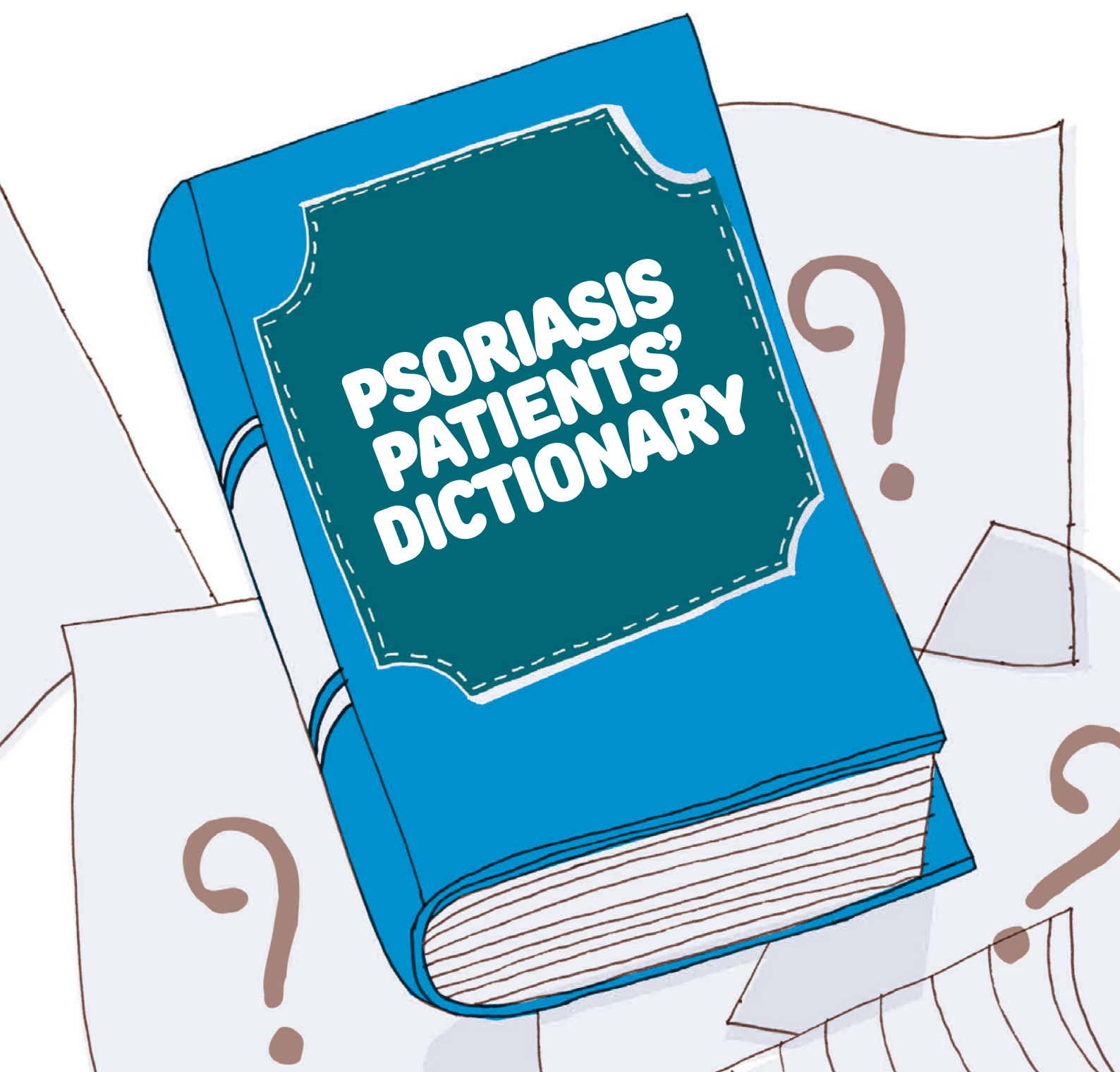


PSORIASIS DICTIONARY FOR PATIENTS

Your guide to help you when speaking to your doctor



FINDING THE RIGHT WORDS

Psoriasis may have already affected aspects of your life but remember that you and your doctor are partners in managing your psoriasis. There is plenty of support available to help you maintain a good quality of life. Perhaps you have felt rushed or left the doctor’s office realising you haven’t discussed something that is important to you. Next time you visit your doctor, share your story and have an honest conversation about how psoriasis affects your daily life.

Finding the right words to describe your symptoms can be difficult; if you can describe your real-life experiences this can help your doctor understand exactly what you are facing, especially when the doctor’s time is limited. This dictionary will prepare you for conversations with your doctor about the care you need to live the life you wish for and deserve.

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IT'S HARD TO GIVE YOUR DOCTOR THE FULL PICTURE ABOUT WHAT'S GOING ON WITH YOUR PSORIASIS.

BEFORE YOU GO TO YOUR DOCTOR

Only you know how psoriasis affects what you do and how you feel. The more information you share with your doctor the better they can partner with you to manage your psoriasis. Answer the questions below before your next doctor's visit and refer to them during the visit to help you have a better conversation about your psoriasis.

