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Psychological aspects of psoriasis

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Psoriasis and Psoriatic Arthritis Alliance



www.papaa.org

What are the aims of this leaflet?

Living with psoriasis can be challenging, stressful and even distressing. This can have a negative impact on an individual's life and even affect their psoriasis. This leaflet aims to describe the different ways that psoriasis may make you feel, think and behave, and offers some practical advice to help you manage this.

What is psoriasis?

Psoriasis (sor-i'ah-sis) is a long-term (chronic) scaling disease of the skin which affects around 1 in 50 people, which is about 1.3 million, or around 2% of the UK population. It usually appears as red raised, scaly patches, known as plaques. In people with skin of colour, the redness is less pronounced, and psoriasis may appear as purple or darkened areas of skin with grey scales. The cause of psoriasis is currently unknown. Any part of the skin surface may be involved but the plaques most commonly appear on the elbows, knees and scalp. It can be itchy but is not usually painful. Nail changes, including pitting and ridging, are present in nearly half of all those who have psoriasis. For those that have psoriasis, around 1 in 4 may develop an associated psoriatic arthritis (PsA), which is about 325,000 people, or around 0.5% of the UK population. PsA causes pain and swelling in the joints and tendons, accompanied by stiffness particularly in the mornings. The most commonly affected sites are the hands, feet, lower back, neck and knees. For more detailed information, see our leaflets **What is psoriasis?** and **What is psoriatic arthritis?**

What happens?

Normally a skin cell matures in 21-28 days and during this time it travels to the surface, where it is lost in a constant, invisible shedding of dead cells. In patches of psoriasis the turnover of skin cells is much faster, around 4-7 days, and this means that even live cells can reach the surface and accumulate with dead cells. This process is the same wherever it occurs on the body. The extent of psoriasis and how it affects an individual varies from person to person. Some people may only be mildly affected with a tiny patch hidden away, which does not bother them, while others may have large, visible areas of skin involved that significantly affect daily life and relationships. Psoriasis is not contagious; therefore, you cannot catch it from another person.

Anxiety

Sometimes described as tension or nerves, anxiety is how we feel in certain situations, usually when under some form of pressure. We all experience feelings of anxiety from time to time but sometimes these feelings can get out of hand, spoil our enjoyment of life and interfere with what we have to do.

Anxiety affects us in four different but closely linked ways:

- **Physical reactions** - heart racing, palpitations, legs feeling weak, stomach churning, shaking, muscle tension and dry mouth, to name but a few
- **Moods/feelings** – nervous, frightened or panicky, feeling the need to escape and get to a safe place, being short tempered, feeling low and not in control of events
- **Behaviours** – avoiding situations where someone may stare at us or make negative comments about our psoriasis; having a drink before going out to help us feel more confident
- **Thoughts** – thinking in a negative, unhelpful way, e.g. “people think I am disgusting”, “nobody will want to go out with me”.

The diagram below shows how these four aspects of anxiety interconnect. For example, if you thought that people might respond negatively to you because of your psoriasis, you might change your behaviour, such as avoiding social activities. This reduced social life may then result in you feeling low in mood. Likewise, changes in our mood can affect our behaviour and physical reactions.

We may not experience all these things, or our symptoms may be slightly different, or perhaps we have some feelings or worries that are much stronger than others.

Stress

Feelings of stress and anxiety are closely linked. Stress is a term that is often used to describe experiences which may be difficult to manage. For example, some people experience stressful life events such as losing a job, having an accident or a family death. When these stressful events happen, the reaction is for chemicals produced in the brain to be released into our body and, as a result, we may feel the physical and psychological effects of tension.

Some people feel under constant stress because they have work, family or money problems. This low level of stress can also create tension. However, these feelings may not always be as obvious as when they follow a big event such as a death or job loss.

Low mood

- Low mood or depression may also occur alongside anxiety and can affect us in a number of ways.
- Reduced energy levels and poor concentration
- Changes in appetite and sleep
- Thinking negative thoughts
- Feeling emotions such as sadness regularly or for prolonged periods of time
- Feeling irritated and annoyed for no apparent reason
- Withdrawing from activities that you used to enjoy.

