



"We rely on the generosity of people like you..."

Each year the Psoriasis Association helps thousands of people whose lives have been affected by psoriasis via our websites, telephone and email helplines and by raising awareness amongst the general public, healthcare professionals and Members of Parliament.

We rely on the generosity of people like you to help us continue our vital work in supporting people, raising awareness and funding research".

*Helen McAteer*

Helen McAteer - Chief Executive

For further information please visit:  
[www.psoriasis-association.org.uk](http://www.psoriasis-association.org.uk)

or call: 08456 760 076

# psoriasis communication

## I wish someone had told me...

## Psoriasis means different things to different people...

There is no 'one-size fits all' approach to learning to live with, and manage psoriasis.

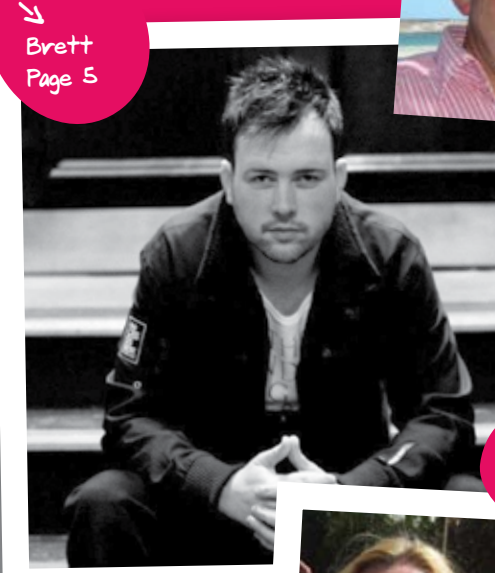
People are affected in different ways, and everyone is unique in how they deal with the condition. The following pages are just a few stories from our members, regarding what they wish someone had told them...



Toby Page 3



Karen Page 2



Brett Page 5



Mike Page 5



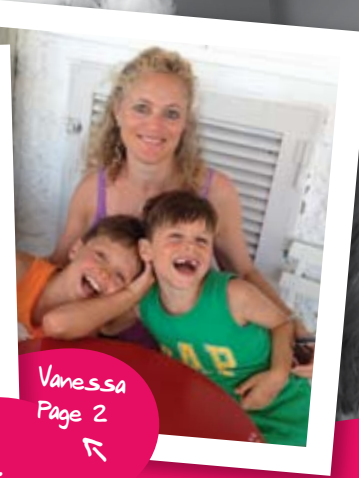
Ray Page 3



Luke Page 3



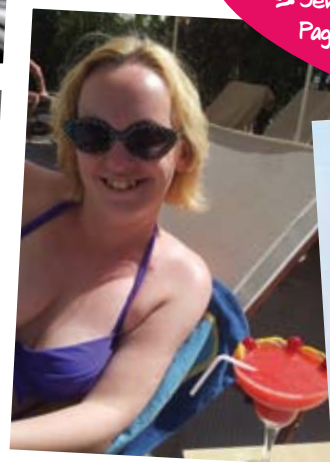
Jonathan Page 2



Vanessa Page 2



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“Your skin disorder is just one small part of your life”

## Helen Hanrahan

**I first developed my psoriasis in my early 20's and decided it was an allergy to popcorn.**

Clearly I should dispel any notions of a medical career! It was quickly cleared by the application of Hydrocortisone 1% and I was then clear-skinned for quite a few years.

Fifteen years ago it returned, and bar one year of relief whilst pregnant, I have had it ever since. I have good spells and bad spells, and despite all information to the contrary I am determined that there must be a cure somewhere. In the meantime, I continue to 'manage' my condition and these are some of the random things that I've learnt over time:

- Your skin is not as noticeable as you think! Remember when you were a teenager and you thought that the only thing people could see was that huge spot on your chin? Psoriasis is the same. We worry that it's the first and only thing that people notice about us. This is quite simply not true – ask your friends!
- Emulsifying ointment is the best thing I've ever discovered. It's thick and greasy, but if you apply this liberally to your skin each morning before taking a shower, it creates a protective barrier on your skin which eases the itch and reduces flaking significantly.
- On very itchy or sore days, I find a warm bath laden with aqueous cream is very soothing.

