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New reimbursed treatment for Aussie adults living with a common inflammatory skin disease – psoriasis

Clinical Associate Professor Stephen Shumack, OAM
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(0:24-0:42)

What is plaque psoriasis?

Plaque psoriasis is the common type of psoriasis that most of us know about – scaly plaques on the elbows, knees, and other areas of the body, sometimes on the hands and feet, and sometimes in the scalp as severe dandruff. It can be irritable, itchy, and can sometimes bleed, particularly when scratched.

(00:45-01:21)

What is severe chronic plaque psoriasis?

Severe chronic plaque psoriasis is where the plaque psoriasis in a particular patient is sufficiently severe to require treatment with tablets or injections, or phototherapy, where they stand in a box and have ultraviolet light put on them, or whether or not the psoriasis is severe to significantly impact a particular patient's quality of life. In other words, they won't socialise. They have trouble at work, they have trouble at sleeping because of the itch and irritation. They have trouble interacting with other people.

(01:24-01:36)

How many Australians are currently living with psoriasis, and how many have severe chronic plaque psoriasis?

We think there are around about 1.6 million people living with plaque psoriasis, and of those, around 19 to 20,000 have what we would call severe plaque psoriasis.

(01:40-02:05)

Who is at risk of developing plaque psoriasis?

Severe plaque psoriasis can basically develop in anyone with plaque psoriasis. It tends to be more common in individuals who come from families who are affected with psoriasis, and sometimes it can flare for other reasons such as stress, such as being on certain medications, such as having other infections at the same time, such as a streptococcal sore throat.

(02:08-02:42)

What are the symptoms of severe chronic plaque psoriasis and where do they appear on the body?

Severe chronic plaque psoriasis demonstrates plaques of skin, which are usually salmon, pink or red or violet in colour, although sometimes they can be grey as well, and they're usually covered with a silvery scale. You can feel these plaques and they usually have a very distinct edge.

The common areas that we see them are the elbows, the knees, or other areas of the body, which are traumatised, say, by itching. And the other areas that we sometimes see them are in the scalp, and also in the hands and feet.

(02:46-02:53)

How persistent are the symptoms of severe chronic plaque psoriasis?

The symptoms and signs of chronic plaque psoriasis will be there lifelong, although they will fluctuate in severity.

(02:57-03:23)

How is severe chronic plaque psoriasis diagnosed?

Severe chronic plaque psoriasis is usually easily diagnosed clinically. The shape, the colour, and the scale of the plaques are usually quite specific for plaque psoriasis as well as their location. Sometimes if there's some doubt, you may look at the fingernails and see little tiny pins across the fingernails, which are pathognomonic classical of chronic plaque psoriasis.

(03:26-03:47)

How does severe chronic plaque psoriasis affect a person physically?

It's visible, and people can see it, which makes interaction with other people are difficult. It becomes itchy, so people scratch it, and irritate it on a regular basis, which means patients scale all over their clothing, the furniture, and other people. And it can bleed because people have scratched the lesions of chronic plaque psoriasis.

(03:51-04:04)

What other areas of the body does severe chronic plaque psoriasis affect?

It becomes very itchy and irritable, particularly in certain areas such as the scalp, and also the groin area, and this can affect the people's ability to sleep. In other words, they wake up all the time scratching and irritating their skin.

(04:07-04:29)

What are the potential implications of living with plaque psoriasis?

Individuals become withdrawn, they can become depressed, and we know around 5 per cent of patients with severe chronic plaque psoriasis have had suicidal thoughts about the significant impact that their condition has on their ongoing life and ability to tolerate and cope in modern society.

(04:32-05:05)

Why do people suspect severe chronic plaque psoriasis is an infectious disease?

In modern society, the biggest issue is people see the psoriasis and they worry about whether or not it's an infectious disease. So people tend to clothe up. They tend to not undertake sports where their skin is visible. They tend not to go to the beach. They tend not to go swimming. They tend not to play sports where they're wearing shorts or T-shirts. So it has a significant impact on really, the quality of life of almost all patients with severe chronic plaque psoriasis.