The effects of stress and anxiety on psoriasis

It is generally accepted that stress on its own does not cause psoriasis. However, research has shown that stress and anxiety can trigger a flare. Also, there is some research which suggests that being stressed can have an effect on the treatments we use, making them work less effectively. It is therefore important for everyone, maybe more so if you have psoriasis, to learn to manage stress and anxiety effectively.

Coping with stress and anxiety

This section describes some ways you can help yourself to cope with stress.

Learn how to breathe more effectively

When we are anxious, our breathing pattern changes, usually becoming rapid and irregular. If this type of breathing pattern continues it can make us feel more anxious and out of breath, which sends a signal to our brain to indicate we are under a potential threat.

You can break this vicious circle by learning to breathe properly and switch off this stress response.

The aim of breathing correctly is to fill your lungs with air as effectively as possible. The diaphragm is a large muscle situated underneath your lungs, at the bottom of your ribcage. As you breathe in, this muscle should push your tummy out, allowing your lungs to expand down into the space it creates.

Breathing exercise: Put one hand on your chest, and one on your tummy. As you breathe in, try to keep the hand still on the top part of your chest, while your inhalation pushes the hand on your tummy out. Achieving this allows your lungs to expand downwards for maximum air intake.

Remember: As you breathe in, try to fill the whole of your lungs, letting them expand down.

Also, once you are breathing properly, you need to learn to breathe regularly, in and out. There should, of course, be no gasping or gulping. Try to make sure that your inward and outward breaths take an equal length of time. Concentrate on letting the air flow in and out evenly.

Next, you need to measure the speed at which you are breathing. Try breathing in while counting slowly to three, and then breathing out, again counting to three. Remember not to hold your breath. Simply breathe in, pushing out your tummy, and then when your lungs are full, breathe out again slowly, controlling the flow of air. Try that for a few seconds: in...2...3... and out...2...3...

Finally, try not to take too many deep breaths in a row or you may become dizzy. Always take a few ordinary breaths in between the deep ones.

Learning how to relax

One way of helping to ease anxiety and worry is to practise muscle relaxation. Research has shown that relaxing your muscles can help reduce the worry and panic you may feel in certain situations. These situations may include going out on a date or dealing with people who are staring or making comments about your skin. Also, if you feel less worried or anxious it may probably be less likely that your psoriasis will flare.

Muscle relaxation exercise: Effective relaxation involves releasing tension in the body. One way of approaching this is to focus on individual groups of muscles, to be aware of how they feel in their tensed and relaxed states, and to relax them one by one.

Work systematically through the muscle groups and try to relax them. Remember to tense your muscles to only about two thirds of their maximum. You don't want to give yourself cramp! If you have joint problems you may want to discuss these exercises with your GP before you try them.

Face

Try tensing all the muscles in your face. Screw up your eyes... frown... wrinkle up your nose... purse your lips... and clench your jaw. Feel the tension and how uncomfortable it is. Hold your face like that for a few seconds.... Now release all the muscles, and relax your face. Feel the warm, heavy feeling spreading over your face, as your muscles begin to relax and the tension flows away.

Neck/shoulders

These areas are often associated with stress and pain. Pull your shoulders up to your ears, and slightly forward, so that you can feel the tense, tight uncomfortable feeling across the whole of the top of your back. Hold that for

a few seconds and feel the strain gradually increasing. Now release the muscles and relax them completely. Again, feel the warmth spreading through the muscles as the tension is released.

Hands/arms

First of all, clench your fingers into fists as tightly as you can. Feel the tension building up within your fists and gradually spreading up your lower arms. Keep that pressure, and notice how uncomfortable it becomes. And again, release your hands, relaxing them completely so that tension flows away and your hands and arms feel relaxed and comfortable. Be aware of the change in sensation caused by releasing the tensed muscles.

Legs

Concentrating on one leg at a time, push your heel hard into the floor. Feel the tension work its way up your calf, through your thigh and into your bottom; a tense, tight, uncomfortable feeling all the way through your leg. Now release the muscles, and notice the warmth spreading through your leg and foot. Try it again with the other leg.

