil that is compatible to your body. In terms of making it, when I first started this back in 2007, I took a coffee grinder, I took the dried product, I grounded it up in the coffee grinder, I then measured out 10 tablespoons of the ground up product, and that 10 tablespoons mixes with 1 cup of oil. So, you can increase, or decrease, that formula. And I will send those directions to anybody who wants it. And what I initially did was I would heat the oil up on the top of the stove, so just remember it's going to smell. Depending on where you live be careful. So, I heat up the oil, you take the product and you sprinkle it over the top when you think it's getting warm. You don't want to bring it to a boil. But you sprinkle it over. If you start to hear a sizzling, like when you put an Alka-Seltzer into a glass of water and hear that sizzling sound,

that's what this will sound like too. When you hear that sound turn the heat off take the rest of the products, you know, sprinkle it over, stir it around, cool it down, strain it, and you're done.

However, today there's even an easier way. There's a product called the, oh, wait a minute. Oh! My brain just went. Wait a minute. Oh, I can't believe this. I can't remember the name. Well the people that are going to email me, I have the name of it and it's going to come to me in a minute. But there's a machine you can buy actually on Amazon that you pour the oil in, put the, you know, measured product into that, press the button for oil, and turn it on, and within an hour you have absolutely gorgeous oil and I can't believe I can't think of the name of this. I'm so sorry, but I will send the name of it to anybody who ask for the directions. So, it's- it's even easier today to make it with this machine. So, it's a very simple process. It's incredibly simple. Anybody can do it. Again, the only thing you need to be careful if you live in a congested area with a lot of people around, it will have an odor to it when you make the oil. OK?

[00:31:13] **Jessica Adelman:**

Thank you.

Does cannabis cause issues with any cardiovascular conditions or POTS?

[0031:21] **Ellen Lenox Smith:**

I have significant POTS. I've passed out and fractured both my legs. I have passed out in stores. It was never about the cannabis for me. I have been using cannabis since 2007. I actually was in the hospital at one time with congestive heart failure, but all this is now being controlled through medication with the POTS and I have never felt that this is activated the POTS at all for me. It was more for me that I needed the medication to get my blood pressure elevated. I've always had extremely low blood pressure and, you know, salt pills became not enough. And, actually, the salt pills brought on the congestive heart failure because the doctor thought he had me on medication, and made a mistake, and I didn't. So, I kept getting, when I kept calling and saying, "I'm really not doing well." he kept putting me on more salt. And it turned out, once I started Midodrine I've, I've been really good and that has controlled it. So, I do not feel, personally, that this has had any effect on my POTS at all. OK?

[00:32:26] **Jessica Adelman:**

Thank you.

Do you build up a tolerance to the dosage or dose it stay fairly consistent?

[00:32:32] **Ellen Lenox Smith:**

Absolutely do not build up a tolerance. When I first started using this, back in '07, I was at four teaspoons to get through the night. Today I am at one teaspoon. So, you're going to find that it will change according to whatever medically is going on with you. Don't panic if you need to keep upping your dose. Just remember I was at four teaspoons and that's OK. Now, it went back, and so it depends on what you might have corrected, and what you strengthened, as to maybe you don't need as much as before. And remember that key is if you're groggy when you wake up, it's too much, just reduce. But, you will find, not because you're building up a tolerance to it, but because more of your medical issues, there might be times you need a little bit more to get through a night because you had a really rough day and you're in a little extensive pain, but I've never ever felt that I needed to increase because I've been using it for so many years, at all. OK?

[00:33:30] **Jessica Adelman:**

This person has a question about the daytime and nighttime cannabis strands.

[00:33:35] **Ellen Lenox Smith:**

Yes.

[00:33:35] **Jessica Adelman:**

Can you use them both in the same day?

