# Where You Are S3E1\_V4

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child, eating disorder, eating, families, disorders, parents, kelly, mealtimes, helpful, food, support, appointment, journey, meal, highlighted, strategies, bryn, behaviors, person, hear

#### **SPEAKERS**

Kelly, Michelle Horn, Bryn Askwith, Dr. Coehlo

Kelly 00:05

Remember who your child is. That underneath the eating disorder and the, perhaps that noisy fights and the refusals and all those things, your child still there. My daughter is lovely, she's funny, she's a great big sister, she's really smart, and she has the biggest heart in the world. Remember that your child is there and focus on those strengths that they do have when the eating disorder seems to be the only thing you see.

Bryn Askwith 00:47

Welcome back to another season of Where You Are, a podcast that helps families and their children promote their mental health and wellness. I'm Bryn Askwith. And I'm back behind the mic with my co-host, Michelle Horn in our first episode of the season, where we look at eating disorders.

Michelle Horn 01:02

Thanks so much, Bryn. I'm really excited to be back for another season of Where You Are.

Bryn Askwith 01:05

An eating disorder is about more than just food. It's a type of mental illness that involves unhealthy thoughts and behaviors towards food, weight, and your body shape. Eating disorders can affect people of any age, race, ethnicity, gender or sexual orientation, and can be a long term challenge for children and youth. Parents and caregivers who are trying to support their child with an eating disorder can often feel overwhelmed and scared as they try to cope with the signs and symptoms and figure out when and where to seek help. And while treatment is key, there are many things that you can do to support your child at home, even after reaching

out for help or while receiving services. This episode, we answer some key questions we often hear from parents and caregivers, including how to support your child around mealtimes, and what to do if your child refuses to get help.

# Michelle Horn 01:52

Joining us on today's episode we have Kelly, a parent of two, who talks with us about supporting one of her youth who has been diagnosed with an eating disorder. Kelly spent many years working with emergency services and later returned to school, where she changed her career to counseling. Currently, as a parent peer support worker, Kelly truly understands how important it is to have someone really hear you and walk with you through difficult times as you support your child's mental health. Also joining us today, we have Dr. Jennifer Coehlo, a psychologist at BC Children's Hospital who works in the provincial specialized eating disorders program. Dr. Coehlo has experience in providing evidence based therapies for eating disorders, and strives to integrate and apply her research findings to improve clinical care for youth and their families. Let's listen to that conversation.

B Bryn Askwith 02:39

Good morning, Kelly. If you could start us off by telling us briefly about your family's experience with eating disorders.

# Kelly 02:54

Our experience started when my eldest daughter was 13. She came out of grade seven. And as I hear even now parents say, a lot of the kids are saying, well, I want to be healthier, I want to eat healthier. And I thought okay, I'm on board with that. Let's just cut out some of the things that we don't want to have. And then high school hit. There was a few OCD behaviors that I noticed over the summer, and everything started to implode. It was difficult for her to walk into a room without putting things exactly as she thought they should be. And it got beyond anything I knew how to deal with. So at that time I had my family doctor refer us to the OCD clinic at Children's. While we were waiting for that appointment, I had thought to myself, you know, I better watch out for eating. And it was no sooner out of my head than I noticed eating behaviors happening. She was decreasing her food, she wouldn't eat certain things that she really liked to eat, she wouldn't eat anymore. I'd had to keep an eye on her water intake to make sure that she was having enough because she was at PE at school. However, as we got to our appointment, the OCD appointment, her eating had gotten a lot worse. And I had phoned ahead, letting them know what my concerns were. And by the second appointment, which was about a week or two later, my daughter was taking something like three peeled grapes to school for lunch. And even at that I didn't know if she was eating them. So at that second appointment, the doctors decided to take some vital signs from her. And at that point, eating disorders got involved. One of the doctors came into the room and admitted her to hospital immediately. And that's where we were for about 10 days. After that process, she was released as an outpatient to eating disorders, and...in the hopes that we would get things going again, because the sooner that you're able to deal with an eating disorder, the better timing for the result that you're looking for. The eating disorder hasn't had time to, perhaps take a lot of hold,

depending upon the person. And that's something to really remember is, every experience is very different. Although you will see a lot of similarities between the children and youth that do have eating disorders.

