

## Psoriatic Arthritis – Self-management and Getting on With Life

**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, I have two lovely guests to have a chat with. Simone Bye is from New South Wales and lives with psoriatic arthritis. She was diagnosed in 2018 and is a mum of two young children. Simone says the hardest part of her journey has been trialling and medically failing so many treatments which has made it very difficult to be the parent she wants to be for her kids. Despite these challenges, she's doing her best to manage her condition and get on with life.

We are also joined by Sarah Comensoli from BJC Health in Sydney. Sarah has a number of roles there as Director, Head of Marketing and Manager of the Allied Health team. She has been practising as an accredited exercise physiologist since 2008 and has worked in a number of clinical and gym settings. Since then, Sara has been instrumental in building the exercise physiology service at BJC Health to be one which is unmatched in delivering care to those with rheumatic disease.

Thank you both for joining this episode of Patient PrepRheum.

**Sarah Comensoli** 01:28

Welcome. Thanks for having us, Naomi.

**Simone Bye** 01:30

I'm pleased to be here.

**Naomi Creek** 01:32

Fantastic. Simone, I'll start with you. You had an incredibly stressful time leading up to your diagnosis and have had a challenging time being able to manage your psoriatic arthritis with medication. Can you tell us more about that?

**Simone Bye** 01:45

Of course, leading up to my diagnosis, I'd had just a series of just awful things. My father died, I had a second-trimester miscarriage and my cousin was dying of terminal cancer. So, the general consensus was that these three things caused massive amounts of stress and that triggered off perhaps a genetic condition, psoriatic arthritis, which is linked to a few other diseases that run rampant in our family - notably type 1 diabetes - so it kind of all made sense.

My father had psoriasis, although he didn't have psoriatic arthritis and I just noticed, you know, I had a sore knee and then I had sore collar bones, and then I had sore wrists and then I had a sore elbow. So, I saw my GP and I was incredibly lucky because his wife has a kind of autoimmune arthritis as well. So, he recognised the symptoms very early and connected me to a rheumatologist. So, I was very lucky. I got diagnosed within six months of symptoms appearing.

**Naomi Creek** 02:37

Wow, Simone, that must have been such a sad time for you to deal with all of those things, and really stressful too. How did you cope with that diagnosis?

**Simone Bye** 02:46

I think I was sort of in disbelief. First was, "What? Like, what is psoriatic arthritis?". I'd never heard of it. I'd heard of rheumatoid arthritis, but I'd never heard of psoriatic arthritis.

The rheumatologist ... that particular one wasn't terribly helpful. I've since changed. He sort of said to me, "Well, at least it's not rheumatoid arthritis". And I was sent home thinking, "Oh, this is nothing", and then got home and started to look it up on the internet and my symptoms got worse and realised that I was in for the long haul with something that was a progressive disease, you know, if we couldn't get on top of it. So, that's sort of where I was then.

**Naomi Creek** 03:17

And did you start some medications straightaway?

**Simone Bye** 03:19

I actually couldn't, because we were doing IVF. We'd just lost a baby and we were doing IVF to try and have our next son, so that meant that there were a lot of medications that I couldn't take.

I did try sulfasalazine, which is I think the only one that's safe for trying to conceive, but like so many drugs, as you'll find out, I had side effects to that one, and we had to discontinue. So, basically, I was on steroids for my IVF anyway, so steroids were really the only line of defence at that point in this journey.

**Naomi Creek** 03:46

And what about after you had your child?

**Simone Bye** 03:50

Well, that took a few years. Finally, that was 2020. So, you know, there was quite a gap between then and when we could do something. And then, of course, you can't use methotrexate or anything like that when you're breastfeeding. So, I had to delay treatment until I'd finished breastfeeding.

I did have an exception to try a biologic, but I just wasn't keen on trialling something while I was pregnant, because, over my life, I've had so many side effects to medication that I just wasn't prepared after we'd lost the last baby to do anything that might jeopardise that.

So basically, late 2020 after my son was weaned, then we started, I started on methotrexate, which I found to be actually a really good drug for me and I'm still on it to this day. I'm on a high dose, the highest dose that you can get as an injectable once a week.

