**Managing Family Life When Your Child Has PKD**

Welcome everyone.

Thank you for joining Managing Family Life When Your Child Has PKD.

My name is Lauren Winchester and I am the Hospitality Host for this session. If you have any questions please type them into the chat box and we'll address as many questions as possible during the Q&A session.

We ask that you please keep your microphone muted throughout the session to ensure good audio quality for everyone.

I'm very pleased to introduce our speaker for this session.

Julian Mayerson is a pediatric psychologist at St. Louis Children's Hospital and an assistant professor of clinical pediatrics at Washington University, School of Medicine. She received her doctorate in Clinical Psychology from Nova Southeastern University.

Her primary specialty is in pediatric, chronic illness specifically end-stage, organ disease and solid, organ transplantation. Her clinical interests include patient and family adjustment to, and coping with chronic illness, adherence to medical regiments, emotional concerns related to chronic illness and pre-transplant psychological evaluations.

Dr. Mayerson’s research interests include post-traumatic growth, quality of life and quality improvement related to psychological programming. Dr. Mayerson, it's my pleasure to turn the presentation over to you.

Thank you so much.

So just the, you know, standard disclaimers. I don't have any financial disclosures, and this is my bio that Lauren so kindly read. So for today's agenda, we are going to going to start by talking a little bit about coping with an adjustment to chronic illness.

I'm going to spend a little bit of time talking about siblings and some strategies for supporting them. General points for managing family life and then a broad overview of coping strategies.

So some key points there are a whole range of normal reactions to illness, and a developmental understanding of where kids and adults are and good support goes a long way in helping families cope. There are usually many different paths to the same destination.

So, we know that there's a multi-layered impact when dealing with chronic illness. So, this diagram sort of illustrates that. In the center you have the patient, and then the next outer layer of that system is the family. Immediate family, sometimes extended family. Then you've got friends and you have school and work and then the community and within that Community can be your local neighborhood, your church community, the medical community. That becomes a big source of support in managing chronic illness.

So we know that living with chronic illness can have an impact on the individual in several different domains.

So physical functioning, for some patients, they have limitations on their physical abilities, and then require increased dependency on others. Work and school functioning, having to miss school for doctor's appointments, hospitalizations. For patients on hemodialysis this can have a huge impact on peer relationships and social life.

So how do friends understand what's going on, or how don't they understand. In the world of COVID peer relationships into social life have been altered dramatically for kids who are in virtual school or who haven't been able to see their friends as frequently and that applies for adults to in terms of social life participation in extracurricular, activities and hobbies.

When you're diagnosed with a chronic illness, and there are certain limitations of activities, you may or may not be able to participate in, and then self-image due to physical changes, scars, or just self-esteem and self-images.

In terms of impact on the family, we know that having a child who has a chronic illness and have a large impact on and caused strain on a marital relationship. And family rules shift. So for some kids, this means taking on new roles and responsibilities. The loss of normal life.

So for many things change, right? It may mean that nobody's making pancakes on Saturdays.

Because, you know, everybody just needs to sleep in after a long week of being in the hospital, or dealing with other things, to not being able to participate in regular extracurricular activities. Or two siblings having to go stay with family or friends or other family members’ homes.

And then increased exposure. So life becomes more of an open book.

Sometimes people are constantly asking questions that you and kids may not be able to or may not want to answer.

So, there's lots of normal reactions to an abnormal situation.

So not only for the patient and other kids in the family, but for adults to, there can be a sense of loss of control, grief over the loss of quote-unquote normal life, anger, guilt, or fear, or Rebellion against being dependent on a parent. Worry about current functioning and what current treatment may be involved. Worry about future functioning. And, often times, for siblings, fear of abandonment or isolation.

So in terms of children's adjustment, most kids do very well and are quite adaptable and resilient when facing stressors. Kids do have a slight risk for internalizing problems. Anxiety and depression are those internalizing programs and what does a slight risk kind of look like? It can be changes in mood, crying, anger, fearfulness. We'll talk a little bit more in a second about some key things to look out for in terms of depression, anxiety.

Changes in academics, paying attention, waxes and wanes, grades decline, acting out in class first, some kids not logging into Virtual School. Physical or somatic complaints, stomach, aches headaches, appetite changes, problem sleeping above and beyond what might be associated with the illness that a child has, if it is the individual who has the illness who is showing some adjustment reactions. And then social and behavioral difficulties, acting out, withdrawing, isolating. For teens and adolescents, engaging in risk-taking behaviors.