Visual imagery

It is sometimes useful, while you're in a relaxed state, to visualise a situation that you are fearful and tense about. The idea is that if you prepare for a situation which you believe will cause you stress or anxiety, you should be able to cope with it better when that situation arises.

So, if you are afraid of going swimming, imagine being at the pool. Who is there? What are their costumes like? Picture the scene in detail. Ask yourself what you are particularly worried about. Are you afraid of being seen in a swimming costume for the first time because of psoriasis? Are you afraid of friends seeing you or strangers? Maybe you are worried that children will point at you. If this image makes you feel tense, then breathe more slowly and try to relax your muscles. By practising visualisation and rehearsing possible responses you will eventually find that you can cope more comfortably with the situation you're frightened of. This is because you have predicted what your reactions will be and developed coping strategies to deal with it. What you are trying to achieve is feeling in control of YOUR reactions - you can't control the reactions of others.

Breathing, muscle relaxation and visualisation are the three most common routes to effective stress management. These methods, particularly breathing, can be used anywhere, anytime, whenever you feel the need to take a few seconds to relax. The others require a bit more time. So, maybe set aside half an hour for yourself, in a quiet room, and practise, using this information.

Understanding and dealing with negative thoughts

We have considered some of the practical strategies you can use to help you manage anxiety and stress. Now let's look at thinking patterns and how they can affect behaviour and quality of life. We will also look at how you can identify, challenge and change negative thought patterns.

About negative thoughts

It is common for people who are anxious or depressed to think in unhelpful and negative ways about their life. This will often affect how they cope with psoriasis. These ways of thinking – sometimes known as thinking errors - can happen regardless of status and levels of intelligence. The list that follows describes some common thinking errors that people make.

- **Over-generalising:** Exaggerating the effect of an unpleasant thing which has happened to you once. For example, imagine that some people make rude comments about you in a pub. You are over-generalising if you then think that every time you go to a pub people will be rude to you.
- **Catastrophising:** This involves thinking of the worst-case scenario. For example, you think that if you went to the hairdressers they would not be willing to cut your hair because your scalp looked so disgusting.
- **Personalisation:** Feeling upset about something that has nothing to do with oneself. It could also involve feeling responsible for a negative or unpleasant event. For example, feeling that the reason that no one sat next to you on the train was because of your skin.

Ignoring the positive: Focusing only on the negative aspects of a situation or of your appearance. For example, somebody pays you a compliment on your appearance, but you think they are just feeling sorry for you.

These negative ways of thinking are unhelpful and only lead to low mood and anxiety. Ultimately, they can interfere with your daily life. So it's important that you try to become aware of these thoughts whenever they occur and learn how to deal with them. This is not easy. These thoughts can be instinctive and happen without you being aware they are there. It may be useful to spend some time paying special attention to these thoughts.

By doing this you will be able to see which thoughts increase your anxiety and low mood. You may be able to notice the situations which seem to produce them. Described below are some simple techniques that, with a bit of practice, may help you overcome anxious thoughts.

Thought stopping

This technique is useful for stopping anxious thoughts in mid-flow. By stopping an anxious thought quickly, you will find it much easier to switch your thoughts

to something which lessens your anxiety. Thought stopping works in the same way that a sudden noise instantly halts your train of thought. In thought stopping the sudden event is produced by you. It involves simply saying the word STOP to yourself. Having said STOP you should instantly switch your thought to something else – using one of the distraction methods described below. When the anxious thought returns, STOP and repeat the process. It is important to use this technique often. This is because, with practice, the word STOP should become quite a powerful way of quickly controlling anxious thoughts.

Simple distraction methods

The idea is to teach yourself to replace your anxious thoughts with neutral thoughts. These neutral thoughts have no emotional association, which means they don't make you feel anxious, happy or any other particular mood.