**Naomi Creek** 04:34

I see. Yeah, so not having that choice of medications has been really extra hard for you. What are some of the other ways you manage your condition day to day?

**Simone Bye** 04:42

I think the biggest thing that I've learned is pacing. Like just to take time. I've been very lucky to be accepted into the pain clinic at RPH Hospital in Sydney and I'm seeing an occupational therapist there.

I've just started and we're actually working on fine-tuning the pacing a little bit more even, instead of, sort of, waiting till I get tired. Starting to maybe use a timer. Stopping before I get tired. A lot of it ... to be honest with young children, there's not a lot you can do. You've just got to get on with life.

I have a very supportive husband who has taken over a lot of the household tasks that I can't do anymore. But a lot of it is just get up, keep on ... I mean, kids are great, because, you know, they don't care. I'm like, "Oh, I'm in so much pain, can you get me my toothbrush, you know?". So, I think that's actually good because it keeps you moving.

**Naomi Creek** 05:25

Yep, exactly, keeping that activity level up. Sarah, you work with a variety of allied health practitioners at BJC Health who help patients like Simone with conditions like psoriatic arthritis. What are some of the ways these therapies help people?

**Sarah Comensoli** 05:40

I guess, firstly, like, I would ... wanted to thank Simone for sharing all that she did. And, I guess, it just really highlights it's different for everyone in terms of that journey to getting diagnosed initially, then those months afterwards. And I think, yeah, in Simone's case, I can just imagine that if someone said, "Well, you know, Simone, now you got to exercise and now you've got to do this and do that". That would have been incredibly challenging. And still is, you know.

So, I guess at BJC, I'm lucky to be supported by a team where we just try and help meet people where they're at, because we know things like managing what you're eating, trying to have a good nutritious diet can be helpful. Things like pacing and having a good, sort of, physical activity regime can also be helpful. We know those strategies can make a real difference to patients' lives, but it's just always about how much anyone can take in at one point.

I've certainly learned to appreciate getting the medications right. That can take months or years and that's an ongoing thing that we need to be very mindful of. But I think, yes, allied health professionals, our job is really to support our patients, and really comes down to what sort of lifestyle they want to live and we're there to support them be able to do that as best we possibly can.

**Naomi Creek 06:45**

Yeah, for someone like Simone who has got kids and is, maybe, not on all the medications that would be helping her to the max. And exercising, how do you motivate someone to, I guess, keep moving or even start a program? Must be hard?

**Sarah Comensoli 07:00**

Yeah, that's a good question. I think something I had to learn, just through experience, was that there's always a way through, and I think, you know, my university training, to be honest, didn't really give me too many tools. Like, I think I came out thinking that everyone would need quite a structured program and they need to do this and they needed to do that. And the reality was, within a few months of being at BJC, I just realised that it just wasn't working, you know, it was terrible. I felt, like, so incapable that I wasn't really making a difference like I wanted to.

So, I think, again, it comes down to sort of figuring out what people want to get out of any particular program that they might do. That's really important, because if we don't have that set with some clarity at the beginning, then motivation and other terms like that become hard. So, I think having some good aims, or at least a clear direction can be very helpful.

And it's just reminding people that it doesn't have to look a particular way. I think with exercise, like even just the term exercise, if you know, all three of us just hearing that word, you might think, "Oh, what do I picture when I think exercise?". Do you picture a gym? Do you picture doing something gentle in bed? Everyone's got quite a different view of what that might look like. But I've learned that it can look like anything, it's just about trying to find something that someone can do consistently.

And that's what's kept, I guess, the clinical part of my role quite fun. I find I get to be quite creative, because someone's program that works really well for them, might be completely rubbish for somebody else. And they might have the same condition.

So, I think you've really got to work with someone where they're at and just remind them that whatever they're willing to give, we can still use in a useful way. So, you've got to get creative, but I often find myself there's always a way, if you're willing to give us a little bit of time, and we chip away at helping you be consistent, then that's a way we can try and make it start

**Naomi Creek 08:44**

Yeah, fantastic. Simone, would you like to say anything about what Sarah's just said?

**Simone Bye** 08:48

I think that one of the problems for me with exercise is that, periodically, I have flares. And when I have a flare, I'm just in so much pain, that movement has made it extra special. So, I guess the thing that I'm learning is that it doesn't always have to be linear, it could be two steps forward and one step back or doing what you can at any given time because it's very demotivating when something's too structured and you just can't do it.

