

Connecting & Staying Active Virtually

Hosts: Rebecca Gillett, MS OTR/L and Julie Eller Guest Speakers: Cindy Senk, volunteer with arthritis, Connect Group Facilitator, certified personal trainer, exercise instructor and yoga teacher; Helen King, volunteer with arthritis, Connect Group Facilitator, Platinum Ambassador, Local Leadership Board Chair

Plenty of research shows how important social interaction and physical activity are to one's health and wellness. People who have strong social connections tend to be happier, healthier, and live longer. Staying active helps everything from pain and stiffness to quality of sleep and mental wellbeing. But when you're staying home and social distancing to reduce your exposure to the new coronavirus, it's a lot harder to maintain a social life and exercise regimen.

In this episode, Rebecca and Julie talk to two guests who also live with arthritis and have found ways to stay connected and active virtually. Cindy Senk and Helen King – both volunteers and dedicated supporters of the Arthritis Foundation – talk about how they're coping with isolation, share their tips and experiences, and discuss Arthritis Foundation tools and resources that help people stay active and connected.

Cindy Senk, who has been living with osteoarthritis for 48 years and with Sjogren's syndrome for six years, is a certified personal trainer, exercise instructor and yoga teacher who has been teaching her students online in response to the coronavirus. An Arthritis Foundation volunteer for 20 years, she serves as chair of the Springfield, Massachusetts, area Walk to Cure Arthritis, she's a Live Yes! Connect group facilitator and she teaches Arthritis Foundation exercise and aquatics programs.

Helen King was diagnosed about six years ago with acute onset rheumatoid arthritis. She also has osteoarthritis, spinal stenosis and degenerative disc disease. In addition to her full-time job, she stays busy volunteering for the Foundation as a Connect group facilitator in Philadelphia, a chair of the local leadership board and a chair of the local Walk to Cure Arthritis committee. She also is a Platinum Ambassador, and she has been an honoree of both the local and national Walks.

Additional Arthritis Foundation resources:

To find or start a virtual support group in your community or to connect with others in online forums, join the Live Yes! Arthritis Network at <u>arthritis.org/LiveYes</u>.

Read more about Cindy Senk's story in her blog.

Read more about <u>Helen King's story</u> in her blog.





Join the army of volunteers who fight for people living with arthritis by signing up to advocate your congressional representatives at <u>https://www.arthritis.org/advocate</u>.

Use the Your Exercise Solution tool to find joint-specific modifications for numerous activities at <u>arthritis.org/YEStool</u>.

Start a walking regimen – or step it up – with help from the <u>Walk With Ease program</u>, and sign up for your local virtual Walk to Cure Arthritis at <u>https://www.arthritis.org/events/wtca</u>.

And help make a difference for yourself and others living with arthritis by sharing your insights at <u>arthritis.org/insights</u>.





LIVE YES! WITH ARTHRITIS PODCAST: Connecting & Staying Active Virtually Released May 12, 2020

PODCAST OPEN:

Welcome to Live Yes! With Arthritis, from the Arthritis Foundation. You may have arthritis, but it doesn't have you. Here, you'll learn things that can help you improve your life and turn No into Yes. This podcast is part of the Live Yes! Arthritis Network — a growing community of people like you who really care about conquering arthritis once and for all. Our hosts are arthritis patients Rebecca and Julie and they are asking the questions you want answers to. Listen in.

Rebecca Gillett:

Welcome to the Live Yes! With Arthritis podcast. I'm Rebecca, an occupational therapist living with rheumatoid arthritis.

Julie Eller:

And I'm Julie, a JA patient who's passionate about making sure all patients have a voice.

Rebecca:

On this episode of the Live Yes! With Arthritis Podcast, we're talking about all of those myths about arthritis out there.

Music Bridge

Rebecca Gillett (00:00:01):

Thanks for tuning in to the podcast. In our world today, we're physically distancing but trying to stay socially connected and active as best we can. But globally people are virtually connecting more and more, and whether it's a birthday party on line or doing some happy hours or family get togethers, we're all trying to stay connected to each other.

Julie Eller (<u>00:00:24</u>):

And it's not just about socially connecting, it's also about trying to learn ways to stay physically active and well for all of us with arthritis and beyond, while we're home. It's important that we're all managing our symptoms and staying active, but doing so virtually can be a new challenge and a new opportunity. So it's really important for us to s-, learn new skills and activities that are out there today.