Try a few of the following to see which suit you best:

- Arithmetic, e.g. counting backwards from 100 in threes (to yourself)
- Spelling exercises, e.g. spelling the numbers one to ten in your head
- Concentrating on the visual and factual aspects of your surroundings. Try to describe to yourself the things that you see, e.g. the wallpaper, carpet pattern, what people are wearing
- Simple distraction methods including ignoring the itch. Get on and do something else, even something mundane, like doing the washing up etc.

Recognising and changing negative thoughts

Another way of becoming more aware of negative thoughts and overcoming them is to write them down as soon as you can after they have occurred. Then challenge and correct them. This may not always be possible or easy, perhaps because you are out socialising or on public transport. In situations where you can't use a notebook or a note-taking app on your smartphone, make a mental note of the thoughts, the situation and how you felt, and write them down later. When you get the chance to write them down, consider the following points.

- What was the situation/what were you doing when the thought occurred?
- What was the negative thought that appeared in your head at the time?
- What emotions did you feel and how strong were they? Rate them on a scale of 0-10 (10 being the strongest feeling).

Now you are able to access your negative thoughts, it is important that you learn to challenge them and turn them into more realistic and positive thoughts. This will help you to improve your mood. Below are some strategies you can use to challenge and change your thoughts.

1. What is the evidence that this thought is true?
2. Am I predicting the future negatively?
3. Are there alternative interpretations which are more realistic?
4. Am I making things appear worse than they really are?
5. Does this thought help me to succeed?
6. Does it matter if things don't turn out exactly right?
7. Am I trying to read other people's minds?

It may be useful to draw out and fill in a thought table like the example shown on the next page. Here we've used examples from real-life situations of people with psoriasis.

Observing, challenging and evaluating our thoughts are not things we normally do. So it may take a while to get used to becoming aware of your thoughts, becoming realistic about them and finding alternative thoughts which will help you manage your mood better. This is quite a skill and, like all skills, it needs practice. So, stick with it and try your best. Sometimes you may feel too upset to write out and deal with your thoughts. If this happens it may be helpful to try out some of the thought distraction techniques described earlier. Even some uplifting music can be a good way of improving your mood.

Psoriasis and your relationships

Psoriasis and family life Usually the person with psoriasis is the one who suffers most. However, sometimes the whole family can feel the psychological distress of psoriasis. Tension can arise for a number of reasons. These include feelings of isolation, rejection, embarrassment and not being understood. To keep family life as happy as possible it is important to:

Communicate: explain how you are feeling. Don't bottle things up as this will only create tension

Think calming thoughts and practise your breathing: even if you feel upset; that's when you need it most. Remember that stress will not only make you and your family feel upset, it can also make your psoriasis worse. Fill in a thought table and try to change those negative thoughts before they get out of hand.

Psoriasis and forming new relationships

Some people with psoriasis report that they feel afraid to enter into new romantic relationships. They actively avoid relationships that may lead to sexual contact. They fear that once the psoriasis is discovered they will be rejected. These fears are often unfounded, as they are usually not based on actual past experience.

To overcome this fear, it is important that you challenge your negative thoughts about forming new relationships. It may be useful to fill out a thought table like the one in the previous section. Instead, if there is someone you are attracted to but are too anxious to approach, then maybe it would be useful to try out some of the relaxation techniques. These may help you to ease this anxiety.

Psoriasis and the early days of a new relationship

When you have begun a new relationship you will probably find that you feel more relaxed and less embarrassed if you tell your partner about your psoriasis. You could start by first telling them you have psoriasis. Then you could show them your psoriasis and explain a few of the facts. If you feel awkward doing this then maybe you could give them some leaflets to read and be ready for some questions that they may have. If your partner has true feelings for you then the psoriasis should not matter. By being honest with your partner you will feel more at ease. Your honesty will also mean that your partner will feel more relaxed and able to ask you questions about your psoriasis and even allay your fears.

Psoriasis and current relationships

People who are already in relationships can also come across problems. Maybe the psoriasis appeared after the relationship began or the psoriasis became more severe during the relationship. Again, you may experience negative thoughts related to rejection. Just as you should with any other life changes, in these situations it is very important to communicate with your partner and explain how you feel.