Some of the exercises I've been given from the physio at the pain clinic, some days I can do them, other days I just literally cannot do them. I can't raise my arms above my head. So, that's certainly been a challenge.

For me, I've found that just trying to be very conscious about moving in everyday life, like not sitting too much or if I'm ... if I've sat to get up to move around. I now have an Airbnb, means that I have to do a lot more physical work than I've done in years. And that, in some ways, has been very good for me because it keeps me moving. In a sense, I'm exercising but my brain isn't telling me, "Oh, gosh, I'm exercising right now", if you know what I mean. But I think as time's gone on, I have recognised how important it is for me to keep moving.

In the beginning, when I just had so much pain and I couldn't see my way through, I didn't realise how important moving was because there is the temptation to just lie there or sit there and be in your pain. So yeah, so it's just such an ever-evolving process of learning how to cope with this disease.

**Sarah Comensoli** 10:09

Sounds like you're doing great, though, Simone and you touched on a couple of really important points, I think, and for any healthcare professionals that might be listening, it's really good to share that, you know ... because I think, again, how we often get trained and taught is in a very linear way. And exercise is great in the fact that yes, if you do it consistently, we hope that the system adapts and things you know, get stronger or get fitter.

But that can all be sort of much, much, much more challenging when you've got an autoimmune condition or something that makes training in a consistent way difficult. So, I think it's what you said spot on. It's good to have different options for different days or, at least ... often say to clients. It's great to just share that with any, you know, people that you're working with that the program some days is great but other days, that's not going to be what I'm able to do just so they've got that appreciation and understanding.

But sounds like you're doing great, and keeping yourself moving throughout the day. That, in itself, is a wonderful thing, let alone ... a structured kind of exercise program. Being incidentally active, we know is still very powerful and very positive. So amazing.

**Simone Bye** 11:09

One more thing I wanted to say too, is that sometimes we have to prioritise what we can do because there's something coming up that we need to do. Some days, I can't do some things because there's

something coming up with my child that I need to prioritise like, you know, The Spoon Theory. You've only got so many spoons in a day sometimes. So, there is that too. Sometimes I have to make a conscious decision. If I do this, I can't do that, though that has to be built into it too.

**Sarah Comensoli 11:33**

Absolutely, but that's great pacing. I said to clients in the past too, like, "What's the point of, like, being so good and so conscientious with your exercise program, if you can't actually then do things that you enjoy?". Like, it doesn't make any sense.

So, at times, yes, you do need to make those trade-offs or a very conscious decision to be, like, "I'm choosing not to exercise today because I'm going to save my energy to do ..." whatever it is. But I think that's good decision making, it's informed decision making and, I think, as we're all on a journey to, sort of, understand our bodies and its capability and that changes with different things that come in our path. So, that sounds like you're really doing the best you can which is great.

**Simone Bye 11:43**

Thank you.

**Naomi Creek 11:55**

I agree. I think it sounds like you're really getting on with life, Simone, and I think that's fantastic. Sarah, I wanted to go back to ... perhaps for people who are listening and interested, to get involved in exercise or movement. BJC run some online classes and that's another great option for people who perhaps are feeling a lot of pain and getting to a gym or to a class or something is ... is extra difficult. So, there are lots of, you know, chair-based things and people can do stuff online to feel like they're involved in getting moving each day.

**Sarah Comensoli 12:42**

Yeah, I think, like, there's never been more options on the table. You know, with exercise, which I think **it's** a great thing and, I guess, being an exercise physiologist, I guess my role in helping people has shifted a little.

I think early on in my career in terms of just the general level of awareness about exercise and its benefits. You know, you spend a lot of time, sort of, educating people on that. Whereas now, I find my role is about helping people choose the right option. I think a lot of people go, "Okay, I know exercise is going to help", or, at some point, they might feel that that's something that can assist them, manage their health. But then it's like, well, "Where do I start? What do I do? Do I do Pilates, do I do reformer Pilates? Do I go to a gym?", so it can be quite overwhelming. And I work in the space, and I still am like, I don't even know what that class means.

