

Living with psoriasis: How are you coping?

This leaflet introduces some suggestions and ideas from Acceptance and Commitment Therapy – a type of therapy proven to be effective in helping people to live well with other chronic conditions. If you have any further questions, please speak to a doctor or nurse caring for you.

Psoriasis can be difficult to live with. As well as the physical aspects of the condition, it can also be emotionally tough to cope with.

- Not being able to predict flare-ups
- Being stared at
- Physical discomfort
- People assuming it's contagious
- Trying to manage it.

These are just some of the difficulties that people with psoriasis have described. The good news is that there are ways of dealing with the difficult emotions that psoriasis can bring. There are a number of ideas and perspectives in this leaflet – see if any are helpful for you.

How could this leaflet help me?

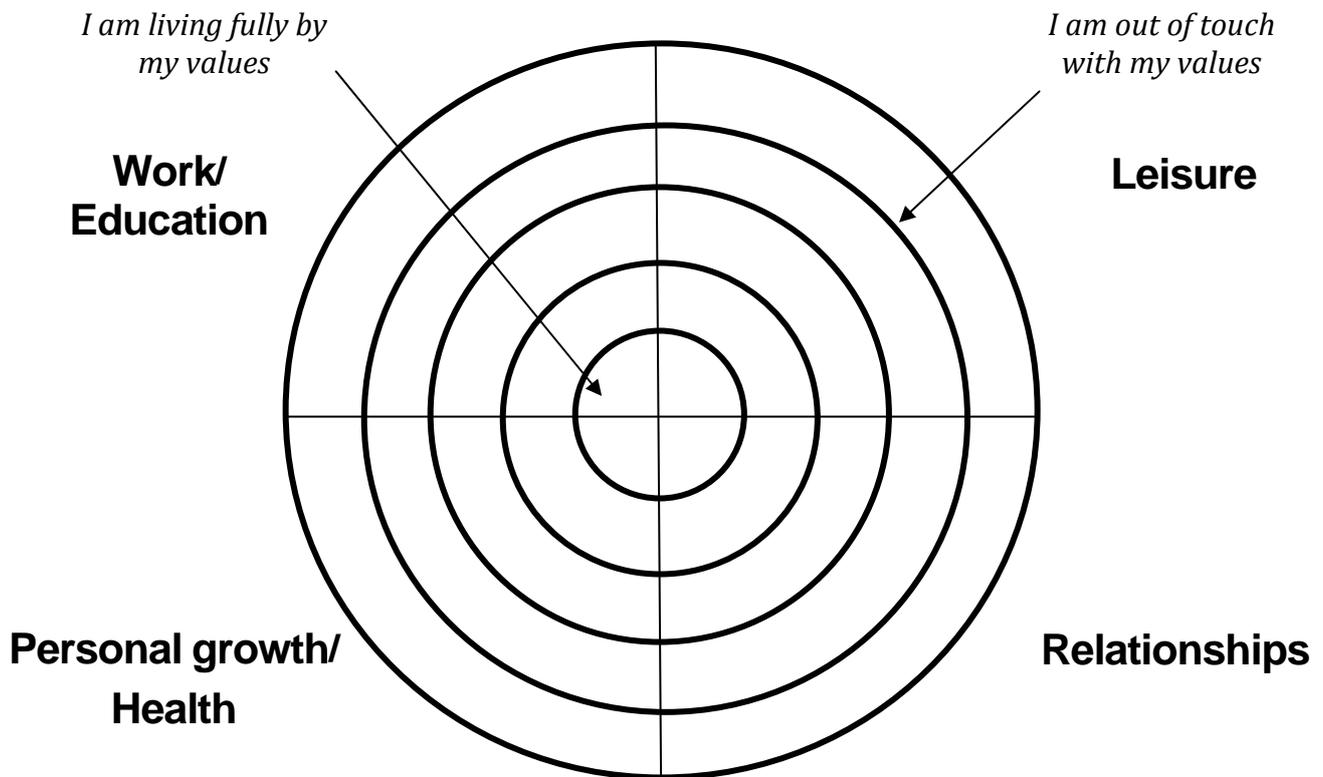
Acceptance and Commitment Therapy is about accepting the things that can not be changed, while still carrying on with your life. It involves continuing to follow your goals even if you are feeling tired, depressed or anxious, and even if your psoriasis is bad.