Psoriasis and sexual relationships

Some individuals may have psoriasis in the groin area and as a result find it painful to have sex. It is important that you prevent any misunderstanding by being honest with your partner. It will then be possible to explore some ways of reducing discomfort.

Males: The skin around the penis is quite delicate, so using a moisturiser with a mild topical steroid will help soothe it and lessen any scaling. Using condoms may make sex less painful. Be aware though that oil-based substances and

ointments will make the condom unsafe. Ask your GP or pharmacist for advice.

If you choose not to use condoms, then applying lubricants before sex may be beneficial. Remember not to have sexual intercourse after applying active treatments. This is because it could affect your partner as they are not intended for internal use.

Females: A good moisturiser will help soften the scaling, making sex less painful. Alternatively, a petroleum jelly-based product may reduce some of the discomfort that you can experience with intimate touching and psoriasis. Remember that oil-based substances make condoms unsafe. Ask your GP or pharmacist for advice.

If sexual intercourse is too painful then there are other ways of showing your loving feelings. Cuddling, stroking and fondling are all good ways of experiencing close intimate contact.

Learning to deal with other people's reactions towards your psoriasis

Many people with psoriasis worry about how to manage other people's reactions towards their skin. Most people you meet may not have encountered anyone with psoriasis before. This may mean that they will take more notice of you. At some point in our lives we have all noticed someone who has an unusual appearance. Maybe you couldn't help but take a longer look at them than normal. That you looked doesn't mean you had cruel intentions or negative thoughts. So don't assume that people who look at you are thinking in this way either. It may be that they haven't even noticed your psoriasis. However, if people are staring at you in a rude manner and/or make comments, there are positive ways you can deal with this.

What you can do if people ask you about your psoriasis

At some point you will be asked about your psoriasis. You can deal with this in several ways.

It may be helpful to develop a brief response, e.g.: "I have a skin condition called psoriasis. Don't worry, it's not a contagious disease – you cannot catch it."

Sometimes you may want to give a more detailed response. This may depend on your mood and who you are with. Remember, most people will be happy with a brief response.

If people don't ask you about your psoriasis then you may wish to mention it yourself. This can help you feel more in control of the situation. Also, if you are out socialising, you may find that you can relax more as you have 'got the psoriasis explanation out of the way'.

What you can do if you notice people staring at you

There is a difference between the kind of looking involved when speaking with someone and the continuous stares that you might encounter. If this happens to you then it is helpful to let the other person know that you are aware of what they're doing and would prefer it to stop.

Direct eye contact, a nod or a smile aimed at the starrer shows that you are aware of them, and also that you are normal. If staring persists then a frown will show your irritation and, usually, embarrass the person into looking away.

In the unlikely event that this doesn't work, you may decide to say something to the starrer, such as: "You may not be aware, but you are staring at me. Please stop" or "I would rather you did not stare at me!" or "Does my skin bother you? It doesn't bother me!" or "Don't worry, it isn't catching!" People don't generally expect such upfront responses and in most cases you'll receive an apology and/or reassurance.

Some days, you will just feel like walking away. However, it is useful for you to have a choice of responses depending on what the situation is. A particular response may even work for you every time.

What you can do if people make comments

Sometimes you may come across people who deliberately make direct rude comments intended for you to hear. As with the staring, the most effective response is to let people know that you are aware of it and that you do not like it. Possibly a firm, confident look will be enough. Also, it's worth remembering that if you look confident in general the comments are less likely to happen in the first place! If you decide to say something you could use the examples below.

"Do I know you?"

"Is that the best you can come up with?"

Remember that a quick, effective comment which you can use in these situations is better than something which is going to start a discussion or, worse still, an argument. Your aim is to have your own selection of responses which you feel comfortable with. It may also be helpful to practise these comments as you come across different situations.

Joining a psoriasis support group

Many people find it helpful to share their experience with other people with psoriasis to provide support, education and information about managing the condition.

Getting a good night's sleep

Some of the physical and psychological symptoms of psoriasis can cause restless or poor sleeping patterns. The following are some suggestions that could help you get to sleep even when you are experiencing psoriasis symptoms.