1. How often has itch bothered you?

Never☐ Sometimes☐ Often☐ Very often☐

2. How often do you experience skin pain?

Never☐ Sometimes☐ Often☐ Very often☐

3. How often are you worried by the appearance of your skin?

Never☐ Sometimes☐ Often☐ Very often☐

4. How often do you have swollen or stiff joints when you wake up?

Never☐ Sometimes☐ Often☐ Very often☐

5. How often do you experience lower back pain in the morning that goes away once you get moving?

Never☐ Sometimes☐ Often☐ Very often☐

6. How often is your sleep disturbed by psoriasis?

Never☐ Sometimes☐ Often☐ Very often☐

7. How often do you wake up in the morning experiencing sadness?

Never☐ Sometimes☐ Often☐ Very often☐

8. How much impact does psoriasis have on your daily activities?
(for example, swimming, going to the hairdressers, lying on a beach)

No impact☐ Moderate impact☐ More impact than I would like☐ Severe impact☐

9. How much impact does psoriasis have on your relationships and sex life?

No impact☐ Moderate impact☐ More impact than I would like☐ Severe impact☐

10. How much impact does psoriasis have on your social interactions?
(for example, hugging people, shaking people's hands, dating)

No impact☐ Moderate impact☐ More impact than I would like☐ Severe impact☐

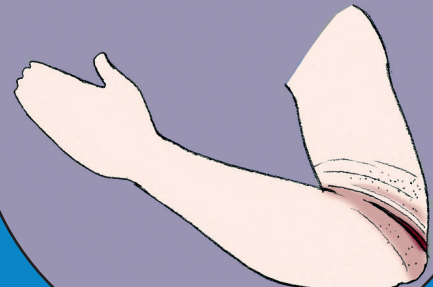
Some important topics to discuss
If you have answered 'Often/Very often' or 'More impact than I would like/Severe impact', list the question topic below and make sure you discuss it with your doctor

SYMPTOMS OVERVIEW

Low self esteem,
social stigma,
isolation



Cracks/bleeding
around joints



Flaking
and bumps
containing
fluid/pus



Psychological effects,
occasional sadness, stress,
embarrassment, anger
and frustration



Nails pitted,
discoloured or
unusual growth



Missed work days
or unemployment

Less
socializing



Joint
discomfort,
swelling,
stiffness or
throbbing



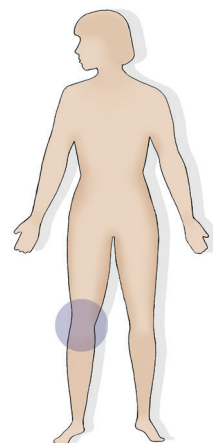
Disturbed
sleep



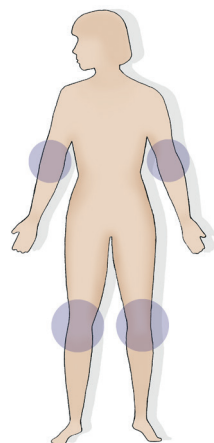
Painful and
small bumps
with fluid/pus
Red/tender skin