Rebecca Gillett (00:00:50):

you can b-, get bored with what you're doing (laughter) every day, right? I mean we're stuck home, we're not going anywhere, so trying to find new things would be great, uh, to help mix it up a little bit.

Julie Eller (00:01:10):

Yeah, you know, I find myself like using video chat far more often with people who live far away from me anyway. So I find myself getting to connect with folks who usually I see in person but chat with on the phone or text back and forth.

Julie Eller (<u>00:01:29</u>):

... I think it's one of those virtual connections that I hope to maintain post uh, pandemic, so I've been really trying to- [crosstalk 00:01:36]

Rebecca Gillett (<u>00:01:36</u>): Yeah.

Julie Eller (00:01:36):

What about you?

Rebecca Gillett (00:01:37):

Yeah, in some situations too it's almost like, why didn't we do this before when you aren't together? (laughter)

Rebecca Gillett (00:01:43):

I have, um, a brunch that I do with my friends and they're doing it like every weekend, but I, I'll join when I can.

Rebecca Gillett (00:01:49):

we have a friend in New Zealand, a friend in Germany, and, you know, navigating different time zones but it's really nice to be able to connect that way. it doesn't make you feel like you are so isolated and, and it really makes a difference, so for us who live with arthritis I think that's definitely something we don't want p-, people to feel like is that they're isolated.

Julie Eller (00:02:13):

That's so right, and that's one of the reasons why we have some great, amazing expert guests today on our show who are true Champions of Yes with the Arthritis Foundation.

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Rebecca Gillett (00:02:34):

Yes, Julie and I really feel like years of experience of living with a form of arthritis helps people to really understand and uh, know what you're going through if you have arthritis, and connecting with others virtually who have arthritis is kind of an important thing to do right now, in these crazy times we're living in So welcome to our podcast today, Cindy Senk and Helen King. I think we'd love for you to each just spend a little bit of time and give a little introduction about yourselves if you don't mind. So we'll start with you, Cindy

Cindy Senk (00:03:12):

Hi, I'm very happy to be here. My name is Cindy Senk and I live in Springfield, Mass. Um, I have two types of arthritis, um, I was diagnosed 48 years ago with osteoarthritis and then about six years ago with Sjogren's disease, , it's kind of guided me throughout my, uh, my life and my career. And I am a fitness professional, uh, that's what I do, uh, for the past many years, 35 plus years now, um, and I'm a certified personal trainer, an exercise instructor, a yoga teacher, um, and I've found that uh, I've learned a lot, uh, in teaching and with my arthritis to be able to share with others.

Cindy Senk (00:03:56):

what I do for the Arthritis Foundation as a volunteer is, for the past 20 years I've been involved so it's been a long time, I'm really very fortunate. Um, so I've been involved with the Walk to Cure Arthritis. I'm currently a chair for the Springfield area walk I'm also a Connect Group facilitator, a network leader, and I do teach the Arthritis Foundation exercise programs as well as aquatics programs. I love the Arthritis Foundation. It's really one of my passions, it's really helped me to be able to manage my challenges well and I, I just very pleased to be here today.

Julie Eller (<u>00:04:58</u>):

Thank you Cindy. Helen, do you want to introduce yourself as well?

Helen King (<u>00:05:01</u>):

Yes, absolutely. I'm excited to be connected virtually, uh, from my dining room all the way in Pennsylvania. I was diagnosed with acute onset aggressive rheumatoid arthritis about six years ago. And I also live with osteoarthritis, spinal stenosis, and degenerative disc disease.

Helen King (00:05:28):

So my RA is fairly well managed with several medications that I take, which allows me to have a full time career in the financial services industry. I've been with the same amazing company for 28 years. I started when I was 12 (laughter). Um, one might say, um, I have a passion for volunteering for the Arthritis Foundation, it has truly become a passion. I am a Live Yes connect facilitator in my local





home town. I'm also a platinum ambassador. I'm a chair for our local leadership board here in the Philadelphia market, and as you know it's walk season, so right now I'm also chairing the walk committee in Philly.

Helen King (<u>00:06:13</u>):

I've had in the past the honor of being both a walk honoree in Philly and the national walk honoree. So yeah, um, did I mention I'm passion? (laughter). So I spend a lot of time volunteering for the Arthritis Foundation. I'm involved with my church, I'm a big sports fan. Um, I'm really hoping, um, that we're not somehow connecting virtually to football when it comes back in the fall (laughter), hoping that we've moved past that by now. But yeah, that's it. That's me.