So, I definitely appreciate it can be a bit tricky, particularly at the start, or if you're wanting to restart after a diagnosis or a break or whatever it might be. But I just think now there's always options and I think when I work with people, at least one-on-one initially, it's trying to get to know that person quite

well to go well, "What options sounds like it's going to suit where you're at?". Because I think it depends on so many factors. People's work life, their home life, their preferences.

Some people... like straight out of the gates, say, "Sarah I hate gyms". Hate, it's a strong word, right? Straight up I'm like okay, that's not going to work. So, then it's all about sort of crafting a place to start. I'd often say a bit ... and then it's being okay, and sometimes we can be our own harshest critic that if that plan doesn't work, that's okay. We can try another one, we can pivot, we can try something online or get you going somewhere. So, there's always options.

And yeah, I think one of the blessings of COVID was kind of that boom of just needing to do things online and being able to support people moving from the comfort of their home and I think that's been very positive. And it has been a good place for people to start, especially if they're a bit intimidated, or they're not sure.

Initially, with our classes, we encourage people just to watch at first, you know, and can go incognito camera off, no sound, just to see. Then they might participate a little bit. So, it's just all about that journey and gradually finding something that works for you. But I think there's a lot of options and if you're in that space of feeling overwhelmed with the options or you're not sure, that's where maybe reaching out and getting someone to help work you through what might be suitable for you can be very helpful saves you time.

**Naomi Creek 14:59**

Yeah, and when people have flares, like Simone was discussing, how do you get people through those times because that could be weeks or longer?

**Sarah Comensoli 15:06**

Yeah, I understand. So, I think a lot of my clients, like ... let's say it's someone that I'm managing in a self-directed way. Let's say they're either going to a gym or they've got a program that they're doing from home. Often clients that I've worked with for a while, they'll have different programs.

And so, it might mean that when things are good, or they're feeling sort of, you know, capable, they've got this series of things to sort of work through that we've sort of figured out over time. But then they go through a flare-up, then it's a whole different set of things which, typically, the body needs things that are less taxing and we can make changes to things like the position you're exercising in, the time that you're exercising for.

There's so many variables that we can play with in terms of crafting a regime that's going to be ... enjoyable is probably a stretch, but at least doable. I sort of aim for doable first and always empowering my patients to say the numbers and the sets and reps, potentially, I give are just the guide. Ultimately, it's up to the person to ... if you feel that you've done five reps, and that's enough for you today, then that's enough. You know, I'd always back my clients in making those decisions.

So, I think it's just having some options and trying to be kind to yourself, because I think you know, as much as I'm an exercise physiologist, of course I'm going on about exercise. It's equally important sometimes to go, you know, today, I feel that my body actually needs to lie down and take it easy. Like, that's okay, it's not about always trying to do more and push more.

So, I think, yeah, just to summarise. Options are good, different programs or just different styles of movement typically tend to be better during a flare, and it might need to be scaled right back. But also back yourself if you're like, I just don't feel like doing it today. That's okay, as well. So, we need a mix of approaches, I think, when we're thinking about helping people over a longer, longer term.

I'll just quickly ... it's a terrible joke, but I remember early on at BJC, we had to try and help our rheumatologist go, what's the difference between an exercise physiologist and a physiotherapist? And one of the analogies we came up with was an exercise physiologist is marriage material. They're in it for the long haul.

So, we're sort of equipped ... and I often I'm thinking, I'm thinking long term, I'm not about just getting you to do something for two or three months, like, anyone who's scary enough can manage that. But with these conditions and with people's lives in general, it's much more important that we help you with strategies that you see yourself doing in the long term. So, marriage material, exercise physiologists, you've heard it here.

And physios are like, what do we call them? Summertime flings. That sounds so bad, but hopefully, you're only seeing them maybe you know, for shorter episodic type care, but obviously depends on the person. And of course, everyone's got the right to build their own team.

**Naomi Creek 17:35**

I love that joke. Great analogy. Simone, would you like to say anything about what Sarah just said?

**Simone Bye 17:40**

I think that was so good, that was so important. Like, the long-term thing is so true. Like, I'm in my mid-50s now. Because of IVF, it took us a very long time to have our children. So, I mean, I was gonna be this fabulous and 50 mum, you know, and then this came along when my daughter was about four and a half.