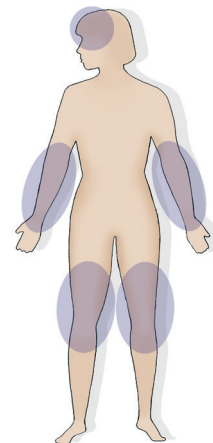
MILD



MODERATE



SEVERE



Dry, red
skin patches
covered in
silver scales



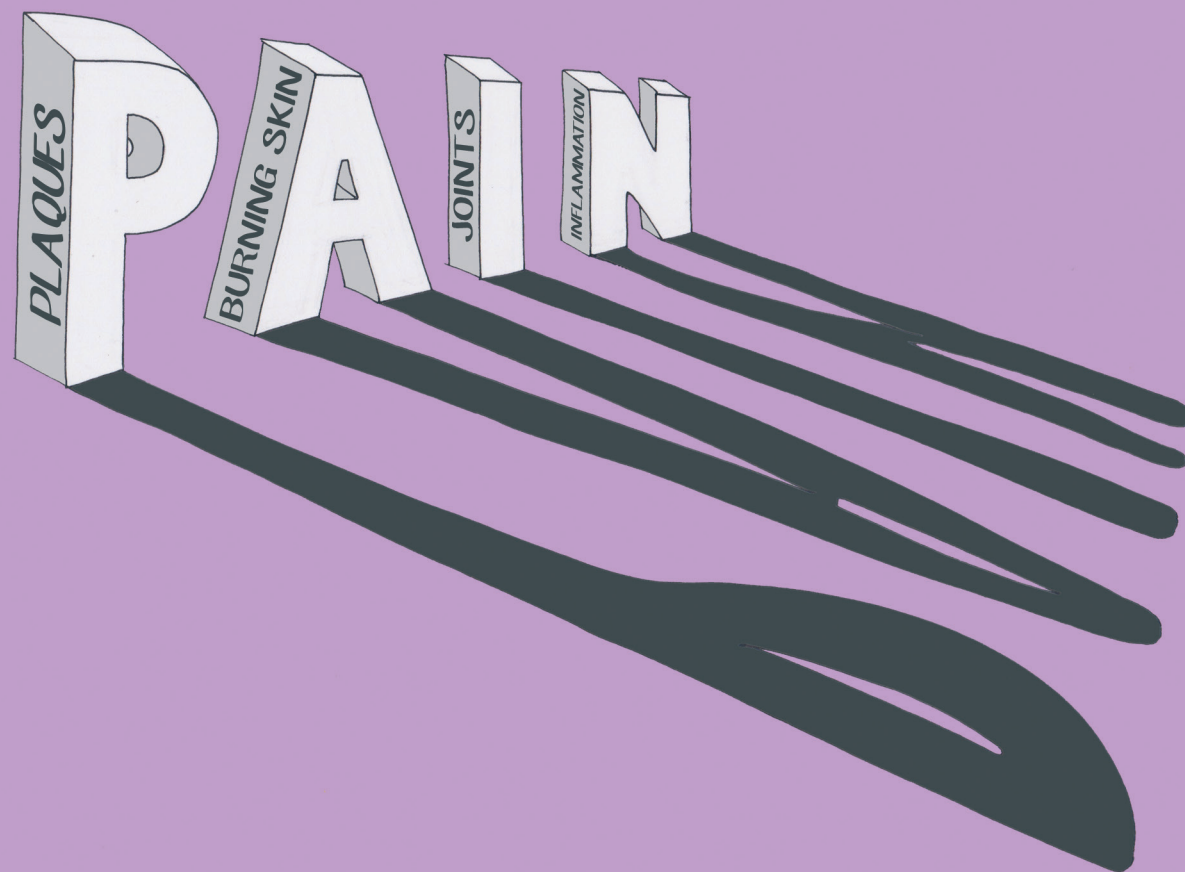
Disturbed
sleep



Temporary
hair loss



PAIN IS ALWAYS THERE. PSORIASIS IS PART OF MY LIFE. IT'S SOMETHING I LIVE WITH, EVERY MINUTE OF EVERY DAY.



PAIN



A DOCTOR SAYS...

"Painful plaques"

"Painful inflammation during a flare"

"Tender and painful skin"

"Joint pain"



A PATIENT SAYS...

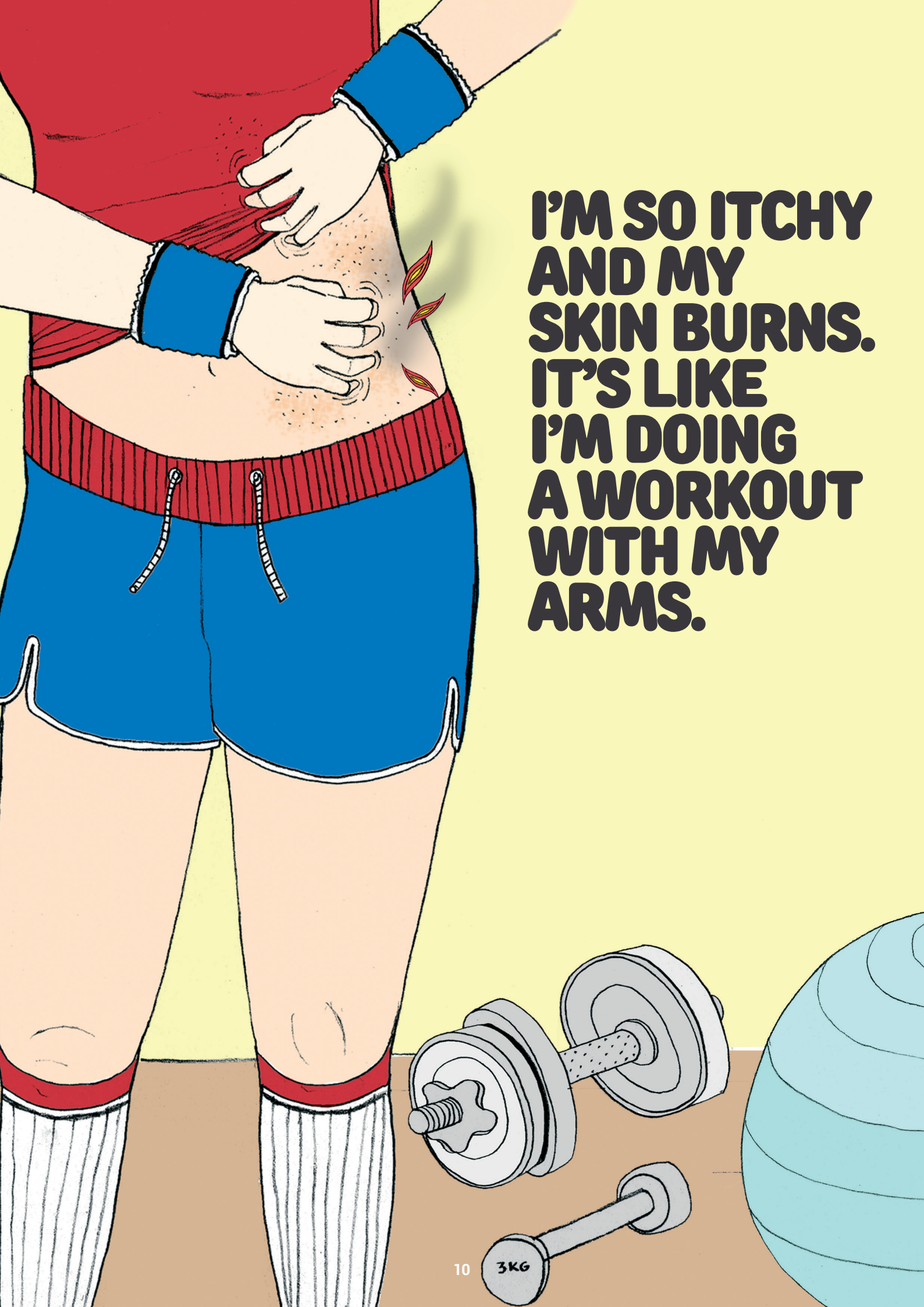
"Stinging and throbbing skin"

