

Patient Journeys and the Road to Diagnosis

Narrator 00:00

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Naomi Creek 00:09

Welcome to Patient PrepRheum, a podcast that explores the importance and often misunderstood aspects of living with autoimmune arthritis and related conditions in Australia.

I'm your host Naomi Creek, National Coordinator at GHLF Australia and, in this episode, we're talking with two women living with psoriatic arthritis.

Kay Boucker is from New South Wales and was diagnosed with psoriatic arthritis in 2013. Kay lived with psoriasis for many years before experiencing other symptoms like fatigue, tendon pain and uveitis, which she said took her GP a long time to be convinced about, but was finally referred to a rheumatologist. Kay also lives with type 2 diabetes and depression and says singing is her happy pill for helping her through life's challenges.

Our second guest is Andrea McMahon from South Australia. Andrea was diagnosed with rheumatoid arthritis, Sjogren's syndrome and fibromyalgia in 2010 and then, four years ago, presented to her rheumatologist with new symptoms of splitting nails and lower back pain where, shortly after, she was also diagnosed with psoriatic arthritis. It's been quite a journey that has taught her patience, pacing and resilience. Andrea remains optimistic for her future and continues her life with as much activity as she can.

Thank you very much for joining us on Patient PrepRheum.

Kay Boucker 01:34

Hello, Naomi.

Andrea McMahon 01:35

Yes. Good morning.

Naomi Creek 01:37

Kay, it sounds like your road to diagnosis with psoriatic arthritis was a bit of a bumpy one. Can you tell us a bit about that?

Kay Boucker 01:45

Yes, it was a bumpy one. I think some of it stemmed from me never having heard of psoriatic arthritis before. My family have got a history of rheumatoid and that was it. I had a whopping ear infection and didn't think much of that. And then my shins all came out in ghastly psoriasis. When I went to the dermatologist, she said, "Have you had a throat infection?". And I said yes. I didn't know why she was asking me that. And she said, "Ah, it can sometimes trigger psoriasis if you've got it".

So, I lived with that. I used to call them my pizza legs. But I lived with that for, in my 40s, probably about 10 years. Then I decided to migrate to Australia from the UK. I got to Australia in my early 50s and psoriasis disappeared. I thought, "Great, it's the sunshine".

And then, woe betide, I started to get the pain, the stiffness, the walking like a duck in the morning, the waddling because you can't move properly. And despite going to the GP's and saying, "I'm really tired, I've got these funny pains", none of it was put together. It was like a jigsaw puzzle that wasn't being put together.

And then I went to the cricket match at the SCG and this teenage boy just came and sat down next to me and he just brushed past my shoulder as he sat down and the pain was excruciating. And it went on and on and I thought, "This is not right".

So I went back to the GP, to a different GP who finally said, I'm going to refer you to a rheumatologist. And when I got to the rheumatologist, within minutes, he said, "You've got psoriatic arthritis". And we started my treatment from then on. So, I've been under treatment since 2013 and I've been through a fair few treatments, just starting a new one now. So, we live in hope.

Naomi Creek 03:36

So, you must have been pretty relieved, I guess to hear a diagnosis, even though it wasn't a great thing to be diagnosed with it. But it put all those pieces together.

Kay Boucker 03:44

I was, absolutely. I suddenly thought, "Okay, you're not going bonkers, and this is real". So, there was that. The upside of that knowing you'd got a diagnosis, but the downside was the diagnosis was not curable. So that's it, you know, you're gonna live with it. And so it was sort of bittersweet.

Naomi Creek 04:02

And you've got a few other conditions as I mentioned in the introduction. Ah, did they come on after you were diagnosed with psoriatic arthritis?