# Bryn Askwith 05:46

Thanks, Kelly. That's quite a journey. Dr. Coehlo, a follow up question for you. I heard Kelly say that, you know, her daughter wouldn't eat certain foods, even the ones she liked. She stopped, you know, drinking water and hydrating. In your eating disorders work with families, are there other signs and symptoms that you see?

# Dr. Coehlo 06:02

I think what can be hard is that a lot of parents share with us that, like we heard Kelly highlight, that initially, they might notice their child focusing a little bit more on health or even fitness and have a hard time figuring out, is this something that it makes sense for them, that they want to support? And when to understand when it's becoming more of a problem. And with eating disorders, some of the signs might be more visible. So physical signs like weight loss, or children or adolescents who are failing to grow as they might have normally before. Might also be behaviors like exercise, skipping meals, or eating larger quantities of food, losing control at times. And it also might be less visible things, like thoughts. Maybe some parents share hearing more thoughts about food, weight, or exercise, or other body image concerns. And a lot of parents share with us that it might not be on their radar in the early days, especially for younger kids. And for males, for example. We met with several parents as part of a research study understanding their journeys through eating disorder treatment and seeking out help. And we heard from some parents of boys that they had never heard about anorexia nervosa with guys, and that it wasn't on their radar because their child was quite young, or because they were a boy.

# B Bryn Askwith 07:24

That's really interesting, what you're sharing about how, you know, eating disorders can affect anyone and look different in each child. I will just take a moment to add for our listeners, that if you are interested in learning more about signs and symptoms of eating disorders, how to talk to your child about your concerns, we have a webinar on our website that really delves into this in more detail. And you can find it at keltymentalhealth.ca. And we'll also put a link to that in the show notes.

# Michelle Horn 07:50

Thank you so much, Bryn. And Dr. Coehlo, if parents are noticing any of these signs or symptoms that you and Kelly have just talked about, can you speak a little bit about where and how they would reach out for help and what that kind of typically might look like for families?

Dr. Coehlo 08:06

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So one of the really key critical factors would be seeing a physician. That might be a family doctor, that might be a pediatrician. Sometimes families aren't connected with a family doctor and may need to take their child to a walk-in clinic in order to have an in person medical evaluation if they're concerned about their child's eating. And what we have heard from a lot of parents is that their expertise of their child can be so important and so helpful in guiding what is needed in the next steps. And it may be that by sharing concerns with a health professional and collaborating with your child's care team about what might make sense in terms of supports that can be really helpful in in parents' journeys.

# Bryn Askwith 08:50

I think now would be a good point to shift the focus of our questions on supporting your child with an eating disorder at home, if we could get into that a little bit more. But before we get into any specific strategies, Dr. Coehlo, in the world of eating disorders, what's the latest evidence that informs the approaches and the strategies that clinicians share with families that they can try at home?

#### Dr. Coehlo 09:09

So recently, there were some new guidelines that were published specifically for child and adolescent eating disorders. And the evidence base for family based therapyâ€"this is also known as FBTâ€"is actually the strongest evidence, so the approach that has the strong recommendation in terms of best outcomes for children and adolescents with a variety of eating disorders, including anorexia nervosa and bulimia nervosa, as well as other eating disorders. And really, I think this family based therapy, or FBT, approach is so successful is because parents are the ones who know their child best. They're really well-placed to help support their child. And I think as Kelly was highlighting, a lot of parents feel overwhelmed about eating disorders, not having the information. But they know that their child really well. And so by bringing together the information that they may need around understanding how to support somebody with an eating disorder, with their own expertise of their child, that really allows for supporting somebody to come back to health and help them work towards reestablishing healthy eating patterns.

# Bryn Askwith 10:22

And so if families were interested in learning more about FBTâ€"sounds like a really interesting approachâ€"where can they learn more about this?

# Dr. Coehlo 10:32

So one of the really helpful resources is a book that I often recommend to families, it's written by the two people who developed the FBT approach. Their names are Lock and Le Grange, and the book is called Help Your Teenager Beat An Eating Disorder. Bryn Askwith 10:46

And are there any other, for example, online resources or video resources? I know, parents, as Kelly described, you know, you're you're so busy and have so many things going on, and you're trying to find the most information that you can. Yeah, is there anything online that would be helpful to parents?

