

## **The Importance of Treating the “Whole” Person with OI**

*Dr. Michelle Fynan interviewed by Petra Harvey, OIF Health Educator*

**Petra Harvey:** *Hello and welcome to the Osteogenesis Imperfecta Foundation’s monthly podcast. My name is Petra Harvey and I am a Health Educator at the OI Foundation. Each month, the OI Foundation brings you information about the diagnosis and treatment of OI presented by an expert in the field of OI and rare bone disease. The podcasts are a part of the ongoing educational effort of the newly formed Brittle Bone Disorders Consortium, part of the National Institutes of Health’s Rare Diseases Clinical Research Network. The professional education activities of the Brittle Bone Disorders Consortium are led by the OIF. Our podcast today will focus on the Importance of Treating the “Whole” Person with OI.*

*We’re very excited to have with us today Dr. Michelle Fynan. Dr. Fynan is a licensed Mental Health Counselor and Board Certified Clinical Sexologist. Welcome and thank you so much for being with us today, Dr. Fynan.*

**Dr. Michelle Fynan:** Thank you so much for having me.

*Great, so we’re going to jump right in. Can you first explain to us what mental health is and the importance of maintaining good mental health habits?*

Absolutely. So, first and foremost, when we think about our health, as people with OI, because I myself also have OI, we typically focus on our physical health because that’s what OI most notably affects. It affects the collagen throughout our bodies. So, the physical effects that we experience like brittle bones, fractures, bowing, the poor muscle tone and pain... what else do we have? We’ve got respiratory issues, fatigue, loose joints... the list goes on. But, a human’s health, regardless of the presence of OI or not, is really more than just physical. So, we’re a soul in a body with thoughts and feelings and treating someone holistically really means treating the whole person. It means that you’re addressing mental health, as well as physical health. So your mental health is your psychological wellbeing. It’s your emotional wellbeing, your social wellbeing, so it’s all of those facets wrapped into one, into your mental health. Because of that, our mental health affects how we feel, it affects how we think and then basically how we act and respond to those feelings and thoughts. So, it affects also how we interact with our environment and how we communicate with other people and how we make decisions and how we view the world. For individuals with OI, mental health affects how we react to our physical health in the same way that our physical health affects our mental health. The two are separate but very much so overlapping parts of our overall health and additionally, it’s really important to know that in the same way that there are many other factors outside of OI that contribute to our physical health, there’s also many factors that contribute to our mental health. So, these things can be biological factors, like brain chemistry, and then there are genetic factors, like our family’s history of mental health concerns, and our life experiences. For those of us with OI, there’s certainly the stressors and even the trauma involved with everything that comes with having a physical disability and unfortunately having OI doesn’t mean that we’re exempt from having all of the other things that can go on with physical health and mental health concerns- it doesn’t exempt us from depression or bipolar disorder or schizophrenia,

anything like that. I know some of us would like that “get out of jail free card” but unfortunately, that is not the case in the same way that people with OI can have other physical ailments. That’s what makes it really so important for us to take care of our physical health all while we are practicing good mental health habits. I’m sure we’ll discuss those today as well.

*That’s really interesting, thanks for sharing that. So, as an adult with OI and a licensed mental health counselor, you understand some of the unique psychosocial challenges that children and adults living with OI may face. Can you share your perspective of common mental health challenges that individuals growing up and aging with OI may encounter?*