Kay Boucker 04:09

Depression. No, we had got a family history of that as well. Our family is riddled with histories. So, the depression was there, but I did get type 2 afterwards, type 2 diabetes. I've also had a cardiac stent and,

when I had that done, the cardiologist said to me, "I see you've got psoriatic arthritis". And I said, "Yes". He said, "Well, when I was at med school, I sat next to a guy who specialised in rheumatology and did you know there's a link between psoriatic arthritis and cardiac problems?" No, didn't know that either. So, there's been a whole heap of things really, which is odd. I mean, my sister also came down with it, came down with psoriatic arthritis. Yes. You know, my mother had multiple sclerosis. So, it's a real strong family link. I believe the autoimmune thing is a strong family history.

Naomi Creek 04:18

I see. Andrea?

Andrea McMahon 04:32

I was just going to say I have a strong family link too, as well. My grandmother had rheumatoid arthritis, although that was never declared but, anecdotally, that she certainly had all the symptoms. She got treatment with the gold injections from those days, and she used to wear the copper bracelets and slept on copper blankets. You know, this was her.

They never called it rheumatoid arthritis, but this is what, in hindsight, she had, and I believe I got the psoriatic arthritis from my mother, and she was never diagnosed with it either. She had all the same symptoms that I have.

Naomi Creek 05:36

Wow, quite some similarities there. Andrea, your diagnosis was a little bit ... a shorter route than Kay's, perhaps, wasn't it? Did you want to share a little bit about how you got to your diagnosis?

Andrea McMahon 05:46

Yeah, I still think it took about 12 months initially, back in 2010, to get there. For me, it was pain in my feet and hands that I couldn't work out. You know, I was having trouble, I had to wear high shoes to work and I couldn't get my feet in the shoes. And I started shopping in the shoe shop where my grandmother shopped to try and get comfortable shoes and then it sort of went on from that and eventually we got there.

I got referred to a rheumatologist and I got diagnosed with ... was initially called inflammatory arthritis. That was my first rheumatologist and then I transferred over to my second rheumatologist, who we share, Naomi, and he was the one that came up with the rheumatoid arthritis diagnosis. And I've now got a new rheumatologist in Adelaide, and she's a terrific young woman who's really on the ball. So, I was concerned about leaving my rheumatologist in Victoria. But there are some other good rheumatologists out there if you look, and I'm very happy with mine.

Naomi Creek 06:44

Yeah, it's great.

Andrea McMahon 06:45

It was not a straightforward diagnosis. And the same with psoriatic arthritis, you just put it down to everything else that's going wrong. And you think, "Oh, yeah, that must be part of it". Particularly with the psoriatic arthritis, they just said, "Oh, the reason your skin isn't too bad is because you're already on all the treatment". So, it wasn't like I thought, you'd look for the skin condition and then get the diagnosis from that. Whereas for me, it was the other things like the back pain and the nails and things that they picked up on and said, "No, your skin's already been managed by your drugs". So that's my story.

Naomi Creek 07:18

Thanks for sharing that, Andrea. And how are you both coping with everything at the moment?

Andrea McMahon 07:23

I think it's a journey. I try not to look at what's at the end of the tunnel. I think you just go through a journey of one foot after the other trying to work out what are the best medications, what's the best way to cope, how to deal with your good days and your bad days.

There is no cure, so you just have to try, and my motto is be the best I can be every day, and some days that's not very good at all. And other days I feel I can take on the world. So, the journey with medication is, you don't take a pill like a cold and flu tablet, and you'll be right in a few days. It is really, you get on these meds and then something changes.

I've just had to go through a very tumultuous six months after being on one biologic for 13 years. And it just stopped working. And that's what happened to my previous one. After a couple of years. It stopped working. So, I'm now on my fourth biologic, and it hasn't been straightforward. So, it's just a journey and your rheumatologists keep you optimistic and there's always something else they can think about.

And you've just got to be on the front foot with your GP and your pain medication. And that's a whole box of worms. I think the pain medication, with how the American system has come in and impacted on the GPs, you know. GPs get tapped on the shoulder if they're prescribing too much pain medication. So, it's finding the right person and proving that you're not some opioid drug addict.