Dr. Coehlo 11:02

So one of the other ones that I would like to highlight was developed by our colleagues in Ottawa at Children's Hospital of Eastern Ontario, and they have a series of video modules for parents to help understand more about eating disorders, and that's available at CANPED .ca.

Bryn Askwith 11:18

Great, thank you. I'll also add that to our podcast episode page and our show notes.

B Bryn Askwith 11:26

You're listening to Where You Are. I'm Bryn Askwith. You can find all the resources in today's episode on our podcast page at keltymentalhealth.ca/podcast. Looking for more resources focused on eating disorders? Go to keltyeatingdisorders.ca, where we offer information for every stage of the eating disorder journey.

Michelle Horn 11:48

So through the Kelty Mental Health Resource Center, we get lots of calls and emails from parents and caregivers who are concerned about their their child's eating disorder or disordered eating behaviors. So the first really common question that we get from families is around supporting a child around meal time. So if your child is refusing to eat, or is not eating certain foods, or mealtimes are just a real struggle. So Kelly, do you have any tips from your personal experience or as a peer support worker talking to other families around supporting your child during mealtimes?

Kelly 12:19

Encouraging the child to eat can be very difficult. They tend to see things such as portion size on their plate, it looks too big, I can't eat that much. You can work around that by the types of foods that you give them. Another really important thing is not to talk about food during dinner. Don't focus on the child and watch a lot of what they are eating or what they're not eating. Distraction can help. Whether that's talking about something during the day, something they've watched, even watching TV sometimes will help. I'd found that in my child's mind, her focus was just completely on food, and how am I going to do this. I had to distract from that, to kind of break that connection that was there between the eating disorder and herself. There are times where they are just not successful meals. And when you're at home, that's really hard. We couldn't at our house tell her that it was the eating disorder telling her not to eat. We

couldn't say that word. We couldn't discuss it. As far as she was concerned it was her. And keeping that eating disorder separate from the child is really important, if you can do that. Because it's good to see that, you know, this is an illness over here that's trying to get you not to eat dinner tonight. But you're over here. And we know that you need to be doing this. So how can we do this? Ask them what you can do to support them.

#### Michelle Horn 14:04

Yeah, and I'd like to bring that to Dr. Coehlo, as well, too. I know you've supported many, many families over the years around mealtimes. Do you have anything to add to what Kelly said?

#### Dr. Coehlo 14:13

I think what's really hard in supporting somebody with an eating disorder is that the food is the medicine. And at the same time, the food is what is really scary. And we know from a really important study that was done back in the 1940s, known as the Minnesota Starvation Study, that it's actually food restriction and the starvation state that can keep the eating disorder symptoms going. And so, for people who have lost a lot of weight, regardless of the reason, even people who don't have eating disorders who lose a lot of weight, they can start to have low mood, anxiety, become very focused on food. Many of the things that we hear from families whose child has an eating disorder. And as they start to eat more and gain back weight that they've lost, we see a lot of those symptoms resolved. So it really tells us that food is medicine and Kelly highlighted that some of the foods that you might choose to give your child can be helpful when portion sizes are overwhelming. So for example, if parents are choosing foods that are more dense, that might look like a smaller portion size than something that are multiple items on a plate, sometimes that can be easier for children and youth. I think a lot of families have shared with us that planning in advance and setting expectations in advance is something that can be really helpful. Expectations might be around how long there is to eat. Expectations might be the expectation of 100% completion, as well. And like we highlighted earlier, families are the ones who know their child best and every family has a different way that works for their family. Some families might plan ahead for a day of eating. Other families might choose to do the week in advance. And be working with their child before meal times with some limited choice. So for example, maybe parents would have two options that they would be talking about for dinner, and be working with their child to decide what of those options they may want to choose.

# Michelle Horn 16:19

So thank you so much, Dr. Coehlo, for all of those tips. I think a lot of parents might be wondering, you know, what they can do if their child just refuses to eat.