Julie Eller (<u>00:06:57</u>):

That's it, she says, that's me, after listing this long pedigree of titles and roles (laughter) and responsibilities and passions, both of you. Thank you so much for everything you do for our community and-

Rebecca Gillett (00:07:09):

Yes.

Julie Eller (<u>00:07:09</u>):

... you guys mentioned a lot of in person event opportunities and in person connection opportunities, and lots of things in those, uh, titles there, and so I'm so glad to have you guys on as we think about how we can bring people together around those important causes virtually.

Rebecca Gillett (00:07:30):

Yeah, it's really hard for a lot of us, I mean, thank you both too for all that you do,

Rebecca Gillett (00:08:28):

So everybody likes to say we're living a new normal, right? (laughter) You're almost in your routine of your new normal in this different world order, but I want to ask each of you, , how are you coping with this having to stay at home and social distancing?

Cindy Senk (00:08:53):

Well, I feel very fortunate because I live in an area of Massachusetts, that I have some, a little bit of land and I'm connected to, um, different places that I can walk through my woods and get into





more woods, um, and I'm a big hiker, walker, runner, so that's allowed me to still be outside a lot, without uh, being in, uh, too close to others.

Cindy Senk (00:09:34):

But I also practice yoga daily. I do uh, breath work and meditation. I'm not really good at sitting and meditating (laughs) even though I am a yoga teacher, so I do a lot of my meditation walking when I'm in the woods.

Rebecca Gillett (00:10:00):

Yeah, I'm with you. Being outdoors and connecting with nature is, is a great way to do it.

Julie Eller (<u>00:10:06</u>):

Cindy I, just to follow up with you there, what are some things that you're doing to help others cope during this time as well?

Cindy Senk (00:10:32):

So what I decided to do was to be able to create some YouTube videos that I could share with my students.

Cindy Senk (00:11:04):

So it started out kind of private, where I just did the YouTube video (laughs) and I shared it with just my students, and then the next thing happened where somebody shared it with somebody else, and then there was this kind of domino effect.

Cindy Senk (00:11:46):

, so it really has turned into this wonderful way for me to create some content for people, whether it's in the chair or on the mat, um, and I've gotten really good feedback. So it was a little daunting, I must say, kind of putting myself out there in the virtual world there (laughs) because you don't know who's seeing what, but I thought, you know what, it's not about me, it's about being of service, and how can I maybe help somebody?

Julie Eller (<u>00:12:31</u>):

Love it. There's so much, uh, there's so much good will in building something like that for others and, making yourself vulnerable by putting yourself out there in a new way to bring people together virtually, Helen, what about for you?





Helen King (<u>00:12:58</u>):

Yeah, so my situation is completely opposite of Cindy's. (laughter) I am in a highly dense populated area right outside of Philadelphia, and then I live in an apartment complex on top of that that is in a town center type area. So there's no woods and nice places to go walk, and what is, has been shut down. I live a stone's throw from Valley Forge National Park, but the park is closed.

Helen King (00:13:46):

the stay at home order is a little harder for me. The social distancing, or physical distancing like I, I like to call it, I think is a little bit easier, because in some ways I feel like those of us with autoimmune form of arthritis are sort of like trained athletes for this. (laughter)

Helen King (<u>00:14:29</u>):

I mean, this has been going on every cold and flu season since I've been diagnosed, right? The washing my hands. My family doesn't come over, um, when they're sick or I'm sick. the stay at home order for me is harder than the actual physical distancing, but I'm working hard at being good at both.

Rebecca Gillett (00:15:13):

what do you think has been the thing that's helped you most to stay connected with family and friends, Helen?

Helen King (<u>00:15:41</u>):

So the thing that has, is the most connecting is my double edged sword, so it's technology, right? (laughter) So I'm able to work from home and stay connected to everybody through Zoom and text messaging and phone and face time, and (laughs) yet I'm not able to disconnect from Zoom, phone (laughter) face time [inaudible 00:16:05] which then leads to issues with my arthritis, because I feel like I'm on from six o'clock in the morning 'til nine o'clock at night. I'm not disconnecting, which is translating for me into not sleeping well and not finding time to do the exercising that's so important for us, right, when we have arthritis-

Rebecca Gillett (00:16:24):

Yes.

Helen King (<u>00:16:25</u>):

... and the sleep. So those are the two, it, it's technology, it's been both wonderful for me (laughs) uh, and it's been the killer.





Rebecca Gillett (<u>00:16:35</u>): Yeah, it's definitely a catch 22.

Julie Eller (<u>00:16:37</u>): Right.