But when you need pain meds, you need pain meds, and that's very tough, Naomi, because how do you, A, prove that you're not, you know, some addictive personality, that's a drug addict, but you actually need it so you can get out of bed in the morning. So, there you go. It's a journey and you've just got to keep one foot after the other.

Naomi Creek 09:07

Thanks. Kay, can you relate to some of those things Andrea is speaking about?

Kay Boucker 09:11

Yeah, I can relate to a lot of it. The thing is ... is when you get psoriatic arthritis or an autoimmune disease, it's quite likely that, like normal people, you'll get other conditions as well. I have severe restless leg syndrome. I also have complex regional pain syndrome, having fallen on my wrist once and punctured my, my cartilage.

So, for me, I try not to take pain meds. However, my water bill is horrendous because I spend hours in a bath in the middle of the night. It is something, sometimes the only thing, that'll just ease the whole body of pain. I sleep in the bath, it's an, it's not unusual. So, it is a journey. It can get you down. Be prepared to feel rubbish some days but just say, "Okay, that's today".

I lost my sister two years ago. She was my best friend and going through that process, I thought, "Okay, if I'm going to recover from that, let's try and make my approach to this illness better". And that's when I joined a choir. I started volunteering on a hospital ward for children one day a week.

I still work 20 hours a week at home. Fortunately, I work for my son and daughter-in-law and, therefore, I've got the support that I need. If I really have a bad day. If I creak out of bed sort of off an hour later than I should, it's okay. It's okay. So, it's about finding places where you can still function, but you have support around you.

My husband is wonderful. He's incredible. I don't really know what it would be like without him. I get breakfast in bed every morning, which is very spoiled, isn't it, you know? But you know, my whole family, they understand what I'm going through.

And that wasn't always the case with everybody around me. They hear the word arthritis, and they go, "Oh, I've got arthritis in my wrist or my ankle", but it's osteoarthritis and it's not the same. It is not the same. I really wish they hadn't put the word arthritis on this condition because it's much more than that, I feel.

I get enthesitis with mine — where your tendons join on your bones — and that was one of my first symptoms as well. I found I couldn't walk uphill. My Achilles tendons were so tight and so painful. There were times that, in order to get to the car, I had to turn around backwards and walk backwards up a hill just to relieve my Achilles tendons. So, it's a constant. I don't try so hard to make people understand anymore or get so mad about it. I just live with it.

Naomi Creek 11:43

It sounds like you've got some wonderful supports there and we so need all of that with all of these conditions that we seem to collect over the years. We laugh about that, but it is the big thing we all have to deal with. What are some of the other people in your life or services that you might use to get you through some of these tough times? Some allied health perhaps, do any of you use them?

Kay Boucker 12:05

I have remedial massage. I started that in the last few months and that's helped a lot, but, apart from that, not really no. I have to say I'm a little bit worried about how I'm going to cope in a few years' time. I'm 65 now and I look at my house and it's not quite as clean as it used to be because I just can't manage it and I'm not sure whether this condition is recognised as a disability where you would get some sort of help.

Naomi Creek 12:31

I can totally appreciate that. I think there are services that would be able to help you with things like cleaning. How about you Andrea, do you use any allied health to help with you and your condition?

Andrea McMahon 12:42

Yes, Naomi, I have tried every aspect of allied health, because I'll give anything a shot to see if it will help. The ones that I go back to are hydrotherapy. I do like hydrotherapy. In South Australia, the Arthritis Association actually sponsors hydrotherapy, so you can go and do a group hydrotherapy with a physio. We have ... I do Pilates. I do in fits and starts.

I haven't been very good with my allied health in the last six months, because I haven't felt up to it. When I'm on a roll, I'll do all those. You can go to an osteo, who I find very good. I've tried acupuncture, I've tried whatever you can try I've tried and so it's not just about mainstream medication, it's about "Well, let's see if this works" and I'll give it a shot. I've done, what's it, when you do the pressure change?