(05:11-05:46)

What are the current treatment options available in Australia for people living with severe chronic plaque psoriasis?

With severe chronic plaque psoriasis there's a number of levels of treatment. The first treatment is usually creams or ointments, which are more effective with people who are less severely affected. Then we move on to things such as ultraviolet light, where people go to a place where light is delivered usually three times a week for a couple of months. And lastly, there are more targeted therapies, such as tablets and injections, which are much better and much more effective and much more appropriate to use in people with severe chronic plaque psoriasis.

(05:50-06:19)

What is the cost to the patient of treating severe chronic plaque psoriasis?

The cost of treating patients with severe chronic plaque psoriasis can become quite significant because of the area involved as far as the skin is concerned. So, patients have got to apply creams, ointments to large areas of their body. They've got to use special shampoos and special cleansers, which are compatible with the condition they've actually got. On top of this, patients have got to buy medications on a regular basis.

(06:25-06:38)

Why is there substantial need for additional treatment options for severe chronic plaque psoriasis?

To have another option means there's another alternative, another choice for our patients, which will hopefully help them get their severe chronic plaque psoriasis under better control long-term.

(06:44-07:03)

What does the introduction of a new medicine for severe chronic plaque psoriasis do in terms of expanding the range of available treatments?

The addition of a new tablet as a treatment for patients with chronic severe plaques psoriasis is excellent, because most of the other options that we have for that group of patients involve injections or patients having to come to the doctor's office on a regular basis.

(07:08-07:33)

What is significant about the PBS listing of a new treatment for severe chronic plaque psoriasis?

These medications are very expensive, so to get them subsidised by the PBS makes a huge difference as far as affordability is concerned, and it provides a choice in these patients where the other available medications may not be suitable for a particular patient, or may not be demonstrating a good enough effect as far as therapy is concerned in these patients.

(07:37-07:55)

What is your message to Australians living with severe chronic plaque psoriasis?

Severe chronic plaque psoriasis can be a very debilitating condition for our patients, both physically, emotionally, and mentally. And to have a new medication available to treat this, can be life-changing in many of the patients with severe chronic plaque psoriasis.

Brian, 57

Award-winning singer-songwriter plagued by severe chronic plaque psoriasis for more than 30 years, MELBOURNE



(08:04-08:13)

For how long do you suspect you were living with plaque psoriasis before your diagnosis?

I had been living with plaque psoriasis for about six months before I received a diagnosis, and by that time, it hadn't gotten quite severe.

(08:16-08:30)

When were you diagnosed with severe chronic plaque psoriasis?

I was diagnosed with severe chronic plaque psoriasis when I was 26 years old by a GP in Adelaide as I was travelling through on tour as a musician. And, um, the diagnosis, um, was devastating.

(08:34-09:00)

How does it feel to live with severe chronic plaque psoriasis?

Living with severe chronic plaque psoriasis is a little bit like a jail term. You feel imprisoned by it, and you also, uh, constantly aware of how, uh, you are viewed through the eyes of other people. We waste too much time doing this. And when we examine ourselves and how we feel about ourselves, this is what's most important, and the change of attitude in how I viewed myself was, it showed me the way through.

(09:03-09:25)

Can you reflect on your constantly shedding skin?

I had skin that would be accumulating in my sleeves and, uh, falling out through the bottom of my, uh, trouser legs. Um, they were constantly shedding skin, leaving it on furniture, uh, having to constantly sweep up around myself. The dust buster was my best friend. And, um, everywhere I went, I left traces of, of skin.

(09:29-09:48)

How did you feel when you were diagnosed with severe chronic plaque psoriasis?

When I was diagnosed with severe chronic plaque psoriasis, it was devastating because the doctor explained to me that it was not curable, and that this was something that I would probably be challenged by for the rest of my life. So that sent me into a spiral of depression. I locked myself away in my recording studio.

(09:51-10:53)

Please describe your symptoms of severe chronic plaque psoriasis.

Small patches at first of psoriasis that, uh, shed, um, large bits of skin, and then that became more, uh, flaking. Um, so it wouldn't be like peeling off skin. It'd be like just shedding flakes. And those, uh, patches on my body grew steadily until they covered a large portion of my body. And, um, if I bumped my knee or my elbow or anywhere where I was affected, it, it could, um, crack and lead to bleeding.