"Red, sore skin that feels like it's burning"

"Aching skin"

PAIN – MEANING

A very unpleasant body sensation caused by illness or injury. You may find your psoriasis very painful and this may mean you have severe psoriasis.



**I'M SO ITCHY
AND MY
SKIN BURNS.
IT'S LIKE
I'M DOING
A WORKOUT
WITH MY
ARMS.**

ITCH



A DOCTOR SAYS...

- "Pruritus"
- "Itch"
- "Intense, distracting irritation"



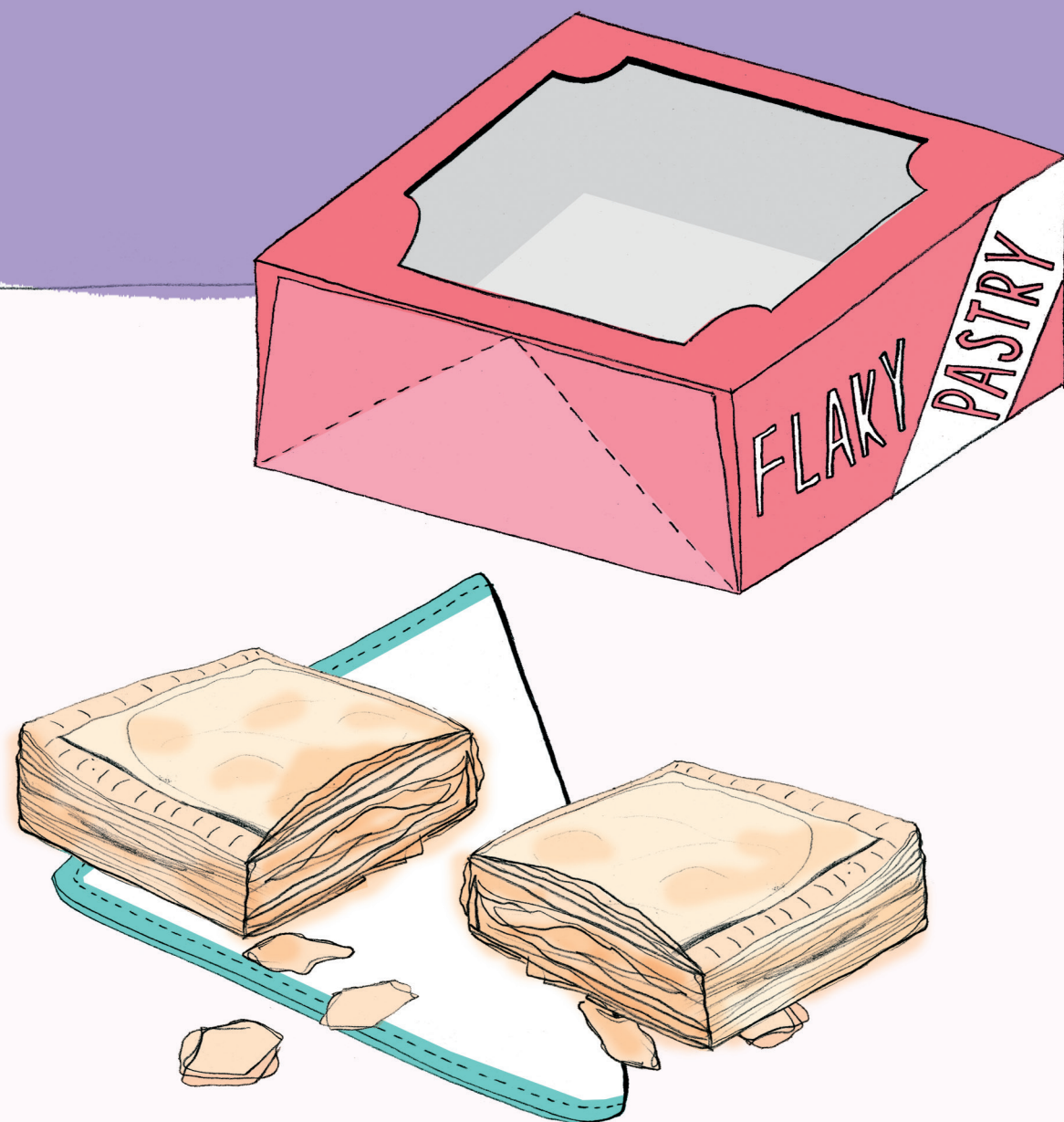
A PATIENT SAYS...

- "Like having mosquito bites everywhere"
- "Scratching makes my skin flake off and bleed"
- "Tingling like being pricked with a bunch of needles"

ITCH – MEANING

An unpleasant sensation that causes you to scratch the affected area. You may experience a lot of itching and this can mean that you have severe psoriasis.

