Sex & Intimacy With Arthritis

Hosts: Rebecca Gillett, MS OTR/L
Guest Co-Host: Pete Scalia
Guests: Victoria Ruffing, RN-BC, Rheumatology; Iris Zink, MSN, ANP, RN-BC

Physical intimacy is an important part of romantic relationships – but arthritis pain and fatigue can make it difficult to participate. It's also a topic many people aren't comfortable talking about.

In this episode, guest experts and hosts talk candidly about the various challenges that arthritis has on relationships and sex. You'll get advice on how to improve intimacy based on their personal and professional experience, including how to better communicate with your partner about the difficulties around intimacy, how to foster a healthier relationship with your body to feel more desirable and how to cultivate a deeper emotional bond to create sparks in and out of the bedroom. You'll also learn practical tips on how to make sex more comfortable, including positions, assistive devices and more.

Additional resources:

A Good Sex Life Is Possible Even with Chronic Pain | Psychology Today

Talking to Your Doctor About Sex & Chronic Illness - Mamas Facing Forward

Intimacy and Sex with RA: Things I Wish I Knew Sooner - Mamas Facing Forward

Feeling Sexy When You're Hurting: Body Image and RA - Mamas Facing Forward

Sex-Interrupted: Igniting Intimacy While Living With Illness or Disability: Zink, Iris, Palter, Jenny, Schultz, Kirsten: 9781636496108: Amazon.com: Books

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PODCAST OPEN:
You're listening to the Live Yes! With Arthritis podcast, created by the Arthritis Foundation to help people with arthritis — and the people who love them — live their best lives. If you're dealing with chronic pain, this podcast is for you. You may have arthritis, but it doesn't have you. Here, learn how you can take control. Our host is Rebecca Gillett, an arthritis patient and occupational therapist, who is joined by others to help you live your Yes.

MUSIC BRIDGE

The following podcast episode contains adult content. Listener discretion is advised.

Rebecca Gillett:
Thanks for joining us on this episode of the Live Yes With Arthritis Podcast. I feel like we're starting a theme of talking about the things that are difficult to talk about sometimes. I know how hard it can be to bring up certain topics to your doctor. But this is a safe space. And today, let's talk about sex and intimacy. That's something that I know some of you are like, "Wait a minute, what? We're really going there?" Yes we are.

But I'm so glad that I'm joined with a special guest co-host today, a friend of the Arthritis Foundation and longtime volunteer. He's also an arthritis patient, my friend Pete Scalia. Thanks for joining me on this conversation, Pete.

Pete Scalia:
Hey, Rebecca, so excited to be with you on the Live Yes With Arthritis Podcast. I've been listening to the podcast for a long time. So, when the opportunity came up to spend some time with you today, I was really looking forward to it. So, this is awesome. Of course, you know, after I got over the initial blushing of wait, what's the topic gonna be again? (laughing) I thought, wow, it's really cool to be a part of the conversation.

My wife, Amy, and I, we shared at Arthritis Foundation events and through my work in TV our journey to parenthood that involved a lot of the topics I'm sure we're gonna talk about with our experts today. So, I'm really looking forward to the conversation.

Rebecca:

Tell our listeners who haven't quite had the pleasure to meet you, Pete, a little bit about yourself.

Pete:
Well, I was diagnosed with rheumatoid arthritis when I was 30 years old. So, it's been almost 19 years now. I had it under control for a good number of years. But when we wanted to start a family, for me, that meant getting off a lot of my medications. And that is when our journey to parenthood began. And it took a lot longer than we thought and resulted in some pretty severe damage to my body. During that process, we ended up dealing with some infertility issues and had our first daughter, Lola, through IVF.

But it was during that process that I ended up having bilateral hip replacements, so I had both my hips replaced while my wife was pregnant, then had both my knees replaced 14 months after that. But then we were blessed with two more kids, our daughter, Sophia, and our son Nico. And we didn't have to go through IVF. It was kind of a miracle.