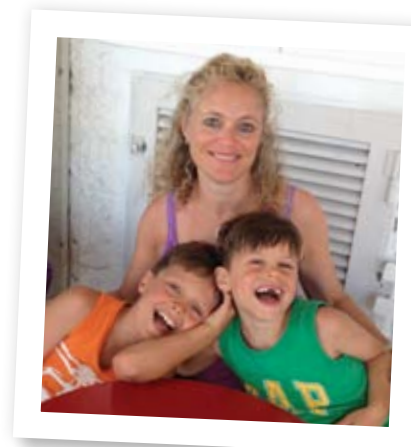
- If you suffer from scalp psoriasis, avoid wearing any dark colours on the upper half of your body. Flakes will show up and you will spend your day feeling self-conscious. It's far preferable to wear paler colours or prints which will conceal any flaking that might occur.
- For most sufferers, the sun is a great help. It may be embarrassing when on holiday to reveal your skin – stop worrying! You'll never see these people again and your priority should be to allow the healing rays of the sun to do their work.
- Never, ever, ever allow your skin to burn. This can result in Koebner's Phenomenon or widespread flaring of psoriasis. As tempting as it is to stay in the sun in the hope of clearing your skin, be sensible, don't overdo it.
- Exercise helps. It releases natural endorphins which lift your mood.
- Dress cleverly to conceal your psoriasis. Maxi dresses with little shrugs during the summer, layered cotton tops during winter, whilst accessories such as scarves or costume jewellery will distract the eye.
- If you are confident in what you are wearing, it will help you to feel much better about your skin.
- Above all, don't let psoriasis define you. You are a bright, interesting and vibrant person.



## Karen Lowe

**Karen Lowe and her son Callum both have psoriasis**

- No-one is perfect... we just happen to know our imperfections.
- People staring doesn't bother me as I have *thick* skin (literally!)
- If people are rude and stare ask them directly - would you like a photo?



## Vanessa Lawrence-French

**Sometimes the burning sensation is overpowering.**

**“I wish I'd known that psoriasis can hurt!”**

In my 20's, I gave up hope of finding a husband and having children. I worried that a man wouldn't accept me, skin and all. But I was wrong.

One thing I always remind myself is that most of the 'general public' don't know about skin disease or can ever imagine what living with a chronic condition could be like. So when they stare or comment or ask if you can be tested for psoriasis (as was recently asked of me!!), you have to just tell yourself they're ignorant!!

“Dr Coles gave me licence to scratch”



## Jonathan Swift

Try not to focus too hard on improvements (treatments can take time to work) - then you will not be disappointed and won't worry about it.

I got my last outbreak under control thanks to Sudocrem 3 times a day.



“Trying to be healthier is not that hard...”

## Toby Hadoke

I wish that someone had told me...

- That the amount of pain and discomfort I was living with was not acceptable and could be treated more effectively.
- That a simple application of Protopic cream would get rid of the large red patches on either side of my face that were there for ten years.
- That talking about how the condition makes you feel isn't self indulgent, that there are people there to allow you to do this, and that it helps.
- That psoriasis doesn't control or define you if you don't want it to.
- That most members of the opposite sex aren't shallow and might not be as repulsed by you as much as you are.
- That wearing beige isn't so bad and hides a multiple of flaky sins.
- That trying to be healthier is not that hard, can be enjoyable, and helps you to be able to cope with the condition better.
- That there are very good support networks out there.
- That it will probably never fully go away. Once you accept that it's easier to manage.



“Being positive will help!”

## Luke Collins

I first came out in psoriasis at the age of 13.

What started out as a patch on my arm and scalp escalated and within a year I was covered from head to toe. Suffering from psoriasis through my teens was hard at first, especially in the summer months. I would be the one out of my group of friends wearing track-suit bottoms and long sleeved shirts to hide my skin whereas my friends would always be in shorts and t shirts.