[00:33:37] **Ellen Lenox Smith:**

Oh, absolutely. But, just make sure you take the day during the day, and the night at nighttime. So, at daytime, I make tinctures. I have a glycerin base tincture, because some patients, if a person has a problem with sugar, and they need daytime relief, the glycerin as a base is very simple to use. I literally take the clippings, or the bud, I put it in a canning jar, I pour whatever it is we are going to be doing, if it's an alcohol base, like a schnapps, I pour it over, seal up the jar, and for two months I shake that. And this CBD and THC get released into the base of the alcohol and then you strain that out two months later and then you take a teaspoon of that, stick it into the side of your cheek, or under your tongue, you hold it there for about 20 seconds, let it absorb in, and then swallow down.

And with a daytime tincture you'll find that you can take that even every 20 minutes. You don't have to panic about that. It's something that's there, it's very fast relief, but it's also going to leave your body faster than when you ingest it like I do at nighttime. So yeah, there's daytime, there's nighttime. You can use the day during the day, the night in the same day. You can then use then the nighttime product. Just remember they both offer the pain relief. One gives you a stimulant to stay awake, and the other is giving more of a sedative sensation to want to go to sleep. OK?

[00:35:08] **Jessica Adelman:**

When using CBD will it show up on a drug test?

[00:35:13] **Ellen Lenox Smith:**

It depends on which CBD you're using. If you're using CBD from a hemp plant, no it will not show up because there's no THC in there. If you're using CBD, which you can get at a distribution centers in a legal state, that will show up because that has THC in it. My understanding is the one way you can use this that will not show up, is that little container of topical I showed you. When you rub that onto your skin, my understanding, is that is the one way it's not going to show up in a blood test. Any other way you're gonna take this, it will. OK?

[00:35:54] **Jessica Adelman:**

I was told there were several different types of CBD oils and people react differently to them. Some cause extreme mood and anxiety issues. Is that true and is that the case with THC?

[00:36:07] **Ellen Lenox Smith:**

With THC, OK... It really, it's so difficult to know what that person is referring to because if it's just plain CBD from a hemp plant, which is not cannabis, you're probably not going to feel that. You're going to get help in your body, but you shouldn't have any sensation at all from it. If you're taking the CBD from a distribution center, in a legal cannabis state, there will most likely be THC in that. So, you're going to have to play with that and make sure you understand what are they selling to you. Is it a daytime CBD? Is it any chance they made it from an indica nighttime plant? So, you want to define what it is you're actually coming back with, so you understand when you're actually supposed to take that. You do not, you don't want to be taking a daytime plant as a stimulant, and then finding out, you know, in that drop, and then finding out it's actually got indica in it and, you know, you want to

go to sleep during the day, that won't work. What was the other part of the question? There was something at the end.

[00:37:13] **Jessica Adelman:**

What—about THC. The difference between the different kinds of strands. For both CBD and THC.

[00:37:20] **Ellen Lenox Smith:**

Yeah. You know, it's, it's a little—little difficult, but as with all of us with Ehlers-Danlos, every person's journey is so different. And it's going to be the same thing for anybody that uses cannabis. If I were with all of you right now in a room, and I passed out the oil I took at nighttime, let's say it's the time about to go to bed, and I shared it with all of you, some of you are going to have success and some of you are not, even though we have exactly the same condition. That's because you have to find the strain that's going to be compatible to you. So, it's very important, do not give up. If you've tried it, it didn't work, don't assume that cannabis isn't meant for you. It just probably means that strain wasn't meant for you. So, you want to try again. If you're dealing with a compassion center or a distribution center in your state, you want to mark down, after you've tried something, and you're not sure it worked out well, mark the name of that product down and how the reaction was. What the reaction was you had, so, when you go back to them next time, and share that information so you can stay away from that strain and try a different one.

Another thing you can think about is, I'm sure you've heard about higher CBD plants. What I have switched to, I use to grow just regular nighttime indica plants. But now I'm making my oil with a little higher CBD plant. And there's many of those out there now. So, the indica higher CBD, and that seems to be incredibly compatible with my body right now. That might change in the future, I don't know, but I like the idea of getting the CBD into my system. There's enough THC in these plants for me to be able to go sleeping and getting the body calm. So, that seems to be the solution for me at this time. OK?