It was also incredibly itchy. Um, my bed sheets would always fill up with, um, skin flakes. It's, um, it's really hard to, uh, to live with. Some of my lesions grew larger than a human hand, um, around my back and my buttocks, my legs, and, um, around the elbows and knees especially. And, uh, my scalp became totally, uh, crusted over with, um, psoriasis as well.

(10:56-11:33)

Where on your body do you get the most severe chronic plaque psoriasis?

The places I get the most psoriasis lesions are on my elbows, uh, my stomach, there's patches on, on my back and my buttocks. Um, and, uh, especially, um, my calves, uh, the, the lower legs and, um, uh, and then some just random spotting,

uh, around the chest. And, and sometimes it appears on my face. That's the really difficult part, um, because you can hide your body with your clothes, but when it appears on your face and your hands, oh, that's really devastating.

(11:36-12:04)

How has living with severe chronic plaque psoriasis affected your quality of life?

Severe chronic plaques psoriasis has affected my life in every area. Um, physical, mental, and social. Uh, physically, uh, my own vision of myself, my self-esteem just dropped out of the bottom of, of my soul and, and to, uh, so this has affected, uh, my intimacy with my wife because I, I developed psoriasis only one year after being married, and, and that, that was devastating.

(12:08-12:48)

How mentally challenging is it to live with severe chronic plaque psoriasis?

It's very challenging to live with severe chronic plaque psoriasis. It takes you to some pretty dark places, and I think, um, the way that I've coped with it is, um, with humour. Uh, I try to laugh as often as possible. I think laughter is the best medicine. Um, I've had to redefine myself in my own mind and to, I've, to embrace and accept my condition was the first step, uh, to healing. Um, mentally the next step was to, um, find the right therapy and the right medication that would work for me.

(12:51-13:30)

Can you reflect on your severe chronic plaque psoriasis being a "journey into self"?

In the early days when I was struggling with this condition, it really spiralled me into depression and into dark places. And the only way that I, um, eventually was able to really come to terms with it, was through a process of acceptance of myself, realising that I'm not defined by this condition, that I still have so much to offer my family, my community, and even the country. Uh, because I have music, I have passion, I have drive and I have ambition. And this will not stop me from, um, achieving the goals that I set for myself.

(13:34-14:07)

How has living with severe chronic plaque psoriasis affected your career as a musician?

My career as a musician took a real hit for a couple of years, and that took me a long time to regain myself and my sense of self and to, um, decide that this disease does not define me. The embarrassment and shame factor of, um, living with psoriasis in public, um, when it appears on your hands and your face and or people notice it, um, somehow, uh, it can fill you with a sense of dread that you, you're being exposed somehow.

(14:10-14:41)

How has living with plaque psoriasis affected the way you dress?

I will always have long sleeves on, long pants, even if the temperature is 45 degrees and as a musician, um, when I'm playing outside and every other musician is in shorts and a tank top or t-shirt and, and that feels unusual. So, uh, and I always wore a hat for, um, for years too, to cover the psoriasis on my scalp. Nowadays I wear a hat because I'm going bald <laugh>. But, um, yes, it definitely has affected the way I dress.

(14:45-15:12)

How has living with plaque psoriasis compromised your social life?

Living with severe chronic plaque psoriasis has affected my social life insofar as I'm less likely to want to, uh, hang out. Um, even going to a friend's place for a party, um, can be an issue for me, especially if they have a swimming pool, especially if the weather is really hot. I'm just, I'm more likely to just hide away.

(15:17-15:40)

What does the PBS listing of a new treatment for chronic severe plaque psoriasis mean to you?

Bringing new treatments to the PBS for severe chronic plaque psoriasis is so important because psoriasis itself does not discriminate between rich people and poor people. It affects people across the board, and therefore, needs to be access accessible for everyone. And there's so many people suffering, and you'd be surprised how many people around you suffer psoriasis and suffer in silent desperation.

(15:43-15:52)

How important is it for patients to have access to a range of available treatment options for severe chronic plaque psoriasis?