I have to admit, though, that my wife has told me many times that: Look, you know, the first child, we went through a lot to conceive. The second child we're like, "Oh my gosh, this is a miracle." But by the third child, my wife told me, "I don't care what other procedures you need to get done. There's one you're getting done before you come anywhere near me." (laughing)

So, we're good, as a family of five. We've been actively involved with the Arthritis Foundation for a number of years. It's just really been an incredible asset for me, personally, to be able to share not just my story, but to meet so many other arthritis warriors from all across the country. And I'm really excited to be a part of the podcast with you today.

Rebecca:
One of the things that I think your story highlighted for me when I first heard about it was that, you know, oftentimes we're talking about family planning and things like that. And we're only thinking about women, we're not really thinking about men and how they, too, have to get off medications. I think that male perspective gets lost because there are a lot of men with arthritis and those that are on biologics who have to think about that.

This is a really important conversation for us to have. And I'm super excited that we have two wonderful guest experts in the world of rheumatology.

Pete:
Yeah. Our first guest is Victoria Ruffing. And Victoria's the director of patient education at Johns Hopkins Arthritis Center in Baltimore, Maryland. And she's a founding member and a past president of the Rheumatology Nurses Society. In addition to her clinical care, she's created dozens of patient education videos for the Johns Hopkins Rheumatology YouTube and Facebook accounts.

Rebecca:
And we're also joined by Iris Zink. She has been a rheumatology nurse practitioner for 22 years. In 2016, she and her husband opened an early arthritis intervention clinic for underserved and uninsured patients. She is also the co-author of the book, "Sex Interrupted: Igniting Intimacy While Living With Illness or Disability." She has a YouTube channel dedicated to addressing intimacy issues living with chronic illness. Victoria and Iris, thanks so much for joining us in this conversation.

Victoria Ruffing:
Glad to be here.

Iris Zink:
Thank you.

Rebecca:
To kick things off, one of the things that I know, as an occupational therapist, when I first started volunteering with the Arthritis Foundation, I would do these presentations and patient education presentations for the community. And when it was done, no matter what the topic, there was always somebody who came back to me with some questions. And most of the time, they were questions about sex and intimacy. "How do I get my partner to understand that I'm in too much pain?" And "How do I get them to realize that I'm not rejecting them, I'm just in pain?" And "How do you even have sex when your hip hurts?"

I realized how taboo the conversation can be and how hard it is to bring up that topic with your doctor. It's not something that's comfortable, but I think, as an occupational therapist, and you guys as nurses, really... Patients are more comfortable talking to us. I was gonna ask, Victoria, what kinds of things do you hear from patients?

Victoria:
I would not consider myself an expert. Let me just put that out there. I think what I have is just practical advice. And I lean more towards helping patients with comfort. I've been in rheumatology for 22 years as well. And way back in the beginning of my rheumatology career, a patient was so upset as she was leaving. And I said, "What's wrong?" And she said, "I don't think I'm ever gonna have a child." And I said, "Well, why do you think that?" And she said, "I really can't spread my legs."

And I thought, wow. That is just so terrible and something I had never thought about, something I knew was not being addressed at all. And so, we talked about some things. And one of the things we talked about was positioning. And supporting her hips and supporting her joints. And pillows under her knees and just ways that she could make herself more comfortable during the act. And she was so grateful, and also, which was surprising to me, was sort of amazed. Because I think she thought that the missionary position was the only way to go.

So, really, those are the kinds of things I talk to patients about. More setting your timing, setting your mood, taking your medications at a specific time, those kinds of things are what I discuss. And I think Iris really is the one that can hone in on the pleasure side of intimacy.

Pete:
I mean, Iris, first of all, the title of the book, "Sex Interrupted: Igniting Intimacy While Living With Illness or Disability"… I know that now, with three kids, "Sex Interrupted" has a totally different meaning (laughing). When we were trying to go through this whole thing, with the IVF and all these different things, especially being a guy… And you're typically expected, like, you know, hey, it shouldn't be a big deal. It should, you know, pretty much always be in the mood. But that wasn't the case. Whether it was from medication or body image and seeing my body change and that sort of thing. How did it come about, writing this book?