[00:39:03] **Jessica Adelman:**

Will it interact with other medications?

[00:39:06] **Ellen Lenox Smith:**

There is—you know you have to be careful, but generally most people have found that they have not had a problem with interactions. I'm sure

there's going to be an exception to the rule out there, but most of us have not had issues. I have had absolutely no problems and I don't really personally know anyone that has, if you want to wean off of something else you've been using for pain, I would suggest you do what I suggested, take a low dose of that, take it in oil like me. Take a low dose, slowly build up, and while you're building up your dose, I would slowly decrease the other medication you have been taking for pain and just see how far you can go and if you're able to totally get off that other medication, or not. But, in terms of interactions, that's one of the beauties of that cannabis, is that doesn't seem to be a big issue for people, at all. OK?

[00:39:59] **Jessica Adelman:**

Thank you.

Is there any hope for those of us who just cannot afford cannabis, for, to help with their EDS?

[00:40:07] **Ellen Lenox Smith:**

If you're in a legal state, do not give up. I would go to the centers. Many states have built in programs to help people that have financial issues. If you're SSI, or SSDI, you know, don't be afraid to speak up and share. If you happen to be lucky enough to be able to be in a state where people are allowed to grow, many times you'll find a grower that can grow for you that will be compassionate and help you out. Or, for us, the cheapest way for us to get established was for us to actually grow at home. We grow our own medicine. I know, in the beauty of that, if you're lucky enough to be in a state that allows it is, I can always be sure I going to have the plants I need for myself and the patients we grow for. Sometimes you go to a center, let's say you found this perfect strain, you go back to get it the next time, and they don't have it. And that's heartbreaking. Cause you've found what works for you and then you go back and it's not there. So, if you're ever able to grow or find somebody you know that grows, that is really an ideal way to do it. It really guarantees you getting what you need for your medication. Did I answer that question?

[00:41:19] **Jessica Adelman:**

Yeah, yeah.

[00:41:20] **Ellen Lenox Smith:**

OK.

[00:41:21] **Jessica Adelman:**

What strains do you grow, or do you recommend that people start with?

[00:41:27] **Ellen Lenox Smith:**

Well, if you're going to try the nighttime oil, the strains that I love, I have one called Critical Cure, again Critical Cure and Strawberry Diesel. Those two are indica, high CBD, so they are nighttime sleeping plants and those have worked really, really well, but there's gonna be many other strains out there that some of you know about that I don't know about. I mean there's so many people that have gotten involved in this industry now that have cross-pollinated and created new strains, so, you know, I, I just think—I think if you can get a higher CBD indica, I would try, I would start out with that, and I would really encourage you, if you're going to go with the oil, I would encourage you to get a couple of nighttime, higher CBD indica plants, product to create that oil instead of just one. I think, I think there's definitely there's an advantage to mixing it. OK?

[00:42:23] **Jessica Adelman:**

What about hybrids? A lot of strains out there right now are hybrids.

[00:42:28] **Ellen Lenox Smith:**

There's tons of them. They will make you dizzy looking at them all. You know, you just—I would trust the people you are talking to in your, in your community, people that have been involved with this. You're going to find when you walk into the distribution centers, they're very professional and the people are extremely helpful. Go in, share your condition, share what your problems are, share what you're trying to accomplish. I think the biggest thing you want to get with Ehlers-Danlos is sleep. If you can get some sleep, you're going to start cope a lot better the next day. So, you know, really try to deal with the nighttime sleeping if you can first, and then find out what they suggest for a break-out pain for the daytime. Whether it's tincture, whether it's candy- be careful with candies, because if you're like me, many of us have problems with too much sugar in our system and feeding into candy [inaudible]. I don't really use the candies, I don't use the edibles. I vaporize if I really get desperate or I use tincture during the day if I need to. Did I answer that question?

[00:43:30] **Jessica Adelman:**

Yes.