Sure. So, I will share my personal perspective as well as what I’ve really come to learn by studying mental health and physical disability. I’ve also learned so much just from being a part of this wonderful OI community that we have and from those who have shared their stories with me. All of these things have really shaped my perspective. So, just a little bit of history about myself- as I mentioned before, I have OI. I have mild OI; it was classified when I was born as OI tarda, then later Type 1 OI. In my lifetime I’ve had upwards of 30 fractures, many of which were in my legs and affected my mobility. I used a wheelchair until I was a junior in high school. In my junior year, I started using a walker. Then, I used a walker for mobility until college and I don’t currently use any assistance at the moment. Even though I don’t currently use the walker or a wheelchair, we know as someone with OI that could definitely be a possibility at any time. Because of the time I spent using them, I still have a really deep appreciation and even love for them, they were a part of me for so long. There’s that connection that I have to the assistive devices. I’ve also got some hearing loss. I’ve had several major surgeries including spinal fusion for scoliosis. I’m about 4’9” and  $\frac{3}{4}$  (don’t forget that  $\frac{3}{4}$ ). So, that’s my physical story, but my mental health story is that I quite currently, deal with at times, quite a bit of anxiety. I’ve had the constant worry about being injured and in the past it would keep me from participating in events. I’ve experienced some post-traumatic stress symptoms including flashbacks and hypervigilance (where you have a heightened sense of awareness with increased anxiety) and avoidance of certain places for fear of getting injured. I talked earlier about how your mental health includes the physiological aspect but also the social side. There’s that social side of being a child and young adult and just feeling different amongst peers. Being stared at, feeling the need to answer questions when people would ask what’s wrong with me... I know that even though this is my personal situation and my personal experiences, I know that many others with OI can attest to feeling the same if not similar feelings and have similar situations. Then there’s the thoughts that come along with that- thoughts that are often constantly on your mind. Like, what if I fracture again, how can I go to this event and still be safe? For children that are progressing into young adulthood- will I be found attractive by someone, will I always be alone? The, of course, aging- we’re thinking about what’s my future going to look like in terms of love and relationships, or will I be overlooked for a job? Or, why wasn’t I invited to this party with my peers? That’s another one that young adults and even children have had. Even just, how the heck am I supposed to reach that, and who put that up there? I know that was me this morning. There’s a theme of worry and anxiety and even some sadness or depression and anger when it comes to the challenges that we face as individuals with a disability. There’s a lot that can really go into the mental health

portion of growing up as someone with a disability, so those are some common mental health challenges that people with OI may encounter.

*Thank you so much for sharing that, that's really helpful. What would you recommend as warning signs for an individual who needs to seek mental health support? How do you know when professional counseling or medication is needed?*

Well I'm a little but biased, as a therapist, because I think that everyone should have mental health support and I fully believe that a mental health counselor should be a part of your multidisciplinary team when we're thinking about who's on my team to be helping me and supporting me with my health. It is just as important as physical health and we really shouldn't be waiting until we see these big glaring warning signs before we start practicing these good mental health habits. So, I really like to talk about early warning signs and it's similar to physical health treatment. So, those of us with OI can probably relate to this idea of instead of waiting until we need to be rushed to the emergency room, let's maybe make an appointment to see our primary care doctor to treat our early warning signs. So, if we have difficulty breathing, that's an emergency situation... but maybe we could've caught the early warning signs of what led up to that. I really want to start by saying, everything is on the continuum. So some of these things may resonate with some people and they may think "oh I do that, this is a horrible problem" but again, we want to really take the whole picture into consideration. When we're looking at early warning signs it might be like avoiding activities that are typically enjoyed. Now, at one time or another we might not want to participate in something that we typically enjoy, but this is when these activities and warning signs are coupled with multiple things to where we're starting to see some red flags go on. For example, avoiding activities that we usually enjoy, pulling away from loved ones and isolating, maybe over eating or under eating, oversleeping or under sleeping, feeling numb or hopelessness, edgy or angry, even having mood swings between all of these emotions, or having those flashbacks or intrusive memories or thoughts. Those are some early warning signs- if we're experiencing that it might be a good idea to just be aware and start thinking about the state of "how is my mental health?" and asking those questions. Then of course any thoughts of self-harm or harming someone else, hearing voices, believing things that aren't true, and really just not being able to function in general. These are definitely things that would raise red flags. As I said before, these warning signs are on a continuum. What I mean by that is some of these are just basic human emotions, like sadness and fear and we may all have at some point in time, a fluctuating level of these emotions. What really determines if professional counseling and maybe even medication is necessary is if these warning signs are really interfering with your life in some way and negatively impacting it. Negatively impacting your job, your relationships and even your happiness, your ability to be functioning in your many different roles. We have many different roles as people and we are so complex. Seeing if there is any negative impact that we're experiencing because of our emotional and psychological wellbeing. So some of the questions that we might ask ourselves are: are you able to push through some of your fears, or are they keeping you from even saying hello to people? Is there a level of social anxiety that is even keeping us, slowly but surely, from talking to others or interacting with others, maybe even getting in the way of us leaving the house? You'd want to ask, am I able to know that having a bad day or bad month will soon turn into a better day or better month, do I have that hope? Do I believe that this is just how things are

going to be forever and I'm never going to be able to talk to anyone and I'm never going to leave the house again? These are very real situations that people experience. Another thing that I like to encourage people to do, because sometimes we lack a level of self-awareness especially when our mental wellbeing is not working at our finest, I like to ask, "What do those closest to you say about your mental health? Is there someone that you really trust their opinion, what would they say?" Sometimes our mental state might not be as evident to us as it may be to those around us. Do they think that you could benefit from mental health support and if you believe there isn't anyone that you can trust, maybe a counselor can be that person for you, someone whose opinion you value that can help you work on that. With that said, I really do believe that we are the experts of ourselves. As people with OI, we often work with a lot of medical professionals who are the experts in their field. But even then, all doctors and mental health counselors, we're all human. As people, we live with ourselves every day. I believe that we typically know if we do need to focus on our mental health. We're the ones feeling the effect of not having things work in that area of our life. I think that deep down we may be noticing those warning signs and maybe ignoring them and pushing them to the side. In the same way with physical health, we know that ignoring problems and those early warning signs are typically not the best way to handle things.