Kay Boucker 13:30

Hyperbaric.

Andrea McMahon 13:30

I've done hyperbaric chamber. I did that every day for two weeks.

Naomi Creek 13:35

Wow.

Andrea McMahon 13:35

Yeah, that was really interesting.

Naomi Creek 13:37

How was that?

Andrea McMahon 13:37

The worst thing was that it made no difference. The best thing was that, during the two hours I was in the hyperbaric chamber, I had no pain.

Naomi Creek 13:45

Oh.

Andrea McMahon 13:46

So, I actually felt good whilst I was in there, then that really upset my mental health because I could then see what life was like without pain. So, it was like, "Oh, okay", because I have it in every joint, my rheumatoid arthritis. It's every joint, so my whole body is in pain. It's like, I had to have a general anaesthetic last week and I say to the anaesthetist, "Can you please inject it really slowly because as you're injecting it, it actually is a time where I feel no pain".

Kay Boucker 14:17

Wow.

Andrea McMahon 14:18

It's the only time in ... during my life, that I have no pain. And so, it wasn't long enough when he injected it. But anyway, it's, "You grab your little wins, don't you Kay?".

Naomi Creek 14:28

A few moments of bliss.

Andrea McMahon 14:29

A few moments. There was a few moments. It's seconds. But yeah, I think you do try all the different things. One of the sort of, alternative things which is a bit outside allied health is that I knit and I knit because I like the meditative effect of it. But also, I think it is a way of keeping my hands moving. I can see that I'm losing the strength in my hands.

And it's just one thing that that I do do and so you can go and find knitting groups or do knitting classes and most good knitting shops do run those sorts of things. And it's an ... also a community you can get involved with, where you're not just talking about comparing medications or whatever if you're in a group that's health-focused, and that's a very positive thing for me, is that we do that.

Naomi Creek 15:14

That's fantastic, Andrea. I've been hearing you. You love to travel as well and you've done some quite big walks overseas. How did you go with even planning something like that, mentally?

Andrea McMahon 15:26

I think there's a way that you can do these things by being smart. And with the big walks, we've done the Camino de Santiago twice, which is the walk across the top of Spain, and we've done across to a city called Santiago. It's a thousand-year-old pilgrimage and there are many, many people that do it. So, it is all about how much you want to walk of the kilometres. For example, I think it's, to do the full walk from France to Spain is 800 kilometres. Well, I ain't up for 800 kilometres, but to get your, what they call your, certificate to say that you've done this pilgrimage, you only have to walk 125 kilometres. So, we've been able to find a company that puts you up in very nice hotels, gives you nice food, has a bus and the bus will stop every kilometre or so. So, if you want to, get on the bus and have a rest or water or just drive to the next stop, which means you'd cut two kilometres or three kilometres out of the day.

Or, you just sit on the bus all day. Not that I've done that, but you can do that. It's just a small tour group and we've done that twice. We've walked up from Portugal with our two daughters, and it's just been fantastic. Because there you go, who would have ever thought I could walk the Camino de Santiago? But I did and got my Compostella. 125 kilometres twice over 11 days.

Naomi Creek 15:27

That's incredible. Andrea, well done. You must have had such a sense of achievement after that.

Andrea McMahon 16:49

I'm still in disbelief, Naomi. It's still very much, "Did I really do that?". And we've planned to do what they call the northern Camino, which is the one down along the seaside of Spain, down from France next year with the same tour company.

So, I'm not carrying a backpack, I'm not sleeping in bunk beds or anything. It's just let's be smart about this and that's how I do it. And I just wanted to pick up on something that you said before, Kay, about how supportive your husband is.