Iris:
So, a patient that I saw that had ankylosing spondylitis asked me at the end of the visit: She said she couldn't spread her legs open wide enough to have intercourse with her husband and what did I think about that? And I had a pause, and she said, "Oh, I've embarrassed you." And I said, "You haven't embarrassed me, I have no idea what the answer to that question is." I said, "Can I have a couple weeks?" And she was super sweet about it. And I called my local librarian and I said, "Get me everything you can find on arthritis and intimacy."

I thought to myself, if she's having this problem, how many more of my patients are having this problem? I would have these lectures around town, and no one would come. And so, I thought, OK, what is going wrong? And I think, you know, Vicky's very smart about positioning. And I have found that my patients figured that out from the get-go. They figured out how to manipulate the positions, so that they could have intercourse.

What my patients were really lacking was communication. Like they did not have the ability to communicate with their partner. There was a huge role shift when someone's diagnosed with an autoimmune disease or a chronic illness in the household. Someone goes from doing a lot of the household duties to not. The partner wants to help. There's, "I don't wanna hurt him or her by asking them to do something that used to be a normal activity." There's this whole problem that happens psychologically, so I really delved into that. And when patients didn't show up, I thought, OK, let's talk to health care providers.

So, I started talking to groups of nurses about talking about intimacy. And wow, nurses are shy about this. And nurses would come up to me after my lecture and say, "You know, if I only had a book of how to talk to the patients about this, I would feel a lot more comfortable." And I'd look at 'em and I'd say, "Susan, I know you have six kids, you know how to have sex." (laughing) But they wanted a book.

Rebecca:
Where do you think most people are having the most difficulty? What factor do you see in talking to patients is the most difficult part? Is it the mechanics? Or is it the intimacy?

Iris:
I know at Johns Hopkins, they have it on their intake form: Are you having any sexual dysfunction? So, first of all, it's making a safe space for that. Because a lot of places don't even ask. Like your gynecologist wants to know about your birth control and your pregnancy needs, but they don't wanna know about your romance or your intimacy issues. No one's asking these questions. It's about opening that door to communication because they just don't know how to talk to their partner about the body changes and the pain that they're experiencing and the fatigue.

And the last thing you wanna do when you're just trying to maintain some degree of normalcy is, at the end of the day, after going through a day with chronic pain and trying to work and trying to maybe take care of your kids and everything, is then your

partner's like, "Hey." And you're like, "Are you kidding me? (laughing) That's the last thing on my mind."

So, it's about talking to people about date night and scheduling it as a priority and making sure you have a babysitter and making sure there's private time for intimacy. And you know, I always normalize it. I'm not talking about penetrative sex. When I'm talking about my patients, I'm talking about intimacy, I'm talking about whatever that means to you.

I have a lot of men who have impotence because of their arthritis or because of their medications. I have a lot of women who can no longer tolerate vaginal penetration. I have a lot of women that can't tolerate orgasm or haven't been able to achieve orgasm because of neuropathy. When I talk about sex, I mean whatever that means to you as a couple. And it's kind of re-establishing that communication.

Rebecca:
Well, you mentioned some medications. Are there specific medications that can hinder sex drive or motivation to even participate? Is there specific medications out there that might be an issue?

Iris:
Yeah. There's an appendix in the book. I think probably the most common offender that I see is gabapentin, believe it or not, which is an anti-seizure medication. I check hormone levels on my new patient visit. Cortisol rushes will make your hormones low, too, just from the stress of the diagnosis. Your prednisone is affecting your adrenal axis.

Pete:
Vicky, you said off the bat that you had a patient who actually mentioned the mechanics of it to you. How do you get that conversation started though? Since somebody might feel physically and mechanically like, well, gee, I guess that's just something I can't do anymore.

Victoria:
I think, for the most part, this is not an area that physicians really have any training or background in, you know? Nurses are nurses. And so, we are educators, we are counselors. And most people will feel comfortable with their nurse. And a simple question: How are things going? And are you having any intimacy issues? They can say yes, no, or they can say, "Now that you brought that up, I was thinking blah blah blah." I find that just opening the door a little bit, maybe they don't bite that first time. But they

will come back, and they would say, "You remember the last time we were together? And I was thinking, could I just run this past you? Or do you have any suggestions?"