So aging is something that can be challenging for anyone but aging with a progressive degenerative disease is a whole other ballgame. So, that long haul, the big picture is definitely where I'm at. I think in the early days, I was definitely looking at what can I do now. What can we do to take the pain away in this moment? And now I do, I look at the big picture completely. I'm marriage material too. I'm in this for the long haul.

**Sarah Comensoli 18:20**

Oh, you sound great Simone.

**Simone Bye 18:21**

I said the other day that I'm a lifer, now. I had a mindset shift a little while ago. And it was wow, you know what, I've just realised, I'm a lifer with this, There's nothing that's going to make this go away. I have to learn how to really learn how to live with it. And, as you say, Sarah, that is looking at the long game.



Like, looking at any little thing I do now could make a big difference to my life in 10 ... 5, 10, 15, 20 years down the track to not being in a wheelchair, to still being able to live in my house that has stairs, which I hate. To be able to play with my kids or as they get older to participate in their lives as fully as I can. Totally, so it's such a good big picture and I think I should probably call you.

**Sarah Comensoli 18:29**

I'm available anytime.

**Naomi Creek 19:04**

It sounds like you are taking life, you know, head on Simone and also you said you recently started an Airbnb. I mean, that's not a small undertaking. So how do you manage that? And I guess, what are the some of the positives and negatives of that? There's, I'm sure that it's quite exciting to do that, but physically quite demanding.

**Simone Bye 19:22**

Physically, it is very demanding and definitely my own house has suffered from having to do that. But um, it's actually been really positive because it does keep me moving. As Sarah said about incidental exercise, there is a lot of incidental exercise doing it. So, it's sort of been good working with the pain clinic to work out ways in which to do exercise, to do my cleaning tasks and change over tasks safely, so that I can manage it within ... I've got three hours in which to do a guest turnaround.

Mentally, like it's been great for my mental health. It's something I really enjoy doing. It fits between the school hours and, in a sense, just because you have a disease that makes it very difficult to work, it doesn't stop the bills from coming in.

So, you know, for us, it's been a game changer to be able to run this little flat that's attached to our house, which is an old butcher shop. So, the butcher shop part has now been turned into a little flat. So, it keeps me moving and keeps me interested in life. It's something I really love doing. I've always loved hospitality. So, to be able to have this little space that is really truly special and get wonderful feedback from our guests has really helped me. Before I had this, I spent way too much time sitting around being sad for myself. This keeps me busy, keeps me moving. And so far, I'm coping, just. I do go to bed really, really early, like 7 pm, I'm done.

**Naomi Creek 20:34**

You touched on the mental health side of things, I guess, the running an Airbnb and having a family and you're doing so many positive things that keep that in check. Do you think the activity side of things helps with that as well? And I wanted to ask Sarah about that, having something to focus on and keeping active. Does ... it has a physiologically ... it changes your mind sometimes, doesn't it, to keep going and to have a positive outlook?

**Sarah Comensoli 21:00**

Yes, I think exercise and mental health is huge. And I think more and more research is coming out now and I think we're better at talking about it now. And it's a little bit more known just the impact that movement and having a routine can make such big changes to your mental health.

And I think yeah, it's understanding that going through a diagnosis that is ultimately going to impact the rest of your life is a huge thing. And Simone, you shared that was off the back of an incredibly stressful time, you know, over those period of months leading up to that. So, that's just, that's a lot.

So, I think, yeah, exercise, we can use it for so many different things. And it's not always about the physical benefits that we get out of it. Like those are great and that can be very important to different people. But if someone's just looking to feel a little bit better mentally, then exercise, we know, is also a strategy that can be incorporated into someone's regime to help them with that. And again, if that's the main aim that the person has ... and how I'd set up a program or how I'd sort of frame my approach would be quite different to someone who, say, is very focused on, you know, getting better in something physically.

So, routine can be very important, movement, although especially if you're in pain, movement can be one of the last things you feel like doing. And I often say to patients, that's a very normal response, pain is uncomfortable, and exercise in its very nature is uncomfortable. So, it's ... don't be too hard on yourself, if you're like, just don't feel like it. That's okay.