I have the most wonderful supportive family too. And I'm very lucky, my two daughters are both, well, one's an ICU doctor and the other one's, say, almost a doctor. And so, it's just so important that they help, they understand. They're there at medical appointments if you need them and it's just, they try very hard. They're not 100 per cent, but they try really hard and that's all you can ask for from your family.

Kay Boucker 17:16

That's right.

Andrea McMahon 17:26

And they don't understand. I don't think anybody would understand this unless they'd been through it.

Kay Boucker 17:52

No, I think you're right. It's sort of a unique experience each to their own, isn't it? And if you are the sort of person that doesn't like to moan about your aches and pains, it can be quite a lonely place. So, for my husband to come to me and say, "You're not good at the moment, are you?", it's lovely to see that he recognises that, that he's identified that because it's quite comforting to know that.

Naomi Creek 18:15

For sure, I think sometimes for our loved ones who are supporting us, it's quite challenging for them as well to know that balance of offering help and support, but also allowing us to remain independent. And I know that for myself, I'm fiercely independent and sometimes I think I push that to the wrong side and then when I really want support, it's not there because I've pushed it away. So, it's really hard for our loved ones to know that balance.

Kay Boucker 18:42

That's exactly right. And I think I mean, I've got two sons as well, so there's no female, soft female, caring, nurturing part there. But I've got a wonderful best friend and so you got to find it, where it's offered, but not be a burden. So that's a balance.

Andrea McMahon 18:58

Yeah, and I think it's important not to bang on about, moaning away day after day. I'm very conscious of not doing that and feel that when I do speak up, I'm at the end of my tether, and the loved ones just need to get that message. And I do love having animals in the house. I think they really help with stress levels and they keep you company. You know, if you're having a day on the couch, they keep you company. They get it.

Kay Boucker 19:26

And also keep you active when you feel up to it There's always a willing dog ready for a walk.

Andrea McMahon 19:32

Yes, mind you, when my husband went out this morning at two degrees I went, "No thanks". With the dogs, it was a bit cold.

Naomi Creek 19:41

We've been talking a lot about support from our loved ones. I wanted to ask you about how important your healthcare team is and the support you get from them and how you feel they work together to provide the best care for you because we do have a lot of conditions we're dealing with and, yeah, just how do you find that whole experience?

Kay Boucker 19:59

For me personally, I literally just rely on my GP and my rheumatologist. And the first rheumatologist I was referred to turned out to be an absolute diamond. And we lived down in the Sutherland Shire in New South Wales then and when I moved up to the Central Coast, I was thinking, "Oh, no, I'm going to have to find another rheumatologist". But he said, "No, you can stay with me". We do Zoom calls, and he can look at me and he says, "I know when you're not right, Kay". I said, "How did you know?". And he said, "I can see it in your eyes", and that's really important. At the moment, we've got a four-week wait to see your GP up here on the Central Coast.

Naomi Creek 20:37

Wow

Kay Boucker 20:38

Yeah, it's a bit challenging, especially when it comes to prescriptions, checkups, that kind of thing. So, I do have to plan very carefully when I'll need to be seen so that I don't have any dropouts in medications, etc.

But I think, between my GP and my rheumy, I've been with them long enough for them to know me well, so that when I go in and say, "I'm not good", you know, which I've had to do recently. I was on one medication for a couple of years and again, that's broken through. So now we're on to my sixth type of medication and it was easy for me to say to him, "Actually, I'm not doing well", and he immediately believed me, because he knows me well enough, you know. So, very important.

Naomi Creek 21:20

Andrea, how about your team of specialists and doctors that you are engaged with?

Andrea McMahon 21:26

Well, as I mentioned before Naomi, it's been very challenging moving states, because I had a very sort of long relationship with many specialists. I do have a number of different specialists and I think I've been able to transfer those over very successfully. It helps having a daughter in the medical system over here, as she gets to hear the people to see and how to navigate your way through the medical system.