**IF MY SKIN WAS A
TYPE OF PASTRY,
IT WOULD BE FLAKY.**



SKIN FLAKING/CRACKING



A DOCTOR SAYS...

"Cracks"

"Flaking"

"Desquamation"



A PATIENT SAYS...

"Flaking skin"

"Everyone knows where you have been – they follow the flakes"

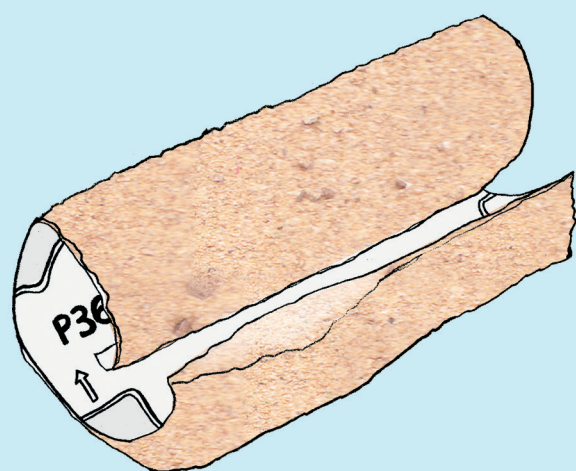
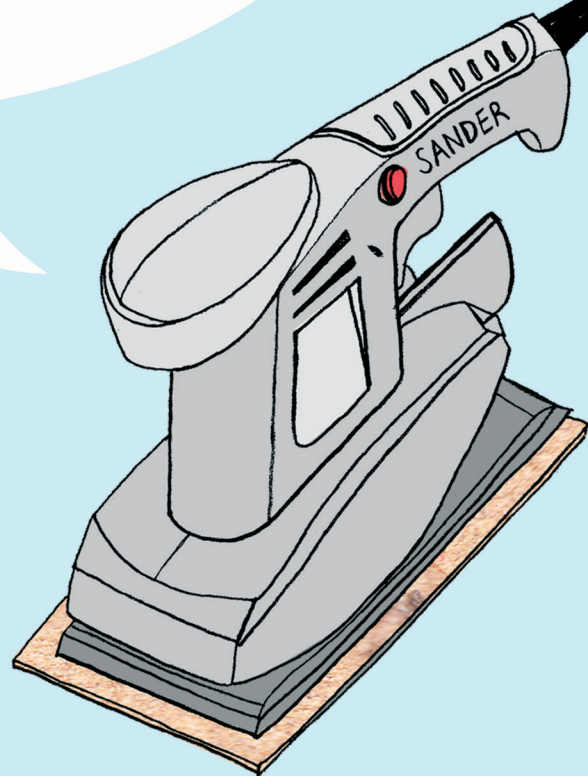
"Skin piling up like tiny snow drifts"

SKIN FLAKING/CRACKING – MEANING

Skin that dries out and begins to peel away in small thin bits (flakes).

When the skin becomes rough and flaky, small tears in it (cracks) can go deeper into the skin layers.

**MY NAILS
FEEL BUMPY, LIKE
SANDPAPER.**



NAIL PITTING



A DOCTOR SAYS..

“Depressions in the surface of the nail”

“Pitted nails”

“Onychosis”

“Irregular nail surface”



A PATIENT SAYS...

“Small dents on the nails”


“Small pinprick holes on the nails”

“Grooves on the nails”

NAIL PITTING – MEANING

One or many small pits appearing on the surface of the nail.

You may experience nail pitting as a mild-moderate symptom of psoriasis.



**I WANT
PEOPLE
TO SAY
'NICE SCARF',
NOT 'WHAT'S
WRONG
WITH YOU?'**

FEELING ANXIOUS IN SOCIAL SITUATIONS



A DOCTOR SAYS...

"Social anxiety"

"Social phobia"

"Excessive nerves"



A PATIENT SAYS...

"People are looking and are bound to notice my skin"