I have been prescribed various different steroid creams over the years but warned that extensive use could thin my skin.

I chose to ignore this advice, as the steroid creams did seem to make things better. However I must stress that long term use has resulted in me bruising very easily and has not actually cured the condition. In my case steroid creams were a short term fix but with long standing detrimental effects.

I am 31 years of age now and have had to live with this condition for 18 years. However, I am a very positive person and this helps a lot. I have a good personality and get on well with people. I accept I have the condition with all its aggravations, but choose not to be pessimistic about it.

I work in an office and it is obvious from looking at my hands that I have a skin condition but nobody seems to have a problem with it and neither do I.

On a positive note I have found that the psoriasis reduces dramatically when I have been abroad where it is hot and sunny. My advice would be; do not cover up and hide your skin, get a good factor of protection on your skin and enjoy the weather when possible.

There are plenty of people out there with a range of health and skin problems, it is not just me and whilst I appreciate psoriasis can be debilitating sometimes, getting stressed over it just makes it worse.

## Ray Jobling

Ray was diagnosed with psoriasis at the age of 14.

Having been offered no explanation of psoriasis for the first 10 years that I had it: I wish that someone had troubled to tell me something before that...

“I wish someone had told me about the Psoriasis Association earlier...”





“Different treatments work for different people at different times in their lives...”

- I have a more positive outlook in realising that my experiences over the last 25 years are of interest to others and enjoy being involved in processes to improve patients’ experiences.
- Fight your corner - do not accept treatment that, given a reasonable chance, is ineffective! Scientific advancements are amazing and there is something out there for you!
- Different treatments work for different people and at different times in their lives - give things a go, you will be surprised!
- Never let anyone say it is *just* a skin condition - how you feel about your condition is unique to you. Do *not* feel guilty about it!
- It is not whether you can cope, it is whether you have been provided with appropriate coping mechanisms! Demand this!
- Do not just talk about your skin with your dermatologist - your physical and mental health are intrinsically linked!
- Be clear about the application of topical treatments - different clinicians have different approaches and misunderstanding can lead to weeks of unnecessary misery.
- Psoriasis is known to wax and wane in its severity - try and recognise potential triggers to avoid and keep your chin up, it will get better!
- Pamper yourself and minimise stress where you can - you deserve it!
- Recognise that psoriasis impacts on all those who are close to you - do not take your frustration out on them!

### Lydia Warner

I was 25 when I developed psoriatic arthritis, and the psoriasis appeared about 6 months later.

- Engage with others with a connection to psoriasis even if it is just through Psoriasis Association communications - not to wallow, but to dissipate the sometimes overwhelming feeling that you are on your own!
- Surround yourself with people who care enough about you that they do not even notice your condition - do not mistake this for apathy on their part!
- Try and be interested in the condition - you are an ‘expert patient’ in this particular field! Psoriasis appears to be unique to individuals and as such you have something to offer clinicians and other sufferers, even by just being empathetic!

### Jenny White

I have had psoriasis my whole life.

I try and take a pretty upbeat approach to the condition and focus on the positive.

My pearl of wisdom would be, as I sit by the pool, the best thing you can do for your psoriasis is learn to relax and forgive your skin for not being perfect.

I have patches of psoriasis on my upper arms, tummy and legs but I’m in a bikini and no one has said a word. They’re all far more interested in their own tans than my skin.

“Focus on the positive...”



“Work with your psoriasis rather than thinking it will go away...”

### John Lightfoot

My psoriasis started when I was 18.

Initially it was the scalp (and moderately severe). The psoriasis has, over the years, pretty much gone from the scalp (minor patches only now), although the main trunk of my body is pretty well covered. I was fortunate, in that my mother had had psoriasis on and off over the years, albeit not as severe as I now have. Fortunate, in that I was not thrown into the deep end of psoriasis all by myself.

Whilst I don’t go swimming that often, I’m not embarrassed to appear with my psoriasis.