I think with my rheumatologist, I'd like to give her a shout-out. She was away on holidays in London over Christmas when I had a particular problem and she was ringing me from London and I thought that was really above and beyond. I needed her help.

It was particularly good when you get the right working relationship with the person and also, we don't have those waits being in a capital city here, Kay, that you have with your GP, fortunately. But my GP, I can't speak highly enough of her, either. You know, having these younger well-trained doctors have really helped me a lot in the transition over to a different state. And then you get all your other specialists that come with all your other issues so, you know, nothing's straightforward. You know it's ...

I find nothing is ever straightforward. It's never just, go in you get this pill and out you go, No, it's never straightforward.

Kay Boucker 22:48

I mean, that was one of the difficulties I had coming from the UK is that it took me ages to work out the Medicare and the medical system here in Australia because it's different to UK. We have the NHS, you go to your GP, you go to your consultant, no money changes hands and out, out you come. And I have, I've actually walked out of specialist appointments and had to be called back to go and pay because I've completely forgotten. When you change systems or processes or places it takes a little while to settle back in again, I think, to a good and trustworthy system with your specialists.

Naomi Creek 23:26

What would you say to people who perhaps aren't happy with their specialist or doctor? I mean having that ... sacking your doctor is a challenging one but you have to do what's right for yourself, don't you?

Andrea McMahon 23:38

Every single time.

Kay Boucker 23:40

Yes, I would say so. You only get one you and you only get one life. So don't waste it by pussyfooting around, upsetting the GP or a specialist. If you don't get on with them, change them.

Naomi Creek 23:52

And what are some of the other things that you think are important for patients going into appointments, whether it's a GP or a rheumatologist? Because rheumatologists, we only get to see often every three months or six months, so you really have to make the most of that time, which is always quite short. What are some of the things you do to maximise that time with your doctors, Andrea?

Andrea McMahon 24:13

Write a list. Sit there with your list. I always put the things that are most important on the bottom of the list. I don't know why, it's almost like, "By the way, I've got this happening", as he's trying to usher me out the door, or she is. Because I get concerned about bringing up the big issues.

But anyway, otherwise you forget things and you get out and go, "Oh gosh, I need to get that script", or whatever. And any doctor, always take your little list in and anything you can cross-pollinate, so if you can take any tests that you've had done like X-rays or CTs or whatever, MRIs, take it to your physio. See what — if they found some problems — see what they can do with it. That would be my advice.

Kay Boucker 24:52

Yeah, I think my advice would be to make sure you have your bloods done on time so that they're ready for your specialist when you go. I find that in the month that ... between appointments, I could have all sorts of things happen and completely forget about them because the next ones come along. So, for example, I always need to know if I've had a bout of uveitis in the time between I last saw my rheumatologist, because that's a real indication of whether my medication is starting to not be effective. So, I go and put everything on, I've got my stuff on the My Health app, and I use that quite a lot to make sure I know what my medications are. I know when I've had my vaccinations, I know when I've had bouts of uveitis that have required an appointment with the ophthalmologist and it's all there. So, it's quite easy to remember, because sometimes I said, "Oh no, I've been fine", and when I look back, I think, "Well you haven't". So, it's easy. I've learned that little.

Andrea McMahon 25:52

Yeah, I have a spreadsheet and I've got all sorts of tabs like current drugs, previous drugs. I've been working on this for 10 years, so well before My Health app, you know. Maybe today I'd start up with that. But I've just used a spreadsheet and the hospitals just love it, because I just put everything on it, my full medical history, because otherwise you sit there going, "Now when did I have my tonsils out?", or something that, you know. You get a bit vague on all these drugs.

And so, just being able to produce everything and you don't spend all that time with the nurses if you're being admitted to hospital going well, "You spell that drug this way", because you just give them a sheet of paper. I know that I got A plus at the hospital last week because I had my spreadsheet.

Kay Boucker 26:37

Oh, well done you.