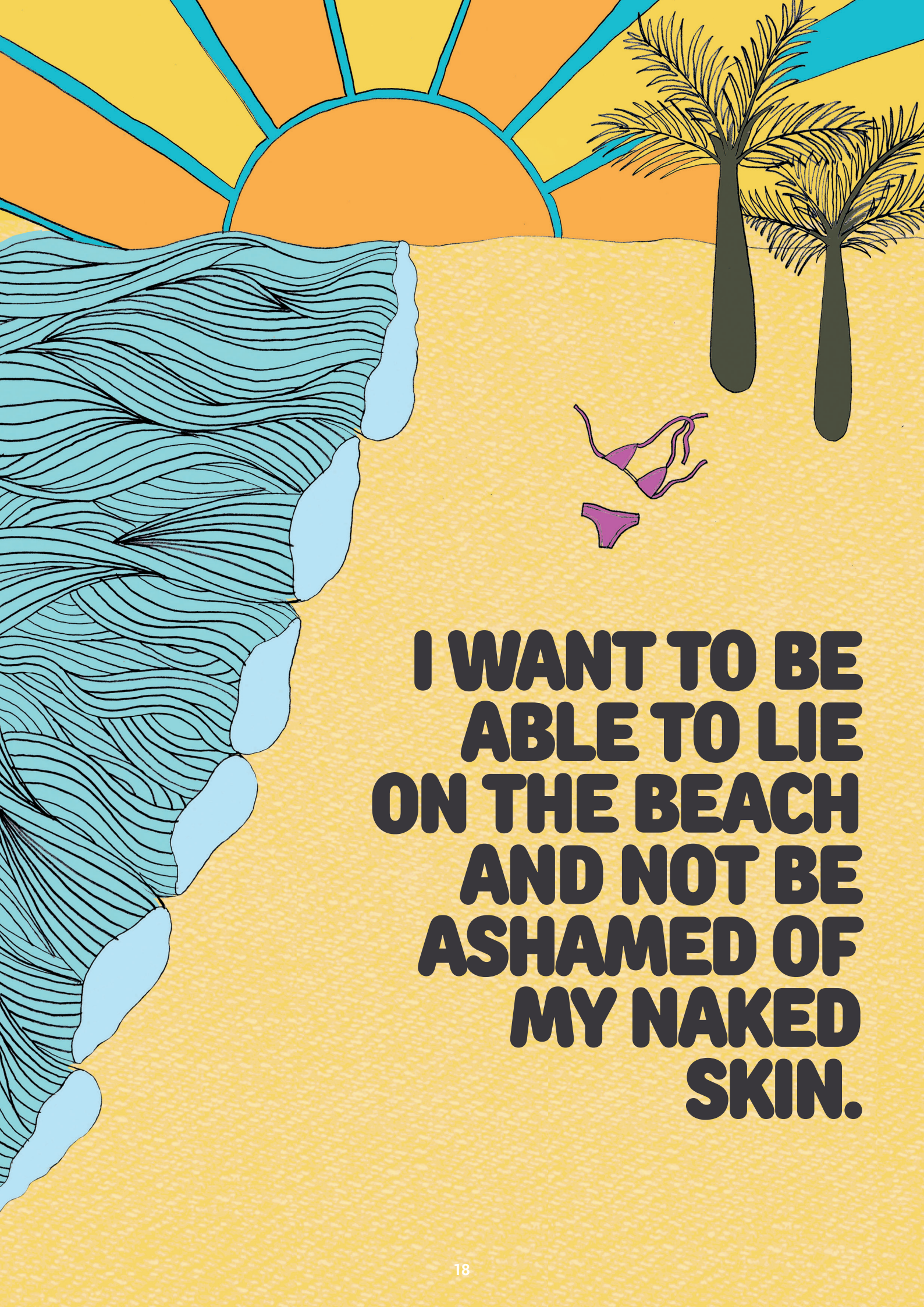
"I feel like I am being judged by people"

"Psoriasis is not contagious but people think it is"

FEELING ANXIOUS – MEANING

Feelings of worry or concern that occur around social situations such as meeting new people or dating.

When you feel embarrassed and anxious and think others will judge you or treat you unkindly.



**I WANT TO BE
ABLE TO LIE
ON THE BEACH
AND NOT BE
ASHAMED OF
MY NAKED
SKIN.**

MISSING SOCIAL ACTIVITIES



A DOCTOR SAYS...

“Social phobia”

“Intense nervousness
in public”

“Self-conscious”



A PATIENT SAYS...

“My life is so different now;
I just want to cover up”

“I feel ashamed about my
skin in public so don’t go
out much”

“Once my friends and
family found out about my
condition, they gradually
distanced themselves”

MISSING SOCIAL ACTIVITIES – MEANING

Feeling the need to hide your condition by staying away from social activities like sport, going to the hairdressers, going out to dinner with friends and forming new relationships.

You may have low self-confidence and poor self-image because of your psoriasis.

**WHEN I
SAY I'M FINE,
MY BACK
ACTUALLY
STILL HURTS.**

JOINT AND BACK PAIN AND STIFFNESS



A DOCTOR SAYS...

- "Arthralgia"
- "Psoriatic arthritis"
- "Lower back pain"
- "Inflamed, tender joints"



A PATIENT SAYS...