This, um, condition affects people differently, and therefore they need the full range of treatments available to them.

(15:55-16:07)

What is your message to other Australians living with severe chronic plaque psoriasis?

My message to Australians suffering severe chronic plaque psoriasis is never give up hope. Do not let the condition define you. Information is power, and a good song will take you far.

Emma, 44,
Hair-&-makeup artist living with severe chronic plaque
psoriasis for more than 25 years, *SYDNEY*



(16:15-16:29)

For how long do you suspect you had been living with plaque psoriasis before your diagnosis?

When I was 17, I figured out that there was something wrong. I was getting spots on my back. So then I went to the doctor and they thought it was probably psoriasis, and within 10 days I was fully covered with plaque psoriasis.

(16:31-16:39)

When were you diagnosed with severe chronic plaque psoriasis?

In 1996 I was diagnosed. I'd just finished year 12. So I think the stress of the exams were pretty hard. And then I got strep throat.

(16:42-16:56)

What event led to your diagnosis with severe chronic plaque psoriasis?

I had somebody notice it on my back, and there were a few spots, and then I was not concerned at the time. And then I think within 10 days after being sick, it then just started to grow, and it started on my back, and then it gradually just covers your body.

(16:59-17:14)

How did you feel when you were diagnosed with severe chronic plaque psoriasis?

I'd just finished school. I was nervous and anxious about what I was going to do the following year. And then to be told I had this lifelong skin problem, it was hard on me. I hit depression and it wasn't something that I wanted to accept, but I did get support.

(17:17-17:24)

Do you have a family history of severe chronic plaque psoriasis?

Growing up, I knew that my mum had psoriasis. She would get small patches, definitely when she was stressed out, and my brother had asthma.

(17:28-17:40)

How would you classify your plaque psoriasis, and in which season are most severe?

It's been moderate-to-severe my whole entire life. I definitely have more flare-ups in wintertime when the weather is dry, cold, and in the summertime, you get a little bit of sun, so you get to help it a little bit along.

(17:43-17:56)

Please describe your symptoms of severe chronic plaque psoriasis.

When you get a flare up, it's red, itchy, painful, you scratch a lot, and it can become very flaky, very dry skin, and it's very painful. At some point it cracks.

(17:59-18:12)

Can you reflect on the embarrassment you have experienced living with severe chronic plaque psoriasis?

I definitely feel embarrassed when I want to wear shorts, skirts, or dresses that are low at the back, and you can see it. You're conscious that people are looking, wondering what that is, or people ask, is that sunburn? And you're like, no, it's psoriasis.

(18:15-18:28)

Where on your body do you get severe chronic plaque psoriasis?

It starts on my back. I notice it on my top of my back, the low of my back, my stomach, and then it goes down my legs, and it can go down my arms, and it's really bad. It becomes, one spot becomes 2,000 spots within 10 days.

(18:31-18:45)

How has winter historically affected your severe chronic plaque psoriasis?

In winter, plaque psoriasis is usually the strongest. It will come out because of the dry air and not being able to get into the sun. You definitely get it worse and you're covering up, so you don't get to really show your skin in winter.

(18:48-19:16)

How mentally challenging is it to live with severe chronic plaque psoriasis?

It's daunting, it's heavy. It makes you feel depressed, makes you feel like you're a little bit different and you've got something to constantly think about. Whether it's that you're shedding everywhere, or the clothes that you wear, or the people that you meet. It has an impact on your life. Definitely. I've had lots of depressive episodes over the last 25 years with psoriasis. It's kept me from being in relationships, or it's made me feel insecure in my relationships.

(19:18-19:41)

How do you feel about yourself when you experience a severe chronic plaque psoriasis flare?

I think when you look at yourself and you've got clear skin, and then all of a sudden something happens, and your skin within 10 days is full of red, flaky, crusty patches, you don't feel good about yourself. It's just, you see around you. You know that you've had good skin, and then you've got already you're presenting red, itchy, scaly, scratchy skin.

(19:44-20:13)

How has living with plaque psoriasis compromised your social life?