[00:43:31] **Ellen Lenox Smith:**

OK.

[00:43:33] **Jessica Adelman:**

In terms of sleep, you said it helps with sleep, does it help more with falling asleep, staying asleep, going into different sleep stages? Do you know anything about how it helps with sleep or what types of sleep problems it helps with?

[00:43:46] **Ellen Lenox Smith:**

All I can tell you, I have, I have a situation where my chest can cave in, my sternum can cave in, and my trachea twists, and despite wearing a BiPAP, which is like a home respirator at night; it forces air, air in, and pulls it back out. As long as this is in position, and I can breathe at night, I take that oil. Within an hour I'm in bed. I close my eyes, and I just gently fade away. The weird thing for me, is I used to be so excited, wake up in the morning and share all these dreams I had with friends, you know, and my family, and I don't have them anymore. I am such deep sleep that I literally wake up and I don't remember anything. All I'm—it shocks me every morning when I wake up that I literally have closed my eyes and the next thing I know its morning. Cause I went so many years not being able to do that at all and having these very vivid dreams, I don't even get that anymore, so I'm in very, very deep sleep, using this oil. OK?

[00:44:48] **Jessica Adelman:**

Can you drive when taking this?

[00:44:52] **Ellen Lenox Smith:**

Absolutely, but remember I take my medication at nighttime. I don't take anything during the day. Unfortunately, because of my surgeries I have not been able to drive for a while, but if I could, I would be able, definitely be able to focus and drive. I-I'm not groggy. I don't get high. I don't, you know, I don't get that sensation. For my body, living with pain, this allows pain relief and therefore I have better quality of life. So, yes, absolutely I can focus and drive. If you took too much and you feel groggy, I would not get behind the wheel. That means your, your dose is wrong, so you need to correct that dose before you try that out. OK? But you should be able to function and live your life, and drive, if you have the right dose in your system. And that's another advantage of taking it at nighttime. You know, it just, the action happens while it's asleep. I wouldn't want to take that nighttime oil and

get behind the wheel then. Trust me. If you wake up, and it's activated, you don't want to be driving. So, you know, it's, it's how and when I take it that definitely driving the next day would not a problem. OK?

[00:45:58] **Jessica Adelman:**

Alright, this person has been given a tincture and it contains alcohol and they have trouble with taking alcohol sometimes. What do you think of these tinctures?

[00:46:09] **Ellen Lenox Smith:**

I think tinctures are great; however, sounds like that person needs to switch from an alcohol base tincture to a glycerin. And if that person wants to email me, I can even send you directions for making glycerin tincture. It can be made in a crockpot within an hour. That is less time than the two months to make it with a, with the alcohol base. So, glycerin is going to taste terribly sweet and there is absolutely no sugar in there. A diabetic can use glycerin. But it is going to taste very sweet, but it will not have any of the alcohol in it, and you're still going to get the going to get the good effects of taking the cannabis that way for break-out pain during the day. So, I highly encourage you to use it, but I would switch if you're having problems with the alcohol, and that's not calming for you and not working. I would switch to a glycerin base and if you want directions, just email me. OK?

[00:47:03] **Jessica Adelman:**

What strain is good for depression?

[00:47:07] **Ellen Lenox Smith:**

There's a strain out there, I wish this person lived near me so I could help them. There's a strain called "A-C-D-C". "ACDC". It's a daytime product. It's cannabis, but borderline almost being a hemp. It's tremendous for anxiety, for PTSD, very calming to the body, not a head high at all from it, wonderful product. So, if you're going to try it out for that I would look for ACDC and I would guess most centers are going to have that. If not, you can even—if you're allowed to grow—you can order the seeds online and grow it for yourself. OK?

[00:47:47] **Jessica Adelman:**

And that was actually a question. Where do you get your seeds? Do you usually get them online?