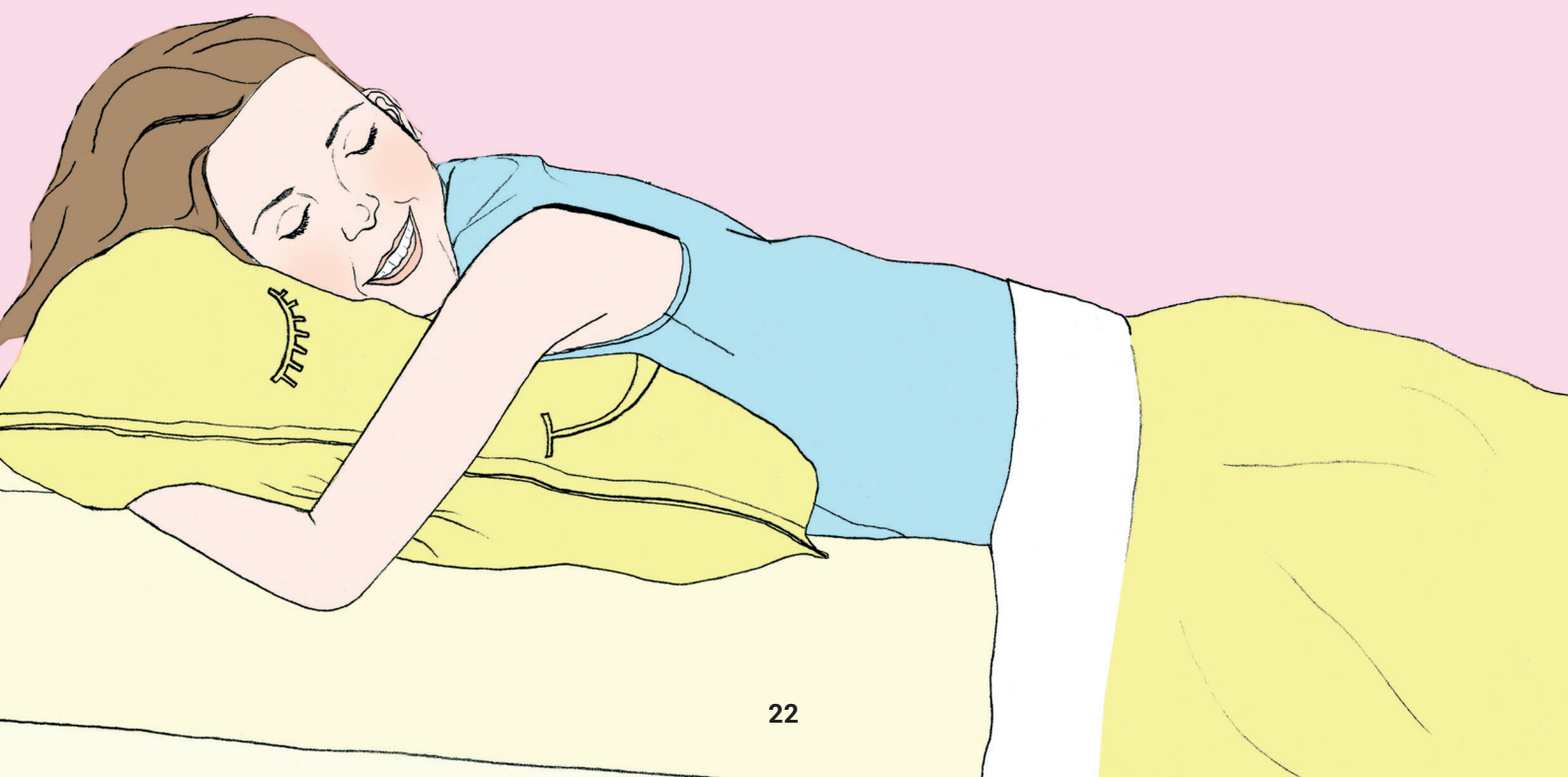
- "I wake up with stiff joints in the morning"
- "I wake up feeling tired and stiff"
- "It takes me a while to get moving sometimes – mostly in the morning"

JOINT AND BACK PAIN AND STIFFNESS – MEANING

Having difficulty moving your joints or back, losing some range of motion. Often there is also pain and swelling.

You may want to move but it is painful and it may take you some time to 'warm-up'.

**I WISH MY PILLOW
WAS MY FRIEND;
I'D LOVE TO WAKE UP
FEELING ALERT.**



DISTURBED SLEEP



A DOCTOR SAYS...

"Insomnia"

"Disturbed sleep pattern"

"Sleep deprivation"

"Fragmented sleep"



A PATIENT SAYS...

"Itching becomes a nightmare when I go to bed; it stops me getting to sleep for hours"

"I have a bad time trying to sleep with this horrible itch"

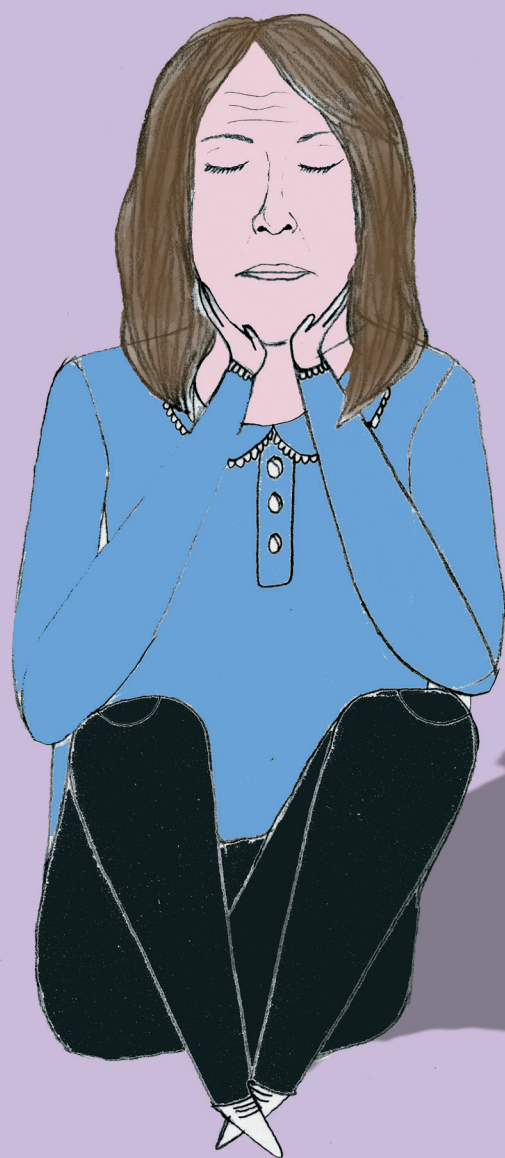
"I just want a decent night's sleep"

DISTURBED SLEEP – MEANING

Difficulty getting to sleep and feeling unrefreshed. Waking up often during the night and having trouble going back to sleep.