*Thank you so much for sharing those warning signs. As a follow-up to those questions- what would you say are some examples of tools or treatments that could help an individual needing more mental health support?*

The good news is there's really a number of accessible tools and treatments out there to improve our mental health. There's even online counseling available to those who have limited mobility and difficulty traveling so for those who are thinking "I have enough trouble even leaving the house even though I want to," online counseling may be available in your state. Mental health counseling is also covered by a number of insurance companies, that's also something to consider. In addition to individual counseling, couples counseling, family counseling, group therapy, support groups, life coaching, etc. In addition to those, there are also a number of things you can do for yourself to improve your mental health. I myself, I'm a big self-help nerd, I love all of the reading and different activities that I can do myself, just to improve the way I feel and to put myself in a positive state of mind. I'm a really big fan of reading and listening to audiobooks that will get me in the right frame, journaling is a fantastic way to do a "brain dump" and get all of those thoughts and feelings out of your head and onto paper. You then have the added bonus of throwing away that paper or burning it (if you'd like) safely of course. This way of symbolically letting it go can really be empowering to do so. Music is a great stress relief. Physical movement at all, like taking a roll or a stroll outside or doing yoga. If your mobility is limited, meditation is a fantastic option for quieting the mind and breathing out the stress and really calming your body and it can be really wonderful for pain management too. The pain is there, but the suffering is something that we can work with. The pain can be managed by medication, but there's also so much that we can do mentally to be managing our pain and our suffering. I really think that that's important for people with OI as well. Just recognizing that feelings are not facts. Even though I may feel like I don't have any friends, that might not necessarily be true, even though I feel like I'm alone, that might not necessarily

be true. So really getting our thoughts in check as well. You definitely want to make sure you seek professional mental health counseling. You want it to be a licensed mental health professional. I know that here in Florida, it's called "licensed mental health counselors" or "LMHC," but there may be a different title in your state. You want to make sure that the person that you're working with is a trained professional if you're looking for mental health counseling. Also, there are coaches if you're looking for more of a life coach and support in that arena, or a career counselor. There are psychologists and psychiatrists there to prescribe the medication if deemed necessary. Your primary care physician can also do so. Nurse practitioners can also do so working under a doctor. It all depends a lot on your state. You can find out if your insurance will cover it, give them a call. Some other suggestions are just trying to connect more with others and really build up your support system. As a new mom, myself, I really now know what the phrase "it takes a village" means, and I think we're all here on Earth to help each other. With that said, helping other people can really improve our level of happiness. Knowing that you were able to improve the life of someone else can really be a pick-me-up. It gets us thinking of others instead of focusing so much internally. So, create your toolbox of coping skills, think about what makes you feel better – is it creating artwork, singing, planning out your day – do those things. Of course, take care of your physical health. Eat real foods, drink enough water, and get fresh air. Some people are really great at taking care of their mental health, but maybe not so great at taking care of their physical health. The two coincide, they definitely affect each other. By taking care of our mental health, we will ideally be able to experience joy and cope with the many stressors of life and just be more productive members of society and really realize our full potential. One of the reasons, if not the main reason, I became a therapist because I believe my life's purpose is to support other people on their journey towards realizing their full potential. As someone with OI I've had my fair share of challenges, but those challenges help me appreciate how amazing life can be. Without the darkness, we can't really appreciate how bright and beautiful the light is, and I really just want that for everyone.

*That's so true. Thank you so much for that good information and thank you so much for sharing with us today. Do you have anything else you'd like to add?*

Just to add, if anyone needs help being linked up with the appropriate medical professional in mental health arena, I'm happy to help. Or if you just have general questions, you can reach me at [DrFynan@gmail.com](mailto:DrFynan@gmail.com).

*Perfect. Thanks again for joining us today. We really appreciate you talking on the subject and sharing your perspective on mental health support. We will be back for another podcast next month, make sure you tune in!*