It's trying again to think of the bigger picture and have those, sort of, longer-term aims and trust in the process that some movement, you might get that little shift in mood straightaway. And that can then lead to the next positive thing that you do that day. And that might make you feel that little bit better to talk to a friend. All those little things. It's just about finding that little thing to start with and then you can sort of piggyback other positive things on top of that.

And not to say that exercise has to be the starting point. For a lot of people, it's not, but it can make changes to how you feel straight away. And I think that's pretty amazing. Especially when we compare it to a lot of medications, you know, at it, I think there's a great quote somewhere where it's like, you know, "If all of the benefits of exercise could be put into a particular pill, it would just be flying off the shelves". It's just so incredible. It's just amazing. It's partially why I'm still doing the clinical work that I do because it's just so amazing. But it's hard.

So, the benefits are there, but the doing of it can be very challenging. So that's where I think it can be great to have some support, you know, get some people around you or some professionals around you that can help you keep at it and adjust it depending on what you're looking for. But the benefits are there.

**Naomi Creek 23:28**

Simone?

**Simone Bye 23:29**

I think for me, I'm one of those people that I would exercise more for the mood than for the body. Like, the body would be a beautiful bonus. But, definitely, I think because you get used to pain in a sense and living with pain, you can ... I'm not saying you can push through it because that's not really a healthy way

to live with pain anyway. But overcoming the psychological effects of pain can be as big, if not bigger than the pain itself.

Because I think the psychological effects affect the people around you more too. You know, they have a pushback, you get irritable, you're tired, you have low energy, or you don't want to do anything, you don't want to go anywhere. So yes, moving and getting that bit of extra exercise in via the B&B has been, you know, a big room shifter for me. Huge, actually, I'd say, and I think my family are happier for it.

#### **Naomi Creek 24:13**

That's wonderful. I think also, it's keeping it interesting. I know, I get a little bit bored, just going for a walk. I mean, I live in an amazing place in Tasmania, but I still have to, sort of, fool myself, I guess to do it. And the way I do things sometimes is to add a couple of components while I'm exercising. So, I do like to take photos with my iPhone and you know of nature and things. So, I try and sort of go, "Okay, I really need to take some new photos", but I actually I'll have to go for a walk to do that. So, it's just like, that makes it interesting for me. And I guess more ... I'm more inclined to go out and do that instead of just going for a walk, and yeah. So, keeping that interest there.

#### **Sarah Comensoli 24:53**

And we're all different because it's just so fascinating what works for you. That would be just a nightmare for someone else that I've spoken to where they're like, "No, when I go for a walk, I don't want a reason. I don't want a location. It's just me and my walk". That's great. And then you've got other people that are just like, "If I don't have an objective, I see no point", you know. So, again, I just find it fascinating. And there's no right or wrong, you know.

So, again, I try and really make sure when clients talk to themselves. It's like, "No, this is who you are it's okay, we've just got to lean into it. Don't try and, I think again, pretend that's not how you feel. It's good to be honest and open". Because again, the people that you might be working with can then use that to help you lean into it more. But there's all sorts of different ways to get there. But that's ... I like taking photos in nature. I've so many flower pictures on my phone, Naomi, it's, I'm almost ... I am embarrassed, when people are, "Why have you got flowers?". I just love them.

#### **Naomi Creek 25:47**

I have lots of photos of that, too and animals, wallabies, so yeah. I wanted to ask about people joining these programs or seeing allied health and perhaps the cost behind that because that can be prohibitive. Um, there are some things you can talk to your GP about, so that chronic disease management plans and things like that where ... where people can get free appointments for allied health. Can you share a bit about that?

#### **Sarah Comensoli 26:10**

Yeah, sure. So, I think, yeah, there's lots of options out there. And I guess if you're, again ...where I really see the value of, maybe, speaking to someone is where you want to get started, but you're either really

worried and fearful. And I think that's very valid when you've, you know, again, maybe got a new diagnosis, you've got some pain, you're not really sure what things are going to suit you. Or again, if maybe you've tried a few things, but you're just not feeling like you're on the right track. I think that's where, again, seeing someone and speaking to someone can be very helpful.