Rebecca Gillett (00:16:37):

Rebecca Gillett (00:17:18):

it's hard to balance that out, you know, so I think everybody is feeling the same thing, you know.

Julie Eller (<u>00:18:58</u>):

Cindy, I wonder, from your perspective, when you're thinking about some of those challenges that you've experienced in combating this pandemic, what are some of those things that really stick out as, "Oh, that's a pressure point for me?"

Cindy Senk (<u>00:19:14</u>):

Yeah, I've, I'm really, have difficulty sitting for long periods, uh, as well, and so what I've found, and I've done this for a lot of years, is I will, if I have to sit and do some things that I know are going to take some time, I have a little alarm that will go off, like every (laugh) part of the hour, or you know 45 minutes or so, and then I'll just do a little bit of chair yoga, you know, [inaudible 00:19:37] cat cow, breath work, just expanding and you know, moving my shoulders around, things like that, or standing up and, and uh, being able to just stretch a little bit that way.

Cindy Senk (00:20:14):

I think that's really important, for, not only for your body but for your brain and your mind as well, um, that it can be physically painful for me after a while of sitting too long, I get really pain in my back that's kind of like again why I decided to do this with an alarm like a red flag

Julie Eller (<u>00:20:47</u>):

Yeah.

Cindy Senk (<u>00:20:47</u>): It really helps me feel better, if I'm not moving then I'm in a lot more trouble.

Julie Eller (<u>00:20:59</u>):





I'm having a hard time not getting up and moving downstairs to the kitchen for a snack and then (laughs) coming back upstairs to my work station. Do you have any tips for me on how I can (laughs) do some kind of healthier movement than the, right back down to snacking town? (laughter)

Cindy Senk (<u>00:21:25</u>):

Well maybe even things like um, uh, exercises to keep the body strong, like sit to stands. Like coming up out of the chair, it's almost like a little squat, you know you kind of get up and then come back down slowly. I really like body weight exercises a lot,

Cindy Senk (00:21:51):

I think breath work can be really, really therapeutic, and just being able to get, again, encourage the movement but not in a way that you have to, like necessarily go get something to eat or whatever. But to be able to just invite your breath in, think about maybe tensions leaving the body. You know the mind is a very powerful thing,

Helen King (<u>00:22:40</u>):

Rebecca Gillett (00:22:52):

drinking water is an important thing. You, you forget that. I think when we're not moving and going places as much too, I find that I forget that I need to drink more water (laughs)

Helen King (<u>00:23:19</u>):

Yeah.

Rebecca Gillett (00:23:19):

I love that you've done chair yoga. There are things like that that I think people don't think about, that you can do exercises in a chair if you don't feel well or you're having a tough day, so for those out there that are having a lot of joint pain and stiffness and the idea of going on a walk or up and down some stairs, do you have some suggestions for them to?

Cindy Senk (00:23:55):

Yes. I think, I'm a big lover of chair yogal practice it, as well as on the mat but I also really love days where I just get on the chair and work um, seated or standing, uh, postures that way.. I think also some of the Arthritis Foundation exercise program uh, movement that you can find on the Arthritis exercise app you know just gentle things like knee extends, you know straightening the leg and bending it, or some of the hand exercises that I find really, really helpful





Rebecca Gillett (01:05:45):

So Cindy, are there exercises that you recommend for people or that you do at home that help if your hands are hurting with your arthritis?

Cindy Senk (01:05:53):

Yes, I use the, uh, exercise that I learned through the, um, Arthritis Foundation exercise program that can be done in the water or on land, and there's a variety of different ones that you can do what really helps me particularly that my thumbs now are both fairly challenged, um, with arthritis, is that I, I fill up the sink with nice warm water, and I place my hands in the sink, and I'll do different types of movements that are a part of this, like the closing and, closing your hands like you're catching a butterfly and then gently opening them.

Cindy Senk (<u>01:06:31</u>):

So it's the flexion and extension of the fingers, just to be able to get movement in my hands. Cindy Senk (<u>00:25:18</u>):

Just to get into a habit, you know, can be really, just helpful for people. Um, we get stuck sitting, and it's really hard. Once you're into that sedentary, situation where it's, it's, it's a lot harder to get up and move. It really is.

Helen King (<u>00:25:54</u>):

I have a completely different point of view than Cindy does. I mean, this is what, this is her passion and this is something that she loves to do, and it seems like it comes so easy and effortless to her. And then there's me. Like, exercise I do because I have tol agree with what Cindy said at the very end, , if you're in pain and you don't feel good and you, you don't have this habit, you know, how do you force yourself to get up? Because you know it's the best thing for you. You know this is what you need to do, right? Motion is lotion. We all, we all hear that.