# Dr. Coehlo 16:27

This is a tricky one, like Kelly highlighted, and especially when food is the medicine. And so a lot of times, families say having logical consequences that are around this concept of food and rest as medicine can be really helpful. So that might include having an expectation that's set in

advance about a plan to make up any missed items if a meal isn't 100% completed. Or it may mean, if the medicine hasn't been taken, the meal hasn't been completed, then needing to have rest in order to conserve energy. So that might mean missing school or other physical activities if a meal isn't completed 100%.

#### Michelle Horn 17:10

Thank you. And I wanted to pick up on another thread, which actually leads into the next common kind of theme that we hear through the calls that we received through the Kelty Centre. You both talked about the importance of communicating and working with the child when it comes to mealtimes. So Dr. Coehlo, you mentioned you know, doing that planning piece and working with the child ahead of meals. And Kelly, you mentioned the importance of knowing your child and what language will be potentially triggering for them or resonate better with them. One of the pieces around communication that we hear from parents can be really hard is we know that, you know, acknowledging your child's feelings and validating their feelings is really important. But parents often say how hard that can be when their child is saying something or doing something that they just know is wrong or don't agree with, so if a child is saying how overweight they look, or why they can't eat dinner. So Dr. Coehlo, do you have any tips for parents on how they can acknowledge or validate their child's feelings, while not necessarily agreeing or giving in to what the child is saying or asking for?

#### Dr. Coehlo 18:09

This is also such a tricky one. I think a lot of times parents share with us that it's really hard to validate at times when a child might be saying that they feel fat, or that they don't want to eat something and that trying to think about the emotions in that situation can be really helpful. A lot of people can relate to emotions in a different way. And so thinking about what are the things that you're scared of and thinking about how how you want to be supported when you're in a situation that might be really hard, like seeing a spider or walking across a bridge or whatever that worry is for you. And thinking about some of those strategies that that can be helpful for you, it doesn't mean that you're agreeing with your child that it is too much food or that they don't need to gain weight. One thing to highlight is that a lot of times we talk about this journey as not being a straight line, that it's almost like climbing up a really gravelly mountain where you might feel like you're slipping back, but you're still moving forward, or you get to what you think is the peak and then realize, oh, there's still a little bit more to go. Sometimes families share that it's really hard when things have improved for a little while, and then they see the eating disorder voice getting stronger again. And one thing that I think families do share with us as they're walking through that journey is that as the eating disorder is getting challenged, that's when you also see the eating disorder voice getting stronger. And so sometimes that is also part of that journey. If it's too quiet, that's when we start to worry because maybe it means we're kind of giving in to some of the things that make the eating disorder a little bit quieter. And there's a really great resource that's available through Mental Health Foundation's website; there's some video series about, what are some of the the words and language that you can use when you're supporting a loved one with an eating disorder, how to respond to comments like "I feel fat", or "I won't eat that". And some of those strategies can be another really helpful tool as you're trying to navigate what are those words that are going to fit for you and fit for your family?

#### Michelle Horn 20:24

That's a really great analogy. One follow up question, you both kind of talked a little bit or made reference to the eating disorder being kind of separate from the child. So getting into it a bit with the eating disorder. Can you Dr. Coehlo, just speak a bit more about that. So for parents who might be wondering, you know, why are we thinking of this eating disorder as something separate from the child?

#### Dr. Coehlo 20:43

A lot of times, we hear from families that their child is really behaving in a way that's uncharacteristic of them, and that they can really see when the eating disorder voice is getting loud. And we've found that, for families, it can be really helpful to think about the eating disorder as separate from their child so that they can really label when they're seeing eating disorder behavior. And this can also be helpful for other members of the family like siblings as well, especially if they're seeing times that are tough, or their sibling really upset to understand that that's the eating disorder that might make them speak in ways that aren't characteristic of themselves. What we find when we're working with families is, even if the young person finds that it's unhelpful for them to use that language directly with them, that parents can find it really helpful to continue thinking about externalizing that eating disorder,

#### Michelle Horn 21:37

That's really helpful. Thank you for that. Kelly, is there anything you would like to add to that in terms of the language that has worked for your family or ways of communicating when that eating disorder voice is really taking over or prevalent?