It's not hard to bring it up. It's less hard than you think. It's just a conversation. I think one thing that we should probably talk a little bit about is communication between the partners. I think that's where things get tough. That's where I think people still have some, I hate to use the word, hang-ups. But some barriers there, to be able to be open and honest with their partner about what their needs are, what they like, what they don't like, what they find uncomfortable or don't find uncomfortable. It's something that I think we need to encourage: to make sure that that communication is there. And that there's no judgment on either side.

Pete:
I know my wife and I have had conversations in hindsight, looking back to those times, especially when you're doing something where if you're trying to get pregnant or you're talking about, like, timing and that sort of thing. But then at the same time, with the medications, you might not be in the mood. It might diminish mood. How do you start that conversation, Iris, when it comes to your partner, without hurting their feelings and saying, you know, whether it's a man or a woman, saying, "I love you, but I'm not in the mood." Or trying to explain what's happening with your body. And how to maintain that healthy emotional relationship with your partner.

Iris:
I always encourage people to start with their clothes on. If you have a conversation about how the sexual interaction went right after, then everyone's going to take that personally. So, never with the clothes off. I always encourage people to have a conversation with their clothes on. And I really always encourage people to start with the word “I.” It's as easy as “I miss you. I miss when we used to have intimacy. I love you so much, but I don't wanna hurt you and I understand with your new chronic disease, or chronic illness and pain, I don't wanna exacerbate your fatigue. But I miss the intimacy.”

“I feel tired all the time, and I'm stiff, and I'm on prednisone, and I look different than I used to. But I still very much love you. Can we figure out how to rekindle our intimacy in a way that can meet both of our needs but that's not gonna be painful?”

Rebecca:
Yeah. And I think that communication piece, like you're saying, it starts way before you even hit the bedroom, you know? And you touched on body image. That's another thing that happens a lot, when we have arthritis. Our body changes. Not only does our

body change, the things we can do with it change. How do we feel sexy for any of that sexy time if you don't feel good about yourself and your body?

Iris:
I talk to the patients a lot about general health. I wanna make sure, despite everything that has happened, that they're still eating healthy and they're still trying to get some kind of exercise and they're trying to work on being mindful and stuff like that, because that makes you sexy. Confidence makes you sexy, you know? As we gain weight, as we age, that, for a lot of women, makes you feel unsexy. But quite the opposite. And I always quote this study, in 1988, at Michigan State University, I was a study participant in a psychological study where they had men in one room and women in another room, this would never work now, where they had men pick the body image that they thought was the most attractive, and men traditionally picked women who are curvy.

And so, I have shared that over and over and over with my patients: You gained five, 10, 15 pounds? I bet your partner's gonna think you're sexy because you've got all these curves now. Your partner's going to want you to be healthy for sure. But you know, you've gotta embrace your new body, your new curves, whatever is going on.

It's about how the patient's perception is, and sometimes that needs psychological counseling. And really just kind of regrouping where things are. And we can't really do this whole podcast without talking about the divorce rate. It's so high in people with fibromyalgia, and it's so high in people who are diagnosed with chronic illness, just because of this breakdown of communication.

Victoria:
One thing I would also, just to throw in there, is don't underestimate the power of writing. I have had patients who have just written down what it is because they can't get the conversation going. And so, they write their partner a letter, and for some, that may be the way to start it. And that's OK. If you're determined, you can find a way to get that communication going.

Pete:
Maybe in that, writing is part of that, you could, like, even doodle some of the things that will work and maybe not work. You have, like...

Victoria:
Maybe you could. (laughing)

Pete:
...a visual representation or something.

Rebecca:
Yeah.

Victoria:
Put up some little stick figures. (laughing)

Pete:
Right, right. Well, I know when it comes to, like, again, with the mechanical aspect of it, and the physical aspect of it, you know, what are some things that might be able to help people? With me personally, I, obviously going through a difficult time, like, before joint replacement, versus after. Clearly the new hips certainly helped with two kids later. When it comes to overcoming that pain... Are there things that can help out? Like with pillows or some sort of thing physically that could make it a little easier for someone?