What do you value?

In order to live the life you want, getting a clear idea of what you value in your life is vital. Some people might value their career over everything, others might be really committed to seeing themselves as a sociable person, or others might value their family life. There are many different things we value about our lives, such as work and leisure, health, spiritual fulfilment and our relationships. What is important to you?



Look at the bull's eye below. In each section, put a cross where you think you are, marking the cross in the centre of the bull's eye if it is totally in touch with your values, and further outside if you are out of touch with your values.



Lundgren Bulls' Eye exercise revised by Russ Harris

Which areas of your life do you feel you are living according to your values?
Which areas are neglected?

What gets in the way of us living according to our values?

Your mind is probably brilliant at worrying and finding problems. Everyone feels worried or down from time to time, and most of us try to fight these natural feelings. However, we can actually cause ourselves more problems in this way – removing ourselves even further from the life we really want.

It is perfectly normal to have periods of feeling unhappy, stressed or worried about things, and having psoriasis probably adds to this. Your mind may constantly return to thoughts about your psoriasis, and this may trigger feelings of hopelessness, frustration, and desperation. These thoughts can often divert us away from what we really value in our lives, so it is important that we don't allow them to take over.

How do you cope with difficult feelings and thoughts relating to the psoriasis?

In order to work out how you normally cope, tick the box next to the strategies you have tried. You might want to add your own to the end of the list.

- I try to push unpleasant thoughts out of my mind
- I avoid difficult situations, for example, by not going out or by covering up
- I try to make my thoughts more rational
- I distract myself with other activities, TV, reading, games, music, hobbies
- I use alcohol or drugs to escape the worry and low mood
- I talk to friends or families about my worries
- I

Some of these strategies might be helpful for you, but if you rely on them too much, this may get you stuck in a routine that may not be the best way of dealing with the situation you are in. Looking at the strategies you ticked above, decide which of them get you closer to the life you want to live and which take you further away from it.

Take Emma as an example. She values her friendships and also loves to go out. But she worries what people will say about her psoriasis. To cope with this stress she has started to avoid going out. This means she does not have to face the worry. Because she has chosen this way of dealing with her worry, she sees her friends less now and leaves the house less often. She is further from the life she values and is less happy because of it.

Controlling your thoughts may not work in the long term

Struggling against these natural worries or anxieties might not help you. Firstly, it is unlikely to work in the long term – trying not to think a certain thought just tends to make it stronger. Secondly, trying to control thoughts or feelings is exhausting! It is like trying to hold your breath – you can do it for a while but takes a lot of effort. If you are stuck in struggle-mode, a change in approach might help.

Try this one minute exercise

Find a place where you can be still. Sit comfortably in an upright position with your back supported. You can close your eyes if you want.

Bring your attention to your breathing. Notice the breath entering and leaving your body. When thoughts distract you (and they will), simply notice the thought, then gently return your attention to your breathing.

Try to keep your attention focused on your breathing for one whole minute.

Thoughts are just thoughts

In the previous exercise you might have noticed that thoughts kept coming into your mind and distracting you from your breathing. This is normal! You are starting to observe thoughts as being separate from you. However powerful or painful they may be, thoughts are just thoughts – creations of your busy brain. Some may be false, some may be true, but the most important question about each thought is: is this helping me? Will it help me live my life and achieve my goals?

Emma might have the thought: "someone will see my skin and say something nasty if I go out tonight". It is only a thought – nothing has happened. But if she takes it seriously, the thought may stop her from doing what she really wants to do and from achieving the social life that she really values.

Your mind: the great story teller

Your mind will have its favourite stories about you that it tells you often. Sometimes it tells you negative stories about being a failure or everybody looking at your skin. When your mind gives you one of these stories, think about giving it a name and greeting it. For example, welcome it, call it the 'I'm a loser story'. Notice it but do not struggle to push it away. Try to be aware of it while getting on with doing things that you value.