Helen King (<u>00:26:41</u>):

for me, I don't set these grandiose expectations for myself. I try to say, okay, three times this week. That's it. Three times. I'm going to do something for 20 minutes, or 10 minutes, or whatever it is. And I write it down, and I schedule that time, because I'm important.

Helen King (<u>00:27:21</u>):

I don't overset those expectations. And then you build on it. So this week it was three times for 10 minutes. Maybe next week it's three times for 15 minutes. Then you build those healthy habits, and I





think I read somewhere it takes 21 days or something like that to create a new habit. So give yourself a break until you can create that new habit.

Rebecca Gillett (00:27:41):

Mm-hmm (affirmative). I love that you schedule it in, because you're making your self care a priority.

Julie Eller (<u>00:28:55</u>):

Yeah, I think scheduling it is, a tactic to kind of make sure you're staying moving and really taking that initiative to take care of yourself. I'm very type A, so when I think about putting something on a calendar I'm like, "Oh, (laughs), n-, perfect, that's taken care of my brain." I love it.

Julie Eller (<u>00:29:11</u>):

Um, but the other thing that helps me always when it comes to exercise is group activity, right? Like having the accountability of an instructor or a community around me working toward kind of a similar goal of health, what are some of your thoughts about how we can accomplish community virtually when it comes to our activity?

Cindy Senk (00:29:44):

I would like to be able to offer, one of the things, uh, that I was thinking is to the Connect group that I have, is to try to get on the Zoom platform and do a, uh, a chair yoga with everybody, 20 minutes, See what the response is, see what people think.

Cindy Senk (00:30:09):

I think that connection to be able to see others and they can maybe see you if they choose to be on the video or not, or just to be able to be part of it.

Cindy Senk (00:31:47):

when Helen was talking earlier about you know, writing it down and making it a habit, one thing that I find helps me, um, and has helped some of my personal training clients or people that I work with, is to try to think about, you know, how good you feel after it's over. You know what I mean? you don't want to do too much if you're having a flare, you're having a lot of ch-challenges in the joint that day, but better, something is better than nothing. Any little movement is better than no movement.

Cindy Senk (00:32:28):





It's about you and your experience and what is going to work for you today, and that's how I try to set up my yoga classes every time, that's where we spend the first few minutes of the class really feel into our bodies, and, and notice how we feel.

PROMO:

Now more than ever, managing your arthritis is extra challenging with stay-at-home orders that keep us isolated. We want to understand how COVID-19 is impacting you, so we can help make a difference. 88% of those with arthritis say they feel anxiety and fear these days. Do you agree? Go to arthritis dot org slash insights and speak out.

Julie Eller (<u>00:33:25</u>):

I'm wondering, Helen, would you mind telling us a little bit about what a Connect group is, and you're both Connect facilitators. I'd love to hear a little bit about how we're shifting in the world of COVID-19 to really connect people virtually.

Helen King (<u>00:33:52</u>):

I started, uh, my Connect group, uh, about five years ago, um, about a year after I was diagnosed with RA. And for me it was, I like looking, um, into my community for people like me, so that um, I could connect with people who could understand what I was going through. You know, family and friends are amazing support system, but there's nothing quite like connecting with someone who is on your same path and can understand when you say, "I'm fatigued."

Helen King (<u>00:34:27</u>):

They understand you feel like you've been run over by a truck, and that, you know, sleep won't help that, whereas your family and friends might not quite understand that.

It's about finding, you know the location and subject matter experts and bringing people together to facilitate. It's peer to peer. Um, it's all volunteer led, and it's really about what the group wants it to be. So all groups are different.

Helen King (<u>00:35:23</u>):

I have over 100 members in my group. Yeah, it's really amazing. And we um, in the physical world (laughs) before, you know the virtual, um, we would try to meet once a month and we would bring in subject matter experts, um, to um, educate.

Helen King (<u>00:35:57</u>):





But the group is really about empowering and connecting. Yes, there's an educational component to it, but it's about empowering and connecting. You know, we really want people to be lifted and learn to, um, advocate for themselves and help manage their disease and sort of take some of that control back, um, that we sort of lose sometimes when we have that unpredictability of, of arthritis.