Victoria:
Well, one thing I would suggest is to time your pain medication. Don't take it 10 minutes before you want to become intimate. You wanna take that at least a half an hour ahead of time so that you're getting it at its peak.

Set yourself up for success. A nice, hot shower so that you're warm and loose. I suggest having some rolled towels or pillows handy for people who do need to prop themselves or support a leg or support an arm or those kinds of things. And there is a Kama Sutra, if you will, for people with spinal cord injuries. And I found that to be very helpful in learning, or in at least describing alternate positioning for people.

As Iris was saying earlier, it doesn't have to be the act of intercourse as well. If you both wanna achieve orgasm, there are other ways besides intercourse. Actually, intercourse doesn't work that often, for women anyway, straight intercourse.

Iris:
I do suggest that people take a hot bath. But then that kind of wrecks your lubrication, you know, so you've gotta kinda weigh that all out. I also talk about morning sex versus night sex. I know you're stiff in the morning, but you do have more energy. And let's, again, plan it. Let's know that Tuesday morning from 10:00 to 11:00, the kids are gonna be somewhere else, and that we're… it's gonna be on, right? So, we're gonna be nice to each other Monday night. (laughing)

Using tools and toys are fabulous. One of the books that I love the most, Miriam Coughman wrote, and it's "Intimacy for People With Chronic Illness." We all use OXO products in the kitchen to make our lives easier. Why would we not use tools in the bedroom? And the problem with arthritis is: The longer you have arthritis, the more neuropathy you have, or the little nervous system dies because the circulation isn't so great anymore. So, you might need a whole bunch more stimulation.

And when I'm giving this lecture dressed up as Wonder Woman, I'm always doing the whole thing like you're (laughing), you're in a chainsaw. Because you may need a lot of stimulation in order to have any hope of getting an orgasm for some women, because they've just lost so much sensation.

Same thing with men: A lot of sensation might've been lost because of spinal cord injury because of replacements, because of the medication that they're on. And so, you've gotta look for a new avenue. But I think for me, lubrication is the most important tool that my patients are using. And then if they are open to any toys, swings, you know, any kind of apparatuses, the pillow, you know, watch "Meet the Fockers," and watch Barbara Streisand (laughing) talk with her people about different positions and how that's OK. It's opening that conversation up.

Pete:
Well, I mean, Iris, hey, I'll just throw out there, too, because you mentioned dressing up like Wonder Woman, maybe that could work for some people, too (laughing). I'm just saying that, you know…

Rebecca:
Yeah.

Pete:
...it might work.

Rebecca:
Some role play, right?

Pete:
Right. (laughing)

Rebecca:

To go on your Wonder Woman theme, you might not feel like Wonder Woman because you feel like your partner is doing everything. And so, they take on that caregiver role. And where did the romance go? How do you strike that balance as a patient? Like, hey, you can stop taking care of me. I'm not gonna break, you know? How do you help patients navigate finding that balance?

Victoria:
Well, I think again, it all boils down to communication. To really make sure that you understand your partner's needs, what your needs are, and that your partner understands your needs. And sometimes, those things may require intervention from a professional. There's nothing wrong with couples therapy. There's nothing wrong with seeing a sex therapist. If you feel like you're at an impasse, or you don't feel that you can do it on your own, it would be OK to see somebody about those things.

Rebecca:
Physical and occupational therapists can both help. I think everybody only thinks of us as OTs, as adapting things. Well, sex is an activity of daily living. It might not be daily. But it's an instrumental activity of daily living, which means it's something that we all need or want, and it's just part of life. An OT and a PT can help you figure out how to adapt positions based on whatever your joint issues are. So, that aspect is another way of getting help, aside from counseling and therapy and that kind of thing.

Iris:
Before we were all in the middle of this pandemic, it was easier for me, because if my patient had their partner in the room, I would bring up the topic of intimacy between them. Now, when we're doing so much by video, we've lost a lot of that. Because I feel like we're all kind of in survival mode. There's been some degree of letting things that are really important, like intimacy, go.