Making peace with your thoughts and emotions

Trying to avoid difficult emotions may be the problem, not the solution. It may take us further away from our values. Sometimes making space for feelings, rather than fighting them or struggling against them, can help us stay on track with our important life goals. The alternative to struggling is to accept them and find a sense of peace with the psoriasis. This does not mean admitting defeat. It means that you can stop struggling.

Think of a man falling into a patch of quicksand. The more he struggles and flails around, the quicker he sinks. Lying on the surface is the best option, although often it goes against our instincts. Not struggling to push away difficult emotions but staying with them is hard, but it may be a better strategy.

How can I make peace with difficult thoughts?

It can be difficult to make peace with difficult thoughts, but with practice, these exercises may help you to step back from the thoughts. Once we see that thoughts are just words in our heads, and not necessarily important, we do not have to take them so seriously or obey them. Here are some ways that you can approach these thoughts.

Step back from the thought

Focus on the upsetting thought, for example, 'They'll think I'm a freak' and think about how it makes you feel. Then add 'I am having the thought that...' in front of the thought to make the sentence 'I am having the thought that they'll think I'm a freak'. Focus on that and see if anything happens. Then try adding 'I notice...' to the beginning of the last thought to make the sentence 'I notice I'm having the thought that they'll think I'm a freak'. Does this help to distance you from the original thought?

Ridicule the thought

Try repeating the thought several times in silly voices, like Donald Duck or Homer Simpson, or singing it in your head to a silly tune.

Observe the thought

Try to visualise the thought and emotion it brings – what does it look like? What colour? What shape? Where is it in your body? Examine it objectively – like a scientist.

Practice mindfulness

Because our minds are so often stuck thinking about the past or the future, we often do not fully experience the present. Mindfulness is the art of noticing and accepting the world around us, including our own thoughts and feelings. Connecting with the present moment helps us to step outside our thoughts.

Body scan exercise

This exercise will help you to connect with your body in the present moment, and to become more aware of your physical surroundings. In turn, this may help you to feel less stressed and less caught up in unhelpful thoughts.

Find a comfortable sitting or lying position. Close your eyes and focus on your breathing, taking slow, deep breaths.

After a while, gently bring your attention to your body, starting with your feet. Notice how they feel, what is touching them, whether you can feel any air movement around them. Imagine breathing into them. On the out-breath, imagine any tension flowing out of them.

Move up your body, bit by bit. Spend a few minutes on each section of your body, connecting with each part of your body, before releasing it and moving on. Focus on your legs, bottom, back and stomach, chest, hands and arms, finally ending with your head and face.

Taking it forward

This is a chance to consider what you would like to change about how you live your life, and how you could change it. In setting goals, try to make them SMART: specific, measurable, achievable, realistic and time-limited. Also, try to set goals that fit with your values, as listed on the second page of this leaflet.

Goal	Date made	Date achieved
1		
2		
3		

Tips for achieving your goals

- Think small, specific and achievable. Not, 'I will build a fantastic social life', but rather, 'I will go out with friends on Tuesday and stay for 30 minutes'.
- Don't be put off by thinking 'I can't do it'. Instead, just try to observe your mind's thoughts using techniques on page 4 and do it anyway.
- Be prepared to face your fear. Change is scary. This is a balance between how much you want to change against the amount of emotion that you are willing to feel.
- Note down thoughts that might stop you from achieving your goals:

- Note down emotions that might stop you from achieving your goals:

As you step towards your goal, mindfully notice these thoughts/ emotions as they come up without allowing them to stop you. Live a life you value.

Contact us

If you have any questions, please contact your clinical nurse specialist (CNS) using the details given on your CNS contact card and/or medicine booklet. These details can also be found at the top of your clinic letter. Another option is to speak with your GP.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) e: pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) e: complaints2@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 e: languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

t: 0800 731 0319 e: members@gstt.nhs.uk w: www.guysandstthomas.nhs.uk/membership

Leaflet number: 3743/VER2

Date published: August 2016

Review date: August 2019

© 2016 Guy's and St Thomas' NHS Foundation Trust