If I start to get full psoriasis come on my body, it's painful and I don't really feel like wearing the clothes that I might want to wear to a social event. You have to wear cotton all the time, loose clothes. You have to be mindful of what you wear. You can't wear fragrance, you can't wear anything with a smell inside. You have to change your diet. It affects you. You don't feel like going out sometimes when you can see yourself and it's hot, it's 35 degrees out and you're covered in psoriasis.

(20:16-20:44)

How has living with severe chronic plaque psoriasis affected your relationships?

Well, you grow up feeling like you're a little bit different. And so, when you've got great skin and someone meets you and you've got this beautiful skin that everybody talks to you about, and then you get plaque psoriasis, and it covers you within 10 days, you feel insecure. That person's going to judge you. Is this something that you're going to have? I'm going to have to deal with. How can I touch you? You don't want to be touched. It's something you don't want to show. So you change as a person. Your personality changes instantly. That affects your relationship.

(20:47-21:05)

How has living with plaque psoriasis compromised your dating life?

Last year I probably had plaque psoriasis for most of the year, and I didn't date because I just didn't want to meet people. I just didn't feel good about myself, and it affected me, and it affects everything about my whole life. So I get pretty deep down, get pretty down about it.

(21:08-21:17)

How has living with plaque psoriasis affected your finances?

When you've got plaque psoriasis, as severe as I get it all over, you do have to buy a lot of creams and potions and lotions, so it can be costly.

(21:20-21:37)

How has living with severe chronic plaque psoriasis affected your working life, as a hair-and-makeup artist?

With my job, I'm always face-to-face with people, and I'm touching their hair, and I'm touching their skin. So when I present a lot of psoriasis on my body, I feel like, a little bit embarrassed when I have to go and do someone's hair and make-up, and I can see that they're looking at my skin. So, I have to explain that it's psoriasis, and you don't catch it.

(21:40-21:56)

How does it feel to live with severe chronic plaque psoriasis?

You feel like you can't be your full self, you don't feel happy all the time. You don't project your true identity of who you are. You can't wear the clothes you want to, act how you want to, because you feel embarrassed, or ashamed, or insecure about it.

(22:00-22:10)

What does the PBS listing of a new treatment for chronic severe plaque psoriasis mean to you?

The new treatment for PBS listing for severe chronic plaque psoriasis definitely helps with giving me access to more treatments, and I have more choice, and it's more affordable.

(22:12-22:21)

Why is it beneficial to have a range of treatment options?

Now we have more options and more access to different treatments. It's helped collectively, be able to attack when you have the flare-ups.

(22:24-22:40)

What is your message to other Australians living with plaque psoriasis?

It's really important that you go to see a dermatologist and you get onto treatment straight away. A lot of people feel insecure, and they don't want to show anybody, not even a doctor, and they live and hide with this skin disease, and you don't have to. There's a lot of treatment out there, and a lot of help.