PROMO:
All over the country, we have support groups to help you manage your arthritis. Groups may meet virtually or face to face, depending on your location and the pandemic. Connect with others who care at https://connectgroups.arthritis.org/.

Rebecca:
Some days, though, no matter what anybody's intention is, you might just not be in the mood. And when you're in a lot of pain, you might not wanna be touched, and that can be misconstrued as: I don't care about you. How do you give advice to people who ask about: How do I say no without hurting their ego?

Iris:
The person with whatever the chronic disease is, or the type of arthritis is, needs to understand what their disease is. And their partner needs to understand what the disease is. I think it's gonna be much easier for me to accept that my partner isn't feeling well if I understand what it is that makes them not feel well. Because many people with arthritis, you can't see what the problem is. It may not be obvious. Maybe it's somebody's hands; well, what's that got to do with the rest of their body?

What if it's the fatigue? I can't see fatigue. What does fatigue mean? So, take a little nap. I think before you can help your partner understand, you've got to be able to say whenever, "No, I really don't want to." I mean that's legitimate for somebody to say, no matter what. But I think in order to say it and feel that you are sparing feelings, or that what you really wanna communicate is: "I still love you, I'm not rejecting you, it's just my body is not gonna let me do this tonight."

Victoria:
I would say, you know, on those nights when you can't, or it's just too much, to have intercourse: "I just can't. I'm overwhelmed by that, but can we do XYZ? Can we schedule for tomorrow? Are there some alternatives that we can explore?" And then, there's also this whole school of thought that we're watching a little too much Netflix, and we're not having enough sex with our partners.

So, there's also this thought, well, just doing it is gonna make everyone feel better. "I know you're not feeling 100%, maybe don't feel great about your body." But if you kinda just let it start with, like, some hand holding and some foot rubbing, you might get more into it. There's that kind of, you know, "Maybe could I just give you a back rub and we can see how that goes?" There's that avenue. Or there's, you know, "Not tonight, but how about tomorrow?"

Pete:
I know you're talking like, with the scheduling thing, and maybe trying to find time for that. Because again, you know, like as a guy, I mean, there's two different types of morning stiffness, right? (laughing) So when you have 'em both at the same time, you have that dilemma of, well, OK, so it's not so great when that happens. So, maybe that is something important to keeping the intimacy going is that it doesn't necessarily have to be sex. Maybe even something just simple, like touching or cuddling or something like that really could help a lot, right?

Victoria:
Right.

Iris:
We talked about the caregiver stress before. And I, referring back to Miriam Coughman's book, she really talked about having an occupational therapist get your sex toy. There are people who do that, and maybe having somebody else help out with the household duties, like somebody else is coming in to clean every two weeks, so your caregiver partner's not doing that anymore. There's leftover time for intimacy. Anything that you can get off of the person's plate is really gonna help a lot. I always say the sexiest thing my husband does is unload the dishwasher. Because wow…

Pete:
I've heard that one here, too.

Iris:
...when I'm not doing tasks around the house that are off my plate, I am feeling a lot more in the mood (laughing), OK?

Rebecca:
Clean the whole house and I'm ready to go. (laughing) Well, there is one thing...

Pete:
I'm scheduling a maid service right now. (laughing)

Rebecca:
There's one thing that can easily kill the mood if you're not in the mood is the smell of pain cream. So, if (laughs) my husband ever walks in the room and he's like, "Oh, it's one of those nights, huh?" So, he knows, OK, you're in pain, fine. You know?

Acts of service is a love language, right? But that is one thing, too, for some people. I'm fortunate to have a husband that does a lot of things. Just that alone, that appreciative perspective I have of all of the things he does to support. That adds to the intimacy. He takes care of me. It does make a difference. I think that adds to it. Keep unloading that dishwasher, Pete. I mean, seriously. (laughs) For a lot of women, especially in moms, we're all trying to balance so many things. And that's, you know, that's the hard part. When am I supposed to have energy to do that, too?