Helen King (<u>00:36:24</u>):

So if you take that and shift it into the virtual world, we can do all of those same things. You know the only thing for me that's missing is I'm a touchy feely person, so if you're sharing a story and you're crying, I want to stick my arm around you. (laughter). That we can't do, (laughter) but everything else we can do, and I would venture to say, and more.

Helen King (<u>00:36:44</u>):

Because it is allowing us to, you know the subject matter expert-

Rebecca Gillett (00:36:49):

Yes.

Helen King (<u>00:36:49</u>):

... doesn't have to live in Philadelphia. Um, we're connecting groups by state and by region, so my members now have more times to connect in a month. Instead of just my one month, I can, I can offer up whatever's happening in my region. So if Cindy is, got a regional meeting going and she's teaching chair yoga, I would have never had access to that before. So now we have access to-

Rebecca Gillett (00:37:15):

Oh, that's ...

Rebecca Gillett (<u>00:37:16</u>): Fantastic.

Helen King (<u>00:37:17</u>): ... more. Um, and I think, people love coming in their pajamas. (laughter)

Julie Eller (<u>00:37:23</u>): That's the real value add, it's the PJs. (laughter)

Helen King (<u>00:37:27</u>):

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That and, I had people who would drive an hour, you know to come to a support group meeting, because we only have, you know, so many support group leaders. So the idea now, they can just turn on a computer and with arthritis you don't have to drive an hour.

Julie Eller (<u>00:38:00</u>):

Yeah, I think there's something really powerful about your story Helen, being able to log into a Zoom call, in my nice cozy PJ pants, maybe I'll wear a nice shirt so no one can tell (laughter) but I would feel much more comfortable taking that first step. So that's a really, really cool thing.

Julie Eller (<u>00:38:42</u>):

Cindy, have you had a chance to have a virtual Connect group meeting just yet?

Cindy Senk (00:38:47):

No, my group is um, a lot newer than than Helen's. Uh, mine's less than a year old, and we have 22 members now, we've had no virtual meetings yet but the last one I had was right before the whole COVID started, which we did a Live Yes with RA, and we had a subject matter expert, that was really good. We had about 30 people come to that.

Julie Eller (<u>00:39:17</u>):

Nice.

Cindy Senk (00:39:17):

there were a lot of great questions. We had a really rheumatologist, younger woman there who was very knowledgeable so out of that we were planning the next meeting and then all of a sudden this all happened. So at this point, um, I've been connected with them basically more individually through emails and things that people have asked me, but II really do want to offer the virtual chair yoga I think that might be a really good way to, , just give something that we can all do together,

Rebecca Gillett (00:40:35):

Even though the Connect groups aren't in person, you're crossing city limits, (laughter) you're crossing state borders, you're going regional, like you're really able to connect with even more people, and I think that's really powerful I'm in Colorado and we only have a support group. We have a support group in Denver and then one an hour south. But it is a barrier for people to, if they live up on the mountains and there isn't a support group near them.

Rebecca Gillett (00:41:10):





But now, we've got Utah, and Montana and Wyoming and Colorado all joining in on a call, and we couldn't have done that before, and like you said, you have a rheumatologist doing the Live Yes RA program for you, this probably makes it easier for our guest experts who come and teach us some things at these things, uh, at these meetings.

Julie Eller (<u>00:41:58</u>):

Yeah, it's very special to think about how we can bring community together even when we are so far apart right now. I think there's something very special about that. And Helen, your story about choosing to become a Connect facilitator I think is very special, because purely for that reason that Rebecca was saying, you know. She has two support groups, one in Denver, one an hour south, um, but it sounds like Helen that you saw that there wasn't one near you and so you decided to kind of be the change a little bit. I wonder if you could talk us through that decision-making process a little bit, and how that informed your passion, like you called it before, um, for the Arthritis Foundation.

Helen King (<u>00:42:39</u>):

Yeah, uh, again, it was about a year after I was diagnosed. It took me about a year to get stable on, um, some medications and you know, um, start to feel like I was wrapping my brain around, um, what was going on my family and friends were important and I, and I was forming that tribe that I think is so important, um, that we need uh, as people that have, um, chronic illness.

Helen King (00:43:14):

but again, I knew there had to be other people going through exactly what I was going through, and it became a driving factor for me, to really find it. I wanted something that was uplifting and empowering and that was going to help educate me and connect me with other people, because we know now, through data, that the more you connect, the better you're connected, the better you do physically, your outcomes physically, mentally, emotionally, and, and even with your doctors, uh, your quality of care is better.