So what are some of the signs of risk for depression? Changes in sleep, changes in appetite and weight, irritability, negativity, being withdrawn or isolating, more easily upset than usual, less enjoyment, less pleasure in things that someone used to enjoy, which is also known as anhedonia. Talk of death or hurting oneself and changes in school performance.

So for signs of anxiety, some kids don't recognize anxiety, and have a hard time verbalizing that they're worried. They'll have tantrum over little things rigid routines rituals having to do things a certain way.

For some kids, they will endure excessive worries.

These are the “should,” the “what ifs” that often snowball. Problem separating from caregivers. This is usually more in younger kids, but can be an older kids as well. Sleep problems. So wanting to sleep with a parent or not being able to fall asleep.

The brain is less rational at night and so sometimes those worries and anxieties are exacerbated in the evening time. Looking restless or edgy.

The kid who's always tapping their leg. Fidgeting. Moving, like they can't sit still. Trouble concentrating and being tearful and overwhelmed.

So, as you can see, there are some overlapping symptoms in between the depressive symptoms in the anxiety symptoms.

So in particular to siblings, we do know there's some research about how siblings adjust when they have a sibling who has a chronic illness.

However, we need some more, most of the research that's out there tends to be focused on siblings of children with cancer. And what the research has found is that kids, most siblings tend to adjust well. They are more at risk for internalizing those symptoms that we just talked about depressed mood, anxiety, worry, then those externalizing symptoms such as acting out in attention, behavioral concerns.

Oftentimes siblings keep their emotions and feelings inside, and this can be for a variety of reasons.

One of those being that they don't want to burden their parents or caregivers as they feel that their parents are already trying to handle a lot. And so you end up with this cycle of parents trying to protect kids and kids trying to project the parents, and everybody sort of walking on eggshells in the house.

Sometimes siblings keep things to themselves because they've gone to caregivers before and that hasn't been effective and they don't feel heard so it's just easier to internalize, keep things to themselves than being, you know, being shut down again. For older siblings, they're often more aware of how the health condition negatively impacts their family life. And therefore, they're more at risk for emotional and behavioral adjustment concerns. They have more awareness and understanding and sometimes they're expected to be more independent or self-sufficient, and they are sometimes given additional responsibilities. So, if you have one older sibling who drives, they may have to drive younger siblings around or help cook dinner, help do laundry other kinds of things, and sometimes parents feel like well they're older so they don't need as much or want as much attention from a parent. And if they end up getting less attention from parents.

So what are the benefits to siblings of having a sibling who has a chronic illness?

So what the literature points to is that some kids actually develop better coping skills because the family is learning to deal with this, they may appreciate life more.

So my research is in an area called post-traumatic growth, which is the idea that after a stressful or challenging life situation that you can have positive changes. And one of those domains is appreciation of life. So sort of the classic or cliché example, is that sibling, who wants to do something in the medical field because of what their family has been through.

Whether that's a physical therapists, respiratory therapist, a nurse, an NP, a nephrologist. So they gain a greater appreciation of life.

Siblings are also may be more responsible, independent, and caring and these experiences lend themselves to opportunities to promote growth and resilience.

So how do we support siblings? First and foremost, and all of these skills apply to the family as a whole, but building skills.

So how do we promote resiliency and coping?

And we're going to talk a little bit about coping skills in another section of this presentation.

Teach in modeling that having a moment together as a family where you guys can have a gratitude moment where you can do some relation skills, together.

Giving lots of praise for a sibling’s effort to use their coping skills or their effort to help out where they can. Building a team. So communicating about medical stuff in a developmentally appropriate way. And depending on how old the child is that has the chronic illness is, how much do they want their siblings to know and giving them that control? But then also giving siblings the information about what's going on.

Oftentimes kids know more than we think they do or that we give them credit for and so having open honest conversations is really the best course of action because oftentimes, what's going on in a kid's head is way worse than what is actually happening.

Giving them doable tasks. So for some of my patients who are on dialysis and their siblings will help by carrying those PD bags upstairs or by sitting with their sibling and playing a game with them while they hook up get hooked up for the night on their PD machine. Things that are age-appropriate, developmentally appropriate, safe for them to do. Talk those siblings up, give them a little bit of boost and lots of very specific labeled praise.

I love the way that you have been helping your sister with her homework. I love the way that you've been helping me by emptying the dishwasher when I ask you to do that. So that very specific, labeled praise.

Some other ways, ramp up that social support and have a point person for that sibling to talk to whether that is, you know, a mom, a dad and aunt and uncle a pastor, a priest, a rabbi. Someone in the family or in that immediate Community, giving them friend time.