# Kelly 21:47

I think what I learned was how to change my vocabulary, such as calories are referred to as energy or nutrition is food. It just takes that commonality away from, "this has this many calories, and that's what you have to eat to to meet your daily quota". That's not great. They will back away from that immediately, because they know. Most of the kids already know exactly what they are eating, because they're so smart. They research it on their own. It's about watching exactly the words that will be landing on the child. And with practice, you can think about that pretty quickly. But at first, it's difficult. So to step back and really think about, how is my child going to see this if I say it this way. And that can make a big difference, if you're at a meal, in a success and a failure. It's not an easy thing. And you learn that along the way. It's nothing anybody can really teach you, I don't think. Certain words and things, yeah, we can give you some ideas about that. But again, you know how your child is going to react or behave because you know them best and work with that.

#### Michelle Horn 23:06

Yeah, and it goes back to what Dr. Coehlo and you were both saying about how, you know, as a parent, you are an expert in your child. And that's why, you know, the parent involvement is so

# Bryn Askwith 23:18

One other question that we often hear from families that call into the Kelty Centre that can be a real struggle for them is how to get their child to services or appointments when they won't go. So Dr. Coehlo, what would you say to families experiencing this challenge? It must seem really scary for parents and caregivers in that moment. And so if you have any strategies or tips, that would be really helpful.

#### Dr. Coehlo 23:41

I think one of the key things is making sure a child is medically stable or medically safe to be at home. And we hear a lot from parents, and Kelly highlighted this as well, that sometimes that medical instability can come very quickly and a child can end up admitted to hospital after a relatively short period of making changes to eating. So it's really important to have a medical review and to be working with a doctor, pediatrician, or other health professional about how frequent medical appointments need to be in order to ensure medical stability. I think the second piece is what to do if a child is saying, "I don't want to go to further appointments" or "I don't need help" or denying that there's a problem. And the good news is thatâ€"I spoke a bit about family based therapy or FBT. There's actually a parent-focused approach, so FBT that only involves parents, not the young person. And that actually has as good outcomes over the longer term as a family-based therapy where the whole family including the young person is involved. So it tells us that parents can really support their child by them learning more about eating disorders and them understanding some strategies that they can take back into the home environment. We don't necessarily need the young person to be engaged in a therapeutic approach in order to make changes to their eating and other mental health. As we've been highlighting, parents are the ones who are best placed to help support changes with their child.

# Michelle Horn 25:22

Thank you. So Kelly, we know that you've been at this for a while. What would you tell yourself as a parent now that you've been on this journey for quite some time? Do you have any advice to your younger self?

# Kelly 25:35

Accept the information that is given when someone tells you that it's not your fault. You haven't caused this to happen. And it's something that you can help heal. And I know as parents, we're used to healing things and picking kids up off the playground. And I found it very, very difficult to be in a position where I couldn't fix this. Why can't I fix this? What have we missed? And I remember really graphically, the one day that I actually stood in the hallway and said, you know what, this isn't my fault. I haven't missed anything. I have a care team, I have people to ask. And I'm going to go along those routes and listen to what other people do as well as listen to my child.

Michelle Horn 26:31

That's wonderful, wonderful advice and words of wisdom from someone who has been in this journey for a while.

Kelly 26:38

We have been at it for a while. And I remember at the beginning, what really struck me before she was admitted to hospital was that, one day, driving her to school, I noticed that she didn'tâ€"she had no light in her eyes. It looked like talking to a completely different person. There was no emotion, no nothing. And through all this, and we've done the revolving circle of services, and she is still working on this. What is so nice now, and as you're working through this, is to remember who your child is that underneath the eating disorder and the, perhaps, noisy fights and the refusals and all those things, your child's still there. My daughter is lovely, she's funny, she's a great big sister, she's really smart. And she has the biggest heart in the world. Remember that your child is there and focus on those strengths that they do have when the eating disorder seems to be the only thing you see. Your child's still there, and she has light in her eyes again now. So we've done something good.

Bryn Askwith 28:06

I think it's really important for parents and caregivers, for sure, to hear the reminder that their, our kids come with so many different strengths. And it's important even on the tough days, the really challenging moments to celebrate these. And I would like to extend a very big thank you to both of you for joining Michelle and I today. There has been so many key takeaways for families and parents listening. Michelle?

Michelle Horn 28:34

Yeah, just a heartfelt thank you to both of you for your time and everything that you've shared today.

Michelle Horn 28:44

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