And I often have a ... aim for myself — although I appreciate to see me one-on-one in one of our clinics costs money. I really make it a personal aim for myself that I should be saving time and money for all the clients that I see, in the ability that I hopefully can help coach them through, make good decisions, say no to things, say yes to things. I'm hopeful that that in itself, obviously in the moderate to long term saves a lot of time and money and stress. So, that's I guess one of my personal aims.

The chronic disease management plans are fantastic. So, yes, you're right, the GP needs to be involved in setting that up for you. It allows you to access five visits with different allied health professionals, or it can be with the same allied health professional, over the course of a 12-month period. So, I think that can be very helpful to help people make a start, and it's in terms of how you use those appointments, and how frequently you have your appointments. That's for you to discuss with your health professional.

So, we're very supportive of you know, seeing people with those programs. Again, I think that's a great place to start. But it's all about, yeah, what you're looking for. And I think it's good to ask questions like, so if you're starting to see a new health professional, whether it's a physio or an EP, or somebody else, you can always ask like, how many sessions do you think I'll need?

Like, obviously, once they get to know you a little bit, once you've got some goals, then hopefully, they can give you a bit of guidance around what they think a good path forward is going to look like. And then it's ultimately up to you to decide if you're on board with that, and what that might mean in terms of your time. And obviously finances as well. But I find the chronic disease management plan is a good place to start.

If people have private health insurance, that can sometimes help in the cost of then consults. But I think that's very much got to be part of building a good plan. You know, there's no point looking around and going shopping for gyms, if that's just not financially going to work for you. So, I'm just always very keen for people to be honest.

We've talked a lot about preferences and what might work depending on logistics, but the financial elements huge as well. So again, just I encourage people to be upfront about what they may or may not be able to afford when they're starting to work with someone or when you're looking around at different exercise options. Again, because we're in it for the long term, yeah, I think you got to think about it financially. If it was just something you had to do for two or three weeks, that would be different. But exercise, we're trying to help people set up for the long term. So, it's good to have again, some different options.

### **Naomi Creek 28:55**

And I guess we've been talking about things we do in our personal time. But there's also other people who work and Simone was talking about her experience with her OT at the pain clinic. And I know that people can get OT assessments for their workplace. And how important do you think that is for people to have a comfortable ergonomic workspace where they are to help them with their pain levels?

**Sarah Comensoli 29:18**

Super, super, super duper important. Most of us still spend a significant time working. Again, it's great these days, some people have a bit more flexibility. They might be able to do some stuff from home and they might still need to go into the office. Either way, though, it tends to be where we still spend a fair bit of time. And we know from research that the environment you're in makes a difference to your mood, your likelihood of exercising, so the environment is really important.

And I think then we need to sort of put the pain and maybe symptoms on top of that. We know good ergonomics, having some options. Sit-stand desks, having just the support around you to be as comfortable as possible can make a huge difference.

So, I encourage clients, like I'm happy to, you know, write letters or just ask for people to have an assessment. A lot of companies these days, they might have HR support where they can get someone to come in and assess. Very supportive of all that and I think, anyway, we can just optimise again, even if there's just lots of, sometimes it's little changes. But if you're doing lots of little changes built up over time, that's a big impact. So, be very supportive of helping people however I can get that set up as best they possibly can.

**Naomi Creek 30:25**

And Simone, you've used the OT's tips in your businesses with the Airbnb. Do you want to share a bit about that?

**Simone Bye 30:32**

We are just starting. I've just starting out with the OT, so we haven't done a huge amount. But, definitely worked on pacing, on looking at my plan for how I organise everything to try and make it a little bit more sense in an energy conservation way to stop me from maybe going back and forth, back and forth to try and do things in advance. Basically, just planning my time and how to use it better. And also working rest periods into that. And still having the goal at the end of the day is to get everything done on time and to have the keys in the lockbox at 2 pm. Ready for the next one. So yes, time management, I guess.

And I hadn't sort of thought about an OT from my point of view. But that's been really helpful. And it was just interesting with Sarah just commenting then on the financial cost, reminding me to go back to my GP and get another with a chronic illness plan. And I do believe they can extend a couple of sessions sometimes too, because I know that they do on a mental health care plan. You know, you get the five, and then you can sometimes, they can add a couple of extra ones on because the financial cost of being sick is ridiculous.