This is, of course, been challenging with COVID, but hopefully now as things are opening back up, kids can have the opportunities to spend time with their friends to get that social support.

And then like we talked about noticing and praising helping.

Invest time. Whenever possible, maintaining a routine and minimizing disruptions having time in quality time. Can you find ten minutes a day or, you know, 10 minutes three times a week where you can have one-on-one time with each of your kids, that's really directed by them.

What do they want to do?

If for a younger kid, that's building Legos. For an older teen that's watching a movie together or talking about what's going on with friends, eliciting, thoughts, and feelings, but not pushing too much. Right saying, talk to me or tell me about your day, but not forcing kids to, well, tell me how you’re feeling. “Tell me how your feeling” is going to put up that barrier. Sit it is a fine line.

And if you do have to delay an activity, communicate why and, you know, changes happen and learning flexibility is a great thing for kids but communicate that it is important for you to want to spend time with them and that you will follow through.

And here's why the delay’s happening.

So in terms of general family life, some general tips and tricks.

Integrating having a chronic illness into family life in the sense of living and enjoying life in spite of PKD.

And it doesn’t define the family, but it is a part of who the family is. Organization. Embrace organization. Calendars whether those are paper or a family Google electronic calendars, having a consistent daily routine.

Linking Healthcare tasks to things that you do every day.

This helps both to normalize it and to help with long-term adherence, whether to medications. Treatments, or other types of healthcare tasks.

Another area is hope. So hope is a person’s belief to produce workable routes to goals.

And the belief that that individual can assist a new movement towards those goals.

Hope helps a person to develop and sustain thoughts of positive outcomes. Even in stressful, circumstances. High levels of Hope have been predictive of adherence to Medical regimens.

So, this doesn't mean that you have to think everything is sunshine and rainbows and unicorns, but being a realist and being hopeful about what might go well, setting small attainable goals.

Optimism, also tied in with hope, and it's the tendency to expect the best possible outcome or dwell in the most hopeful aspects of a situation. People who are positive about the future exert, a continuing effort, so being more optimistic, more positive can mean you are putting effort into adhering to a medication regimen of all of the recommendations from the medical team. Optimism can make people more planful in the face of stressful events.

So ties into that organization and integration piece I spoke about.

And it's focusing on what can be can changed or controlled and there is so much about chronic illness that cannot be changed or controlled and so focusing what can we do as a family to make the best of a bad situation?

Because sometimes things can be bad and not so fun.

Owning your story.

So the story of your family of you can be a sad, hopeless, angry one, or it can be more positive and helpful. Like I said, it doesn't have to be super positive but thinking about what does this story say about us and what are words to describe the experience?

So, different words that families I've worked with before have used to describe themselves as a family to describe their children include straight strong. Excuse Me, Brave, tough learning about yourself.

my to describe their children include strong, excuse me, brave, tough learning about yourself and the family, survival, overcoming struggle,e being closer as a family, and thankful.

So like I mentioned with siblings, those general tips and tricks of building a team for yourself who's your go-to to help in navigating this it takes a village and that multi-layered level to live and manage chronic illness. Social support, have a point person for yourself, someone that you can talk to and ideally that’s not your kids because there are some things that kids should not know. And oftentimes, some times, having someone who isn't your spouse. If you have that available option for support a friend, your parents, your aunt, your pastor or Rabbi excetera, and that can be really helpful. Investing time in each other, in the family life and then asking for help, there is no shame in asking for help and in modeling that as parents for our children.

So what we do know is those who struggle the most tend to focus on the past and what they have missed or lost. They focus on what they cannot do versus what they can.

They tend to focus on the most distressing aspects of the situation, and they avoid thinking or talking about their or their child's disease. And this is a fine line, right? Not everybody outside of the family or even within the family needs to know anything and everything, but choosing not to disclose about a child's disease at all can lead to some challenges and coping.

Then the last point is then people who adopt the belief that they're generally helpless, and that there's nothing that they can do, tend to have some challenges with coping.

So what are some coping strategies? Kind of a buzzword.

So there's lots of different areas and those social strategies that I've touched on a little bit before, peer support, seeking professional support, therapy, either family therapy or individual therapy.

Then there's the cognitive strategies.

So perspective-taking is the ability to understand or relate to an experience from different or varied points of view.

Sometimes being able to suspend your personal point of view, gives you the opportunity to view the situation from another's perspective, and decide how to respond once you have a fuller appreciation of the situation. Having flexibility like this can be helpful in shifting your behavior and attitudes. When current strategies of things are compromising wellbeing. Assisting and maintaining balance in important life domains. Promoting recognition of and adaptation to a variety of situational demands.