Find a treatment regime that works for you and stick to it – mine has partly come from personal experience and partly from the Psoriasis Association. Having tried various emollients and prescription topical treatments, I saw a note in Pso from someone advising that they use Vaseline Intensive Care, so I tried it too and found that it also suited me.

Have the understanding that there is no magical cure as yet; work with your psoriasis rather than thinking that it will go away.

The pleasure of the full de-scale; relaxing in a hot bath of Radox, or a session in a steam-room or sauna.

## Brett Domendziak

I got psoriasis when I was 22.

It appeared out of nowhere, just a little bit on my scalp and then it started to appear on my arms and legs, very slowly.

I wish I had asked more questions to my GP and my Dermatologist, about how to deal with psoriasis. Speak to your GP regularly, then you are not alone in the battle to try and make it better.

Try to be honest with your GP, even if you are uncomfortable talking about it, you must keep them involved and up to date with everything or they won't be able to treat you effectively.

*"Take the responsibility of having psoriasis on yourself; you need to be in control of it"*



## Mike Andrews

*I was diagnosed with psoriasis in my early 20's*

I wish I'd had the confidence to say to people, 'I have psoriasis', and then explained to them what it is, instead of avoiding the issue.

*"Most of my useful information has come from being a member of the Psoriasis Association..."*



## Heather Kerr

I was diagnosed with psoriasis as a baby.

My mum took me to the doctor with nappy rash only to be told that it was psoriasis. So good on the doc for a very early and correct diagnosis!

I try to discuss my psoriasis whenever I can. I tell people to moisturise. This was the big thing missing throughout my life until I became a member of the Psoriasis Association and discovered this through reading the magazine. In fact most of my useful information has come through being a member of the organisation and I try to promote this when I can.

Moisturising makes such a big difference to managing plaque psoriasis. Also knowing that soaps dry out the skin, it is so important to moisturise after showering and before applying any topical treatment.

Don't be put off by fashionable clothes and think you can't be fashionable because of your skin.

You may not want to show affected skin, but careful consideration of clothing can mean you can look your best. It took me a long time to be fashion aware because I always thought there wouldn't be anything suitable that I could afford.

Following completion of the Edinburgh Marathon, my psoriasis was as bad as I could remember since I was about 8 years old, so it was great to let people see it and know that it doesn't stop you achieving what you really want to do. Don't let it get in the way of life and living in the moment.

## Andy Seymour

*I have had psoriasis all my life —*

I found that not having dairy or processed meat, taking fish oil and drinking lots of water helped my psoriasis.



# I wish someone had told me...

## A BIG thank you

The Psoriasis Association is all about communication; sharing, talking and listening.

Without the help of the following people this brochure would not have been made...

- Jonathan Swift
- Helen Hanrahan
- Mike Andrews
- Karen Lowe
- Toby Hadoke
- Vanessa Lawrence-French
- Ray Jobling
- Lydia Warner
- Luke Collins
- Jennifer White
- Andy Seymour
- Heather Kerr
- John Lightfoot
- Brett Domendziak

**Thank you for your unique insight and sharing your experiences.**

## A bit about us

We're here to help...

The Psoriasis Association is the leading national charity and membership organisation for people affected by psoriasis - patients, families, carers and health professionals in the UK.

- We offer good quality, reliable and independent information and advice to all who contact us.
- We receive an average of 27,000 web visits per month to our main website.
- We raise awareness of the condition and work with other key health officials and health professionals, representing the interests of members at a local and national level.
- We send a copy of our members' magazine, Pso, to all Dermatology and Rheumatology departments in the UK.
- We fund and promote research into the causes, treatments and care of people with psoriasis.

## Support us

We couldn't do it without you...

We value the experiences of our members in helping to shape our ongoing work as we understand that you are the experts when it comes to dealing with psoriasis.

If you would like to share the pearls of wisdom you have picked up whilst living with psoriasis, please visit the Connect forum on our website at:

**[www.psoriasis-association.org.uk/connect](http://www.psoriasis-association.org.uk/connect)**

It is important that you regularly see your doctor to review your psoriasis, to ensure that you are on the most effective treatment.