[00:47:53] **Ellen Lenox Smith:**

That's a very good question, and don't laugh at this, but when we first started, we had no idea what we were doing. We were allowed to grow. We knew it was going to be cheaper to take our retirement money and set up a grow, and a friend of mine actually gave us some seeds from the 1960s. Who knows what we grew, but we grew these plants, and son of a gun, converted into oil and slept like a baby. I have no idea what I first started with, but my body was so excited to have something to help the pain. What I have done since then, because we do grow all the time, is you actually take the plant, you take a clipping off the plant, you put it into a cloner, and you let that root, and then you put that into soil and you let that plant grow. It's about a three-month process from starting with a clone, which is a rooted shoot of a plant that you've had, to actually getting the product. Takes about three months. So, it's a long process. So, I'm losing my train of thought. What were we just...? I'm so sorry! Ah! Remind of that question. I'm so sorry.

[00:49:00] **Jessica Adelman:**

Just, where do you source your seeds.

[00:49:03] **Ellen Lenox Smith:**

Oh, yes. OK. So, cloning is the best way to do it. If you know somebody growing, I would ask them if you could take a clipping from there's, or even ask if they could clone it for you. The advantage of that, is if you start with seeds, just regular seeds, and you can go online and order them, and they'll will have a description of what this plant does. You buy the seeds, you put it in the soil, you do not want to keep a male plant. Male pants are going to produce seeds and that's not the type of cannabis that you want. So, when you sprout those seeds, you have to wait for them to identify themselves, if they're male or female, and then you have to throw all the male plants away and just deal with the female. So, initially, we tried that, and it's a pain in the butt. So, the other option you have is to go online and pay extra for a for a seed that is going to be guaranteed to be a female seed. And those do exist. But even better yet than that, is maybe at your distribution center, if you have a state that allows you to grow, or from a person you know that's growing, get a clipping, clone that, root it, and put that right into the soil. That way you're taking it from a female plant and it's guaranteed to be a female plant. It's going to stay that sex, and that-that is what you want to grow, is female. OK?

[00:50:25] **Jessica Adelman:**

It looks like there is a little bit of confusion about oil versus tincture. What the different uses are and how you consume them.

[00:50:35] **Ellen Lenox Smith:**

OK. So, oil I take at nighttime. That's what I take before I go to bed. Tincture is for break-out pain during the day. OK? So, tincture again, can be a glycerin base or an alcohol base. And oil is, you're going to pick what base of oil you want for the nighttime medication. So, tincture daytime relief. Oil for nighttime sleeping. Does that help a little bit?

[00:51:05] **Jessica Adelman:**

I think so.

[00:51:07] **Ellen Lenox Smith:**

OK.

[00:51:08] **Jessica Adelman:**

So, does the, the form that you put that in, does that effect its use? Or is it, is that just how you prefer?

[00:51:19] **Ellen Lenox Smith:**

Well—well, you mean— well, the tincture is going to be made out of sativa daytime plants. So, anytime you deal with a sativa daytime plant, you're gonna get pain relief and a stimulant to stay awake during your day. The oil is made out of nighttime, "I want to sleep" indica plant. So, you don't want to mix those two up. Now, you could technically make a tincture out of the nighttime plants. But a tincture's not going to stay in your system as long as when you put it into the oil and swallow down. A tincture gets absorbed in the cheek and under the tongue. Oil you're swallowing and ingesting it in. So, that's why the oil stays with your system so long- so long. Where the tincture you can take frequently without—during the day for breakout pain. Does that make any sense?

[00:52:11] **Jessica Adelman:**

Yes. And the other question, which is how exactly do you consume the oil and the tincture? Do you just eat it, do you mix it with something? How does that work?

[00:52:21] **Ellen Lenox Smith:**

OK. So, the tincture you take a teaspoon, it's just liquid, you're going to pour

into a teaspoon and just put in into your cheek, or under your tongue. Hold it for 20 seconds and swallow it down. And if anybody wants directions to making this, I have them, I'd be happy to forward them to you.