We've talked a lot about having a healthy sex life and drive and keeping that with your partner. But I don't wanna skim over the fact that there might be listeners who are listening who don't have a partner. So, do you have patients with arthritis who come to you who have concerns about their sexual health and they don't have a partner?

Iris:
Absolutely. And I hope Vicky has a lot more advice about this: If you are newly diagnosed with an autoimmune disease and you're dating, and when do you reveal that? I love it when ladies come to me and tell me that they wanna maintain intimacy but they don't have a partner, because then we can talk about toys, which is super fun. And talk about lubrication and things like that. I have a sex therapist that I have on speed dial so that I can refer my patients to the sex therapist, or give them a catalog of toys. There's so much on the internet now that is available. And remind them that the occupational therapist can help them with gadgets and devices and help them manipulate them. But it's very, very important to maintain a sex life, even if you're a solo partner, because it helps with pain.

If you have an orgasm, your pain threshold goes up by 110%, according to the Rutgers study. That is huge. It really helps with pain. It helps physiologically with your immune system, when you have an orgasm. You're better able to fight infection, which we all need right now. So, these are really, really important things for everyone.

Rebecca:
Well, there's some motivation right there, Pete.

Pete:
I was gonna say yeah.

Rebecca:
A pain reliever.

Pete:
I'm gonna give that entire list right there, all the benefits. I'm gonna tell my wife about all of that tonight (laughing), for sure. It's good for my health, right?

Rebecca:
Yeah, the endorphin release, I think we forget about that, right? One of the things that we talk about is staying physically active when you have arthritis. So, this is a form of physical activity.

Iris:
It sure is.

Rebecca:
Did you want to add to that, Victoria?

Victoria:
It seems to me that too soon is… it can be scary. But too late can be scary. So, it's really, I think, a matter of sort of waiting for that door to open. I guess if I had to give it a third date discussion or something like that. It depends. I think you're gonna know. And if it's not the right person to bring it up with, then that's not the right person.

Iris:
That's why the support groups are so important, and the Arthritis Foundation is so important, because that allows individuals to have a platform where they can talk to other people who've been there and done that. And what do you do? And what worked for you?

PROMO:
Whenever you need help, the Arthritis Foundation's Helpline is here for you. Whether it's about insurance coverage, a provider you need help from or something else, get in touch with us by phone toll-free at 800-283-7800. Or send us an email at arthritis.org/I-Need-Help.

Rebecca:
We have a segment where listeners can ask questions, and we post it on social media. We did post some questions and say, "What questions would you have for our experts?" And, you know, I'm not surprised that we didn't get a lot of questions, because I think people are afraid to post those questions publicly. One person said, "Good topic. What are some positions that those of us with arthritis should avoid?" She has osteoarthritis.

Victoria:
If you have osteoarthritis, then you may have had a hip replacement or a knee replacement. And obviously, or hopefully, your physical therapist has told you to what degree that joint should go. And taught you some precautions for those joints. So, you don't wanna go beyond that. Think back to what your physical therapist may have told you. Positions to avoid? I can't think offhand of what to avoid, except if it makes you uncomfortable, avoid it.

Iris:
Right.

Victoria:
If there's discomfort involved, you don't want to do something that's really hurting your hips or hurting your knees. One thing to remember is, you do not have to be an acrobat. Nobody needs you to be an acrobat. It may look good on TV, but that is not happening.

Rebecca:
That is not real life, people. (laughing)

Iris:
The whole experience is not gonna be what it looks like on TV.

I mean, there's "Shades of Gray." There's no spontaneous "it's on," the candles are there, and there's (laughing) the great music and everything, because the kids are knocking at the door, the dogs are barking, you're falling off the bed, somebody's farting.

Pete:
Right.

Iris:
It's just never works out like that. That's why having a sense of humor is so important. I would say the same thing for osteoarthritis, there's no position that is taboo or that you shouldn't do. It's about doing stuff that doesn't cause you to have intense nerve pain going down your legs.

Comforting yourself with pillows would be fabulous. You might not wanna use the sex swing if you've got any instability. It's just about being wise about how things are going. Hopefully they've seen an occupational therapist so they're not, you know, putting so much pressure on their thumb because they're holding themselves on the bed. It's doing things that are not hurting you, that you don't have pain afterwards.