And assisting individuals and remaining open to experiences while maintaining the capacity to choose -personal, values-based actions. Another cognitive strategy is letting go.

So when the stress of completing every tasks and every task in fulfilling requirements and meeting deadlines and both Family Life, work life, all of that starts to feel overwhelming.

Practicing letting go is one strategy that can be helpful and it involves targeting and timing.

So, what can you let go of? And when can you let go of it? Targeting can help you to know better what you can let go of. So asking yourself, is this tasks necessary and important to me? Am I attached to this task in some way that I need not be. How much control do I truly have to have or need to have in this situation?

Other letting go strategies, channeling into positive actions. Anchoring yourself in the future.

Coming back to that organization and transforming the narrative. Rewriting a more balanced, compassionate perspective of yourself of the situation, giving yourself some grace.

Meaning-based strategies.

So what aspect of life is most meaningful to you? Gratitude? So oftentimes I'll recommend that when you get up for breakfast say one thing that you are grateful for when you get up out of bed and then before bed and getting back into bed, what was one thing that you were grateful for throughout the day. Recognizing and reconnecting to values.

Some physical strategies for coping - daily exercise, breathing techniques, lots of play, Leisure distraction activities.

So some traditional self-care techniques, pursuing enjoyable activities, which are personal relaxation, exercise, music, for some people going for a drive. After work, kind of decompression, or if you’ve been in the hospital, right after being in the hospital, decompression, prayer, professional relaxation. Deep breathing, mindfulness, what's called progressive muscle relaxation which is tensing and releasing the muscles.

Grounding, guided imagery, and seeking professional support.

So these are just some little images of some coping techniques, and the 54321 coping or grounding technique is a really easy strategy.

Oftentimes, when you're feeling out of control, having an anxiety attack, panic attack, or just feeling like everything is moving in a hundred and fifty miles an hour.

So it's acknowledging five things you can see, four things you can touch, three things you can hear, two things you can smell, or that you like the smell of, and one thing that you can taste or like the taste of. Making a personal Mantra and this can be words. I also like the idea of images, so some images that carry a lot of weight that I talk about a fair amount with my patients and families are butterflies.

Butterflies start as a caterpillar and they go through a stressful experience and transformation, and come out the other side and More Beautiful.

The other is a palm tree so palm trees are really unique. They don't break. So if you've ever seen a palm tree in a hurricane? And maybe I like this one a lot because I’m from Florida. But in a hurricane a palm tree will completely bend and the leaves may fall off, some coconuts may fall off, but that palm tree never breaks.

And so I have patients who will tie the words of I bend, so I don't break, with the image of a palm tree.

And things as simple as they'll have their phone background be a palm tree, or their phone case or just little visual cues.

Breathing mantras. So on when you inhale saying my mind is relaxed, and then on the exhale saying my body is relaxed. On the inhale saying I am safe, and on the exhale, I am secure.

So, meditation and mindfulness. Self-compassion, the idea that we are very kind to others, and not always so kind to ourselves.

So there's some great audio out there of just a short self-compassion break. Leaves on a Stream is one of my personal favorite meditation, mindfulness exercises. The idea of imagining that all of the thoughts that we have good, bad and ugly, leaving our brains, putting them on the leaf and letting them float down the river.

And then some other kinds of meditations that if you just type them into YouTube, there are some great things out there.

So there are some wonderful relaxation resources and mobile health applications out there that are free.

My personal favorite is Insight timer, they have over 95,000 free, guided meditations broken up into categories: sleep, anxiety, stress, mood, self-esteem

They even have a specific parent section. That has some great guided meditations for kids. There's some wonderful app specific to kids. Stop Do Think Sesame Street for the younger kids. Calm Kingdom.

Netflix and Headspace recently came out with a great series called a guide to meditation. And then they also have one about a guide to sleep.

So some take-home points for promoting positive coping within your family. Staying involved, planning, and giving choices, supporting friendships and social relationships, being hopeful, listening, being flexible where that's possible.

Staying organized, teaching and modeling coping skills.

Practicing them together as a family. Coordinating with school so that teachers, school counselors are aware of what's going on and provide support. Taking care of yourself.

It is that for those who have been on an airplane, when you get on an airplane and they do the safety demonstration, they tell you to put your mask on before those of others.

Oh, yeah.

That makes sense.

And then you become a parent or a caregiver and that goes out the window.

But in all honesty, if you can't breathe, how can you support someone else?

Remembering siblings and then trying to have fun together as a family when that is possible.

So, thank you so much.

I will be happy to take any questions, comments.

Thank you, Dr. Mayerson.