Andrea McMahon 26:38

Yeah, and I got that from my mother, by the way, she had a spreadsheet too.

Naomi Creek 26:43

Wow, who doesn't have a good spreadsheet?

Kay Boucker 26:45

Good spreadsheet.

Naomi Creek 26:46

Now I wanted to go back and touch on mental health, which we talked about. You guys have a great outlook on life, despite all the things that you're dealing with, but what would you say to others who might be feeling a little lost with coping with things?

Kay Boucker 27:00

I would say, "Don't be afraid to go and get help, to go and talk to a counsellor". They're very good and I was very lucky. I chose an online counselling service. And, by doing that, I could read the bios of all the psychologists that were available and I found the one that I thought, "Yeah, I sort of resonate with her".

And she was brilliant. She was really good. She asked me questions that I hadn't really posed to myself and it could be quite confronting, but that would be certainly one piece of advice. The other would be something that my mother always used to say. She said, bear in mind, this was when I lived in the UK now. "Now Kay, when you feel down, go outside and look at the daffodils". And I think that nature has a lot to offer. Just a few moments in nature can bring you peace.

And my best friend is wonderful. My sister was wonderful. She's passed away now. But there was some lady on television who used to um, tidy cupboards a lot. And she always used to say it sparks joy. If it sparks joy, then it's good. So, it's finding those things for me. It's been singing. I come home from choir and I'm buzzing and I think all the endorphins help me. I sleep better. Yeah, it's just finding those things. Don't have a good think about. What sparks joy for you.

Naomi Creek 28:18

Fantastic. Andrea?

Andrea McMahon 28:19

Actually, my older daughter, the ICU doctor, she often says that to me each day. She says, "Mum, what's going to spark joy for you today?". She does. It can just be the little things. Might be the bunch of flowers or walk along the beach, whatever it is and I just want to reiterate, often you can't see outside yourself to know that you need help.

And so it's always good to raise the flag now, whether it's through reading Beyond Blue or any of those self-help sites. But for me, it was having a very good psychologist for many years who was able to, I say, keep my head straight and just really keep me in the positive area of looking for the optimistic thing. Looking what's not worrying. That ... the fact that there's no end to this tunnel, there's no light at the end of the tunnel at this stage. There's no cure, we can just bounce around medications and hope for the best, but I don't focus on that. I just think well, we just be the best you can be and spark joy.

Naomi Creek 29:23

Yep, fantastic advice. And do you think, acceptance of living with a lifelong condition? I know the word acceptance can sometimes ruffle some feathers with some people because you're sort of caving into your condition, I guess. But it can be a liberating thought, do you think, if we can find a way to live with our condition? Do you think that helps our mindset with life?

Kay Boucker 29:44

Absolutely, definitely and I think it's also very important to realise millions of people are living with millions of conditions. And they might be physical illness, it might be mental illness, there might be war, there might be poverty, famine, the whole world. There's pain in there, a lot, and ... got to look at ourselves and say, "I've got food to eat, I've got a roof over my head, I've got lovely friends. Ok, so I've got wobbly joints", but it's putting — I like to try and put it into perspective. And I think that helps.

Naomi Creek 30:16

I hear you.

Andrea McMahon 30:17

I don't think I've accepted my disease. I think I tolerate it, but I don't think I've really got to that acceptance point, because I am a glass-half-full type of gal and I will always be thinking that there is research out there that maybe in my lifetime will end up being able to cure this.

And I just think that as you look back to my grandmother who had such little support with her rheumatoid arthritis and died totally crippled. So, I'm just confident that the best way forward for me is to be optimistic. "Sure, I have this now" is how I look at my disease, "But I don't think I'm going to die like my grandmother, all wizened and unable". Her hands would ... with what you see in the textbooks for rheumatoid arthritis, without the treatments that we have available today.