- Have a relaxing bath before you go to bed and, better still, practise a relaxation technique. Apply your moisturisers when your skin is not completely dry; it may help to soften stubborn hard skin
- Go to bed at the same time each night and rise at the same time each morning. Set a bedtime when you normally get sleepy
- Provide a proper sleeping environment: dark, quiet, and not too hot, cold or humid. Try not to watch TV or use computers in the half-hour leading up to bed as that will send signals to your brain to 'wake up!'
- Avoid substances that interfere with sleep – coffee, tea or fizzy drinks containing caffeine
- Avoid strenuous exercise late in the evening
- Try not to take your worries to bed. If you have something on your mind before or at bedtime, write out a list of things that you need to think about. Now decide a time to think about them the next day. Remember, you won't sort them out at night and you could use this time better by sleeping.

Managing your psoriasis treatments Psoriasis treatments can help to control symptoms and improve quality of life, however some people may find it difficult to use their treatment as prescribed. Psoriasis treatments can be emotionally and practically demanding. Some people may find they lack the time and motivation to use treatments regularly, whilst also managing work, family and social commitments, and other activities important for overall health such as taking regular exercise. Some people may worry about using particular treatments. They may have fears about adverse treatment effects or worry about the loss of effectiveness of their treatment. Some people fear that they may run out of treatment options.

It is important to discuss how you feel about your treatment with your doctor because psoriasis treatment is part of the whole experience of living with psoriasis. It can sometimes feel difficult to be open about your treatment concerns and worries, however most doctors will be understanding and will help you find potential solutions. Before your appointment, it may help to think about the sorts of things that interfere with you being able to use your psoriasis treatment. Writing down some notes and bringing these with you to your appointment may help you to remember what you want to discuss with your doctor. Some more examples of how to discuss your psoriasis and treatment with your doctor are provided below.

Seeking help from your doctor

You may feel awkward speaking to your doctor or a healthcare professional about how you feel about your psoriasis and treatment. Perhaps you think that the doctor's time is precious and should not be wasted. Or maybe you feel that the doctor may not be interested in your worries. The following points should help you overcome this problem.

- Before the appointment, think about the concerns you have and plan the questions you want to ask
- Write down some notes to help you remember what you want to find out. Doing this will give you much more confidence when you ask
- Try to be clear and specific about what you want, or what is worrying you. This will make it easier for the doctor to answer fully
- If you don't feel comfortable asking questions you could take a friend or relative with you to ask questions for you. This person can also help you understand and remember the answers
- Your doctor may suggest talking to a counsellor or professional psychologist; many people find this helpful, so it's worth considering.

You might come away from the appointment feeling that it was less helpful than you had hoped. If this happens or if you disagreed with what was said, then you could consider getting a second opinion. Most doctors and healthcare professionals should be very understanding about this.

Can I get financial support?

Many people worry about what happens if they cannot work or need financial help because of the effects of their condition. Fortunately for many, with good therapy and management their condition can be controlled and allow for a full and active working life. But if you find that, even for a short period of time, you are likely to need help, visit www.gov.uk and search for '**financial support**'.

Are there any self-help programmes?

Yes, PAPAA funded a research programme with the University of Manchester to develop a cognitive behavioural therapy (CBT) programme. That research led to the development of an online self-help activity called Electronic Targeted Intervention for Psoriasis – eTIPs, which is available free to access at www.papaa.org/cbt

Useful contacts

For information about health matters in general and how to access services in the UK, the following websites provide national and local information.

- NHS UK: www.nhs.uk
- NHS England www.england.nhs.uk/

- NHS Scotland: www.scot.nhs.uk/
- Health in Wales: www.wales.nhs.uk
- HSCNI Services (Northern Ireland): <http://online.hscni.net>

These sites are the official sites for the National Health Service and provide links and signposting services to recognised organisations and charities.

About this information

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Please be aware that research and development of treatments is ongoing. For the latest information or any amendments to this material, visit our website. The site contains information on treatments and includes patient experiences and case histories.

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