Pete:
It's just amazing, like you even mentioned, like that swing. And I think of how incredibly practical that would be (laughing) for someone with arthritis. But the thing is, with three

kids, how do you convince 'em that it's not for them? Why is there suddenly, there's this amazing swing, or floating Papasan chair or something and that's: No, that's mommy and daddy's special chair. I guess, you know, gotta explain it.

Rebecca:
It's only for adults. (laughing)

Pete:
I just start thinking of, if you are having issues with mobility or something, it would solve so many problems. I don't know, maybe some sort of program where we can get one of those into the home of everyone in the country somehow, but… (laughing)

Rebecca:
Take away that gravity piece. Iris, I love what you said. You've gotta have a sense of humor in navigating all of this. You have to have a sense of adventure and openness and willingness to talk about it with your partner. To be able to make sure that you're maintaining that level of intimacy, to keep that relationship strong, right? And I think it's such an important piece. So, I'm really, really glad that we were able to have this conversation today and appreciate you guys joining me in the conversation.

PROMO:
Vim is a one-of-a-kind pain management app that can help you track your condition, set goals and connect with others. It's free and it's customized to your own situation. Download Vim at https://www.arthritis.org/vim. And take back what chronic pain takes away.

Rebecca:
Before we go, we always like to end every episode with our top takeaways. I'm gonna start with you, Victoria, if you could share your top three takeaways for our listeners on sex and intimacy when you have arthritis.

Victoria:
Well, I think my number one would be: Understand what you can about your disease and your medications. And help your partner to understand that, too. I think before we talk about anything, I think we need to really understand. Number two would be to develop some style of communication that's going to work between you and your partner. And number three, I think, is relax.

Rebecca:

Yeah relax, just do it. Iris?

Iris:
Just do it. Ashley Graham has a great quote: She said every time she and her husband are bickering, she knows it's because they haven't had intimacy in a while, and they just smooth everything out. So, maintain intimacy, whatever that means to you. It doesn't mean penetration, you know. Communication, communication, communication, that is so important for intimacy in whatever form. I love Vicky's suggestion about journaling or writing it down and giving your husband or partner a card with information that could be helpful. There is a book.

So, you could always get the "Sex Interrupted" book... just laying there, and say, "You know, I picked this up because I heard this crazy nurse practitioner talking about it. Let's have a conversation." Because the whole book is about communication and the importance of maintaining intimacy no matter what.

Rebecca:
Pete, do you have any takeaways you want to share?

Pete:
I think just having this conversation is key. Like you said, a lot of times, especially for men, a lot of times guys are reluctant to talk about their health in general, right? If you're dealing with arthritis and you're dealing with that pain, or you're dealing with the side effects of the medication, don't be afraid to talk to your doctor about it, to your nurse about it, somebody to get that conversation going because you need to do that for your own well-being. But then especially that communication with your partner. And having that dialog is so important. But just know that there are those of us out there who are probably going through something similar, and that you're not alone in this journey.

Rebecca:
Yeah, definitely not alone. And thank you very much, Victoria. Thank you very much Iris, and Pete, for having this important conversation with me today. And it's not gonna be the last. I'm sure we'll have more conversations to come. For those of you listening, if you haven't downloaded our new app from the Arthritis Foundation, Vim, I highly encourage you to do so. You can connect with others in the community who, like Pete just said, get it. And find out some resources and education and tools to help you manage your arthritis.

Don't forget, it's not just physical activity and nutrition and all of the activities of daily living; your sexual health is a part of your health. And make sure you open up to your doctor or nurses, or anybody that's a health care provider that you're comfortable with. But most important, like Pete said, communicating with your partner. Thank you guys for joining me today. I really enjoyed having this conversation with you guys.

Pete:
Thanks, Rebecca.

Victoria:
Thanks for having us.

Rebecca:
Due to the nature of the content in this episode, if you have any questions or comments for our guest experts, please feel free to email us at podcast@arthritis.org.

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