I think we're lucky to be well treated. That I think there is more, and I'm confident that we will get there, given the investment into this area of autoimmune diseases. I would also be keen to go down genetic testing for my daughters, at some point, if they were keen to know the answer.

I think the big problem with all this now is, until the government comes out and says life insurance because they've got that in front of them at the moment. Life insurance cannot take these genetic tests into account when they're refusing people life insurance. I'm hopeful that's imminent, that once that's finalised, then I'd be encouraging my girls to find out what's ahead of them if they do have the gene. So that's how I think about it.

Naomi Creek 31:55

Have you had that discussion with them?

Andrea McMahon 31:57

Yes, actually. Yeah, I have.

Naomi Creek 31:59

And how do they feel about it?

Andrea 32:00

It's interesting. A lot of pushback about it, not wanting to know, but I think knowledge is power. The more you know, the better you can be. I think stress plays a big role in all autoimmune and if you can avoid really stressful situations that might trigger the gene, then I think that it'd be a wise thing to counsel them to do. I think there's a lot to be gained by finding out what could be in future for them.

Naomi Creek 32:28

Yeah.

Andrea McMahon 32:28

Yes, I think also career choice. Now, this is not the case, but let's just hypothetically say I had a child that wanted to be a surgeon. Is that the best thing to be doing? If you're heading down RA diagnosis? I don't know, but it'd be nice to know if you were going to end up with RA, would you still choose that type of surgery? Maybe you'd look at orthopedics instead of plastics, you know where you need your fine motor skills? I don't know. Knowledge is power.

Kay Boucker 32:28

I think you're right, Andrea. My oldest son has now developed psoriasis and I'm thinking, "Oh no, here we go". But I would rather he was forewarned, forearmed and alert to all the symptoms that I didn't understand when it happened to me so that he can at least get treatment early on. He can at least keep himself physically fit and be the best that he can be physically and mentally to cope with what might come if he has it.

Naomi Creek 33:26

I like that philosophy. You've probably answered this question, which is our last question for the episode, but ... what your advice would be to someone who's just starting out with psoriatic arthritis? It might have just been diagnosed, you've mentioned a few things, but there might be something else. What would you say your best piece of advice would be for someone?

Kay Boucker 33:46

I think I'd probably say, "Do your research. Understand the disease. Pick your specialists wisely and even look at your lifestyle factors, your diet, all that kind of thing that may ease the journey a little bit better than some of us have had it when we had no knowledge", really. I worked in GP surgeries and medical hospitals, X-ray departments for 30 odd years and I never heard the word, the ... psoriatic arthritis. It's unbelievable, isn't it? But I think today, I would hope I'd hear it more often.

Naomi Creek 34:21

And Andrea, what's your piece of advice for someone newly diagnosed?

Andrea McMahon 34:25

I found one of the most helpful things was to join the self-help group through the Arthritis Foundation, the young women's group, which is how I met you, Naomi. And I found listening to people, understanding all the different things that can go on because, like you, I knew nothing. I knew nothing about these autoimmune diseases and trying to learn what it was all about was really helpful to learn anecdotally.

And sure, you have to have a filter about what some people say and don't take it as your gospel for medical advice. There's nothing like your rheumatologist for that. But that would be, go and seek out the help within our society that is available. There are arthritis foundations, there are different areas. You know, I mentioned Beyond Blue before, you don't have to reinvent the wheel. You're not the first person to get this diagnosis and just to keep on learning. That would be my take on it.

Naomi Creek 35:24

Thank you. Yep. Wonderful advice. Well, that brings us to the end of our episode. I want to thank you both so much for our enlightening conversation and I want to wish you both very well for the future and your health. And I'm sure the things that we talked about today will really resonate with our listeners. So, thank you.

Kay Boucker 35:42

Thank you, Naomi.

Andrea McMahon 35:43

Thank you very much for having me, Naomi.

Naomi Creek 35:45

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Narrator 36:17

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