And I think you touched also too, on being able to do online exercise, because the physical cost of going somewhere can sometimes just derail you. And that was one of the best things that came out of COVID was, you know, telehealth and being able to do online exercise classes and see, you know, health professionals such as yourself. And a Zoom call has just been an absolute game changer for people with

chronic pain and saves money as well because you're not having to pay for parking and transport costs, which on top of medication and care can be really prohibitive.

#### **Sarah Comensoli 32:00**

It can definitely add up. And even if you're doing it to help you manage things as best you can, it still can be very expensive.

I just have one other tip when you're thinking of spending money on any type of exercise, it's worth doing a bit of reflecting to go, what do you personally need to actually pay for? Like, what are you paying for? Because sometimes people ask me, Do I need a personal trainer? Should I get a personal trainer? Should I do this?

So, some of us at different times — because I think again, it changes at different times in our life — it is worth paying for having someone stand over you and tell you what to do. Right? There's some clients are like, I need to pay for that. Because that's the only way I'm going to do some exercise. So, like, okay, now that hopefully isn't most of us, right?

At other stages, maybe joining a gym or joining a centre, what you're paying for is access to all the equipment. Okay? So sometimes people are like, well, I want to do this, I want to do a bit of that. And I need some ways, but I don't have them at home. I don't have space for them at home. So again, it's worthwhile tangibly to then go well, I need to find somewhere, where the equipment is what I'm paying for. Then it doesn't matter if you get a white fluffy towel, it doesn't matter if the receptionists are friendly or not.

So sometimes I really get people to think what is it that you want to actually pay for? Is it the supervision? Is it the stick? Is it the environment? And that sometimes can help narrow down the options. Because I think these days, it can be tempting to go, "Oh, if you just paid two extra dollars, you get access to this, you get access to that". But that might not be of any interest to you. And I think sometimes people get caught, yeah paying for things they don't need or they don't want.

So, and if you're not sure it's just, yeah, good question to go, "What do I ... what am I most going to benefit from at the moment?", and then that's where you still might need to spend but be prepared to ... then you can sort of stint out in other areas. So that's even how I make my own decisions around what gyms I go to and things. I know what I want, and then I'm happy to not pay for lots of other things so that I can still make it work.

#### **Naomi Creek 33:53**

Fantastic advice. I like that a lot. I think we're getting close to the end of our episode, I wanted to ask you both, what is your best advice for someone who's just starting out with psoriatic arthritis? Simone?

#### **Simone Bye 34:08**

I would honestly say my best advice would be to join something like a Facebook group. I joined a psoriatic arthritis Facebook group and found more information on there in a short period of time for people who are actually living with the disease and have been living with it for a long time. I found that incredibly helpful.

It helped me know what to ask my rheumatologist when I went back again. It gave me some insight into possible medications. It cut through a lot of the medical jargon that you often get with a, like, a learned professional, who they know everything about this disease and that, I think there's a level of assumption that they have about their clients.

So, I would say join something like a Facebook group and ask lots of questions and just be really informed and be your own advocate. I had experience with that because we've done IVF and you have to be your own advocate a lot there and I'd say to yep, learn as much as you can about your disease, join some groups, get some support, then be your own advocate.

**Naomi Creek** 34:57

Wonderful, Sarah?

**Sarah Comensoli** 34:59

Oh, I can't top that. That's really good advice. I think maybe I'll just go in addition to that. I agree with everything Simone said, cos then it's about once you're informed, then it's about finding your crew, and then it's just about whether it's your rheumatologist. You know, just bit by bit, based on the things you might want to work on. Just finding the people that you can build some trust with who can support you, because I think at different times, having that support around you can be very helpful.

And just be kind to yourself. One thing at a time. It's a life-changing thing. So be kind to yourself. Get the information and then you can choose which sort of path and which things you might be open to, you know, learning a bit more about and then taking some action.

**Naomi Creek** 35:39

Wonderful advice. Well, that brings us to the end of our episode. I want to thank you so much for the great conversation and amazing insights into psoriatic arthritis.

**Simone Bye** 35:50

Thank you.

**Sarah Comensoli** 35:51

Thank you.

**Naomi Creek** 35:51

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**Narrator** 36:24

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