ends#

OVERLAY

TIME CODE	DESCRIPTION
(22:43-22:59)	Close up – Man rubbing severe chronic plaque psoriasis on his chest.
(23:00-23:04)	Mid shot – Man with severe chronic plaque psoriasis on his back.
(23:05-23:09)	Close up – Man’s arms crossed over, showing severe chronic plaque psoriasis on elbows and forearms.
(23:10-23:14)	Close up – Severe chronic plaque psoriasis on man’s hand and knuckles.
(23:15-23:19)	Extreme close up – severe chronic plaque psoriasis on man’s scalp and hair.
(23:20-23:29)	Mid shot – A/Prof Shumack looking at images of man living with severe chronic plaque psoriasis on computer.
(23:30-23:38)	Extreme close up – A/Prof Shumack’s face.
(23:39-23:42)	Mid shot – A/Prof Shumack walking through door exiting his consult room.
(23:43-23:49)	Wide shot – A/Prof Shumack walking down corridor and handing receptionist patient files.
(23:50-23:57)	Mid shot – A/Prof Shumack walking over to receptionist and handing her patient files.
(23:58-24:03)	Wide shot – A/Prof Shumack greeting patient, shaking his hand, and gesturing to patient to walk down hallway.
(24:04-24:22)	Wide shot – A/Prof Shumack walking with patient down corridor and gesturing to him to sit down.
(24:23-24:27)	Mid shot – A/Prof Shumack pointing to psoriasis on patient’s knees and left elbow.
(24:28-24:31)	Close up – Patient’s left elbow.
(24:32-24:38)	Mid shot – A/Prof Shumack observing and pointing to patient’s elbows and knees.
(24:39-24:42)	Wide shot – A/Prof Shumack checking patient’s skin.
(24:43-24:50)	Close up – A/Prof Shumack checking patient’s skin.
(24:51-25:07)	Wide shot – Patient discussing and pointing to psoriasis on his legs and elbows.
(25:08-25:24)	Wide shot – Emma sitting on patient bed and talking with A/Prof Shumack.
(25:25-25:32)	Mid shot – A/Prof Shumack talking to Emma on bed.
(25:33-25:49)	Mid shot – Camera zooming in and out of Emma lifting her shirt to show A/Prof Shumack her psoriasis on tummy.
(25:50-26:05)	Wide shot – Emma sitting on patient bed. Camera zooming into her elbow and out as A/Prof Shumack examines her severe chronic plaque psoriasis.
(26:06-26:15)	Wide shot – Emma standing and shaking A/Prof Shumack’s hand and escorting patient out of room.
(26:16-26:18)	Mid shot – Emma walking through doorway, A/Prof Shumack following behind her.
(26:19-26:24)	Wide shot – Brian walking into Southern Dermatology practice.
(26:25-26:28)	Mid shot – Brian walking into Southern Dermatology practice.
(26:29-26:35)	Wide shot – Brian walking up to practice reception. Dr De Cruz shaking Brian’s hand and escorting him to his room.
(26:36-26:43)	Wide shot - Brian walking with Dr De Cruz down practice hallway. Dr De Cruz gesturing to Brian to walk through doorway.
(26:44-27:32)	Wide shot – Brian walking through doorway, Dr De Cruz closing door behind Brian and inviting him to sit down. Brian sitting in patient chair and chatting with Dr De Cruz. Brian pulling his shorts up showing Dr De Cruz his skin. Dr De Cruz holding medical instrument starting to observe Brian’s severe chronic plaque psoriasis.
(27:33-27:54)	Close up – Dr De Cruz observing Brian’s severe chronic plaque psoriasis, Brian rolling down his pants, then rolling up his sleeves, showing Dr De Cruz his left elbow. Dr De Cruz extending and rotating Brian’s left arm.
(27:55-28:16)	Mid shot – Dr De Cruz examining Brian’s skin through medical eye equipment. Dr De Cruz looking up and down Brian’s left arm.

	Dr De Cruz examining under side of Brian's arm and discussing the state of his chronic plaque psoriasis with him.
(28:17-28:32)	Mid shot – Brian playing the ukulele.
(28:33-28:42)	Extreme close up – Brian playing the ukulele.
(28:43-28:52)	Close up – Brian playing the ukulele.
(28:53-28:56)	Wide shot – Brian walking with Jenny (wife) outside Sound System Studios holding guitar case.
(28:57-29:03)	Mid shot – Jenny opening wooden door. Brian walking through wooden door, opening main door to Sound System Studios. Jenny following Brian and closing the door behind her.
(29:04-29:14)	Mid shot – Brian singing and playing the guitar on stage.
(29:15-29:22)	Wide shot – Brian singing and playing the guitar on stage next to Jenny, singing.
(29:23-29:29)	Close up – Brian playing the guitar.
(29:30-29:43)	Wide shot – Brian singing and playing the guitar on stage next to Jenny, signing.
(29:44-29:50)	Close up – Emma applying make-up to her face in mirror.
(29:51-29:59)	Close up – Emma applying lipstick and smiling at herself in pocket-sized mirror.
(30:00-30:06)	Mid shot – Emma curling customer's hair.
(30:07-30:23)	Close up – Emma curling customer's hair, focusing on Emma's hands.
(30:24-30:49)	Mid shot – Emma finishing curling customer's hair and spraying with hairspray; client smiling at herself in mirror.

ends#

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