The oil, you're going to mix with some food. You do not take, I mean, when would you ever just take a teaspoon of oil and swallow it down? You wouldn't. So, you want to mix it with a little food, and take that about an hour before you go to bed and let that settle in. But, remember when you ingest that way it's not gonna kick in quickly like the tincture. This is a nighttime relief, but it's—because it's ingested it's going to take time to activate. It can take up to an hour when you first start. So, don't get discouraged and think nothing's happening. All of a sudden, you're going to say, "Oh boy, I really gotta get to bed." What I suggest for people to do, is take it an hour before bed, a half hour later, get into bed and get settled. So, when it does begin to activate, you're ready to just close your eyes and go to sleep. OK?

[00:53:25] **Jessica Adelman:**

Can hemp CBD products help with sleeping, waking up in the middle of the night, and everything like that? Or, is that something that only a THC prod- product could help with?

[00:53:36] **Ellen Lenox Smith:**

Well, it doesn't hurt to try it. You might be in a state that's illegal and that's something that is legal to use. Again, it has no THC in it, which is why it's hemp. Hemp is not cannabis. It looks similar, but it's not the same because the THC is missing. Maybe for you, maybe you've had nothing that you've been able to use that's worked. Maybe for a while that's going to be magical for you.

So, I would certainly encourage you to try it. It's wonderful for your body. The question is, is it going to be enough to give you pain relief? And if you find it's not helping the pain then at that point, you probably need to switch, switch it up and get into the real cannabis plant with the THC in it, and don't be scared of THC. It's, it's really needed for pain relief.

[00:54:24] **Jessica Adelman:**

Can you talk about the average cost of using these products for your EDS?

[00:54:31] **Ellen Lenox Smith:**

Sure. As I said, we do home-growing and we're caregivers for patients in the state. We keep our costs down and it still kills me to have to charge

anything. We charge \$150 for an ounce—an ounce is about the size of a canning jar—so that will last you quite a long time. If you go into a distribution center, that same ounce is probably gonna be more like \$250 and up, depending on what they are going to decide to charge you. So, again, if you're able to grow or find somebody to grow for you, that will tend to be cheaper than going to a center. Although the centers are professional and very helpful, they are wonderful for some people that's the best thing for them, so you're just going to have to decide what's your, your best match.

But if you're able to grow, that is the cheapest way to get it. And, again, find somebody who's growing if you can't grow, see if you can't get a deal from them. Like maybe they're throwing those big fan leaves away, and you can get CBD out of those fan leaves and juice them. Maybe they aren't doing anything with their clippings. Those clippings are loaded with CBD and THC. Everything you need to make that oil or that tincture is in those clippings. And then again, if you remember that first picture of the bud, they just trim it down, and they take all the little pieces away, and you just dry that out. And those clippings can be used exactly for vaporizing, making the oil, making the tincture. OK?

[00:55:56] **Jessica Adelman:**

Thank you.

It is just about that time, we are, we're not going to be taking any more questions. Thank, thank you so much Ellen, for being here. We had this really great presentation today. A lot of people who have commented, have not asked a question, they've said "thank you", and that you did a great job. So, thank you so much for being here.

[00:56:15] **Ellen Lenox Smith:**

Well, thank you. And I am happy to respond to anybody. You have my email address up on the screen. If there is any way I can be of help for you, please don't hesitate. We're all in this together and all we can do is try to pass it forward. You know, I've had—I write about this, and it's funny, people occasionally write, "Why are you pushing this on me," and please, don't take this as me pushing cannabis on anybody. It happened to work for me. I know we are all reactive to so many things. It's just something to consider to try. It's turned my life around, and given me life back, so I can't keep my mouth shut about it. So, thank you once again. I appreciate it.

[00:56:51] **Jessica Adelman:**

Thank you, so much. For those of you who came in late, the webinar will be available on our YouTube page and on our website within the next few days, so you can go back and watch it. Thank you, Ellen, again, for your presentation. Thank you, the rest of you all, for coming. And I hope you all have a great day.

[00:57:09] **Ellen Lenox Smith:**

You take care. Thank you for listening folks. Stay well. Bye-bye now.