Helen King (<u>00:44:14</u>):

And so really that's what I was looking for. I, I wanted to understand it, and I wanted people to understand me. once I put my big toe in ... Like you, Julie, I'm a type A personality (laughter), it really started to snowball because, it only took that first person, to impact that first person, to make that connection with that first person, to get that email from that first person to say, "I can't thank you enough for your meeting today, you really changed how I look at this," or, "You've motivated me to go back to my doctor and have a conversation about maybe a different medication." When you start hearing those things, I don't know I can't describe it. Because gratifying and grateful and all those words don't really sum it up.





Helen King (00:45:09):

And so you just realize that these connections, whether it's through a, a true Connect group or being connected to the Arthritis Foundation where you're making these connections and forming these friendships, I mean really that's what it's all about. And that's, I say it all the time when I talk about the Arthritis Foundation. I really don't know where I'd be in my journey without the foundation.

Cindy Senk (<u>00:45:55</u>):

Mm-hmm (affirmative).

Rebecca Gillett (00:46:00):

Aw. [inaudible 00:46:00] I can't even respond. (laughter) I, I, we share that feeling with you Helen, you know? I think Julie and I both feel that way, and similar, I didn't start a Connect group like you but, you know, similar journey. You dip your toe and you realize, "Oh wait, I like how it feels in this water."

Helen King (<u>00:46:17</u>):

Mm-hmm (affirmative).

Rebecca Gillett (00:46:18):

But it, it really is, a very different feeling to know, "Wait, I'm not alone, first of all. There are people who get how I feel. And wait, my tips and advice that have worked for me might help somebody else," and when you hear back that it does help someone, it really makes a difference. And so Cindy, I wonder if you've had the same experience as Helen.

Cindy Senk (<u>00:46:43</u>):

Yes, absolutely. I came in through the fitness door, you know 20 years ago, basically, and learning how to teach the, uh, Arthritis Foundation exercise program and then the aquatics program and then the Walk with Ease program, um, and I really have found very similarly to what Helen said, that, it's the same response, where someone says, "Well, I can now lift my arm up and get the soup out of the cabinet and I couldn't do that before," or, "I can get out of a chair easier," or whatever it may be. You know, "My pain levels are better, I feel more connected to people." So those are the driving factors and forces the way I've been connected through all these years has been through the fitness [inaudible 00:47:27] so to speak.

Cindy Senk (00:47:27):

I wouldn't be in such a positive place if I didn't have the Arthritis Foundation, you know, information and guidance and, the rheumatologist that I have, and all of that, it really has made a difference in





keeping me as functional as I can be at the age that I'm at at this point, and I can still do almost everything that I like. There's some things that are frustrating (laughs) but for the most part I really am very fortunate, and I try to then share, like you said, share that with others. and if you can help them in some little way then it's all worth it. It's all worth it. That's how I, totally feel the same way, yes.

Julie Eller (00:48:14):

I hear that sums it up very nicely. I think all of us (laughs) on today's episode feel that, if you can do a small thing and you, and you can see that change, or you just know that it's there, that it just makes every step of the journey really worth it.

Julie Eller (00:48:44):

And that has certainly been something that the Arthritis Foundation has held for me and many, many, many people in our community. My question is, you know for someone who's just dipping their toe in the water, and maybe it's not even their big toe. Maybe it's their pinky toe. They're just kind of testing out what's going on here. What advice would you have for them as they kind of explore this, this journey with our community?

Rebecca Gillett (00:49:18):

Well, I think first it's getting connected. it depends on where you are in your diagnosis journey. For Helen, um, kudos to you. I mean, it's hard when you're newly diagnosed to, to try to even connect with other people if you're not ready to admit that, you have this chronic disease and, and you need to take care of it. So um, kudos to you for doing that within a year. I, I didn't do anything for myself for the first two years.

Rebecca Gillett (00:49:47):

So first and foremost actually would be getting educated on your disease and what you can do to take control. the Arthritis Foundation for me was the same experience. It's where I learned even more, um, about how to manage and take control. And then I started meeting other people like me and it made all the difference to know that I was not alone and there were other people who could share their experience with me that helped me get through,

Helen King (<u>00:50:35</u>):

my advice would be, find a Connect group, and here's why. So when you go to a Connect group, you don't have to speak. You don't have to share your story.

Helen King (<u>00:50:51</u>):





But you can sit in a room and understand that you're not alone, and that there are other people that understand your journey. I mean one of the things that I do at every, whether it's a physical or virtual Connect group, is you know, after I go through some, you know, housekeeping rules, is you know, everybody share their story if you're comfortable. And if you're not, that's okay. all the resources and everything, the power behind the Arthritis Foundation, comes out and through a Connect Group. So that's why I'd say that's where you should start.

Cindy Senk (00:51:54):

Yes, I totally agree with Helen, , that's exactly what I was going to say too is the idea that someone can just be there. They can participate, they can listen. You know, they can empower themselves. I mean I think that's a really key point is, uh, it's like with anything you do, the more you learn, the more you can make good decisions for yourself and practice self care.

Julie Eller (00:52:48):

Just come, don't have the pressure to speak yourself. Um, I think opening the door with some of these virtual connections makes it easier, maybe, to take that first step, uh, and to find out more about those events and the Connect groups near you or virtually near you. You can go right on our website and join our Live Yes Arthritis Network to learn more. And I think my parting words on this question will be, even if you're not ready right now to engage actively in a Connect group or in an online community forum discussion or in any of our programs that we're asking you to bring your story and be vulnerable and share.

Julie Eller (<u>00:53:33</u>):

Even if you're not ready for that, just knowing that those things exist and that they will be here for you when you are ready, that is my favorite thing about the Arthritis Foundation, because certainly when I was a kid and I was first diagnosed it was more than enough for my family to just be a family living with a child wh- who had arthritis, right? We didn't do many walks, we didn't do many Connect groups, we didn't do any advocacy.

Julie Eller (00:53:58):

Um, but in my young adulthood, my family and myself have been able to open the door to those programs and those resources, now that we're ready to,

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Rebecca Gillett (00:54:26):

You know we always like to end our podcast asking our guests, what are your top three takeaways for people with arthritis that are listening, So I'll start with you, Helen, what do you think your three takeaways are to share with others?

Helen King (<u>00:54:48</u>):

Well my three takeaways would be number one, so we know through actual data, you know, that we get connected and we stay connected to the Arthritis Foundation, that we have better outcomes. mentally, emotionally, physically, and the quality of care that you get with your doctor because you become a better advocate about your health care. So that's number one.

Helen King (<u>00:55:17</u>):

Number two, you know that old saying, you know misery loves company? Well, I feel that being connected with the Arthritis Foundation is sort of the direct opposite of that. finding your tribe is so important, and those people that can lift you up and support you and empower you so that it's more like the old saying, a rising tide lifts all boats.

Helen King (<u>00:55:42</u>):

And then the third is, you know arthritis and our symptoms, including all the flares that we go through, are, it's so unpredictable, and it can be so frustrating when your entire day can be derailed because you woke up in the morning and it's not what you expected the day to be because you're in pain or, um, you know you have that fatigue that we all deal with. Um, so it might make you feel like you have no control, or less control. And so I say staying connected and being empowered and learning to advocate for yourself gives you some of that control back,

Rebecca Gillett (00:56:30):

I love it. That's, that's the theme, right?

Cindy Senk (<u>00:56:32</u>): Mm-hmm (affirmative).

Julie Eller (00:56:33): What about you Cindy, what are your three takeaways?





Cindy Senk (00:56:36):

I think it's really important to encourage and empower people to practice self care, that will then help create or develop a positive attitude. And really, I think as a yoga teacher I always see people as beings of light, like you know everybody has a light to shine and share, so I just think it's important for people to realize that, they can affect others in a positive way, which leads into my second (laughs) my second point.

Cindy Senk (00:57:11):

, being of service to others in some way, however that may manifest. Whatever it can be, you're going to feel so much better, uh, and like Helen said, I think it was that you get so much more back from what you give.

Cindy Senk (00:57:40):

the third one is gratitude. Really being grateful. Every day, in my morning intentions, I'm always grateful and thankful, uh, for what I have, and what I can do, and my ability to be of service to others in whatever way I can.

Julie Eller (00:58:02):

I can't imagine a better set of two top three takeaways for our podcast today. Those have been just really uplifting for me in a time that ... You know isolation and physical distance can feel dark, and feel scary, and feel stressful, , I so appreciate getting to talk with both of you today, because I felt some of that weight lift off of my shoulders and I think that that's not unique to this conversation, that feeling of community and connection being something that can reduce and relieve your stress and make you feel more full. So thank you for all that you do, and thanks for joining us today, guys.

Rebecca Gillett (00:58:52):

Thank you guys so much.

Cindy Senk (<u>00:58:53</u>): Thank you.

Helen King (<u>00:58:55</u>): Thank you.

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