You may have a lack of sleep because of your itch symptoms.

**EVEN IF YOU HAVE
CLEAR SKIN, YOU STILL
SUFFER FROM SADNESS
BECAUSE YOU ALWAYS
FEAR THE PSORIASIS
WILL COME BACK.**



FEELING SAD



A DOCTOR SAYS...

"Feeling down"

"Low mood and energy"

"Stress"

"Mood disorder"

"Sadness"



A PATIENT SAYS...

"I'm often silent but
am screaming inside"

"I can't just wake up
one day and be happy"

"I miss the old me"

FEELING SAD – MEANING

Feeling down, unhappy and gloomy.

Not upbeat and optimistic about the future.

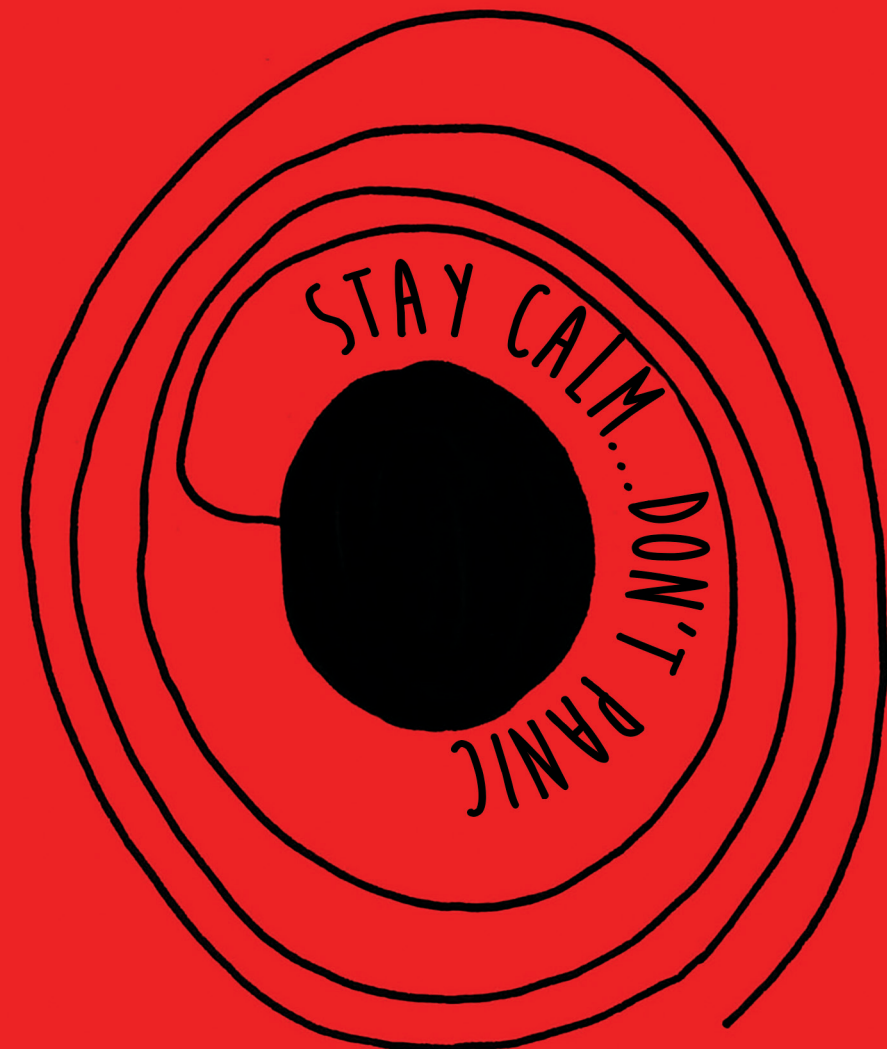
**FLAKING IS VERY EMBARRASSING;
I AVOID DARK CLOTHES
SO THAT NO-ONE CAN SEE
HOW BAD IT IS.**



**I FIND IT HARD TO HAVE
CLOSE INTIMATE CONTACT
WITH OTHERS. I AM
ALWAYS WORRYING ABOUT
HOW I LOOK AND BEING
STARED AT FOR ALL THE
WRONG REASONS.**



**WHEN DOCTORS DESCRIBE
THE CONDITION, I START TO HAVE
NEGATIVE THOUGHTS AND GET
STRESSED FOR NO REASON.**



**I WANT TO STAY CALM BUT
I BEGIN TO PANIC ABOUT
WHAT MAY LIE AHEAD.**



**THERE ARE DAYS WHEN I
JUST WANT TO HIDE FROM
THE WORLD, BUT SOME
PSORIASIS SUPPORT GROUPS
ARE HELPING ME COME
OUT OF MY SHELL.**



ACKNOWLEDGMENTS

This dictionary was co-created with patient groups in Europe and Drs Anthony Bewley and Curdin Conrad. We appreciate their vital contribution and thank them for their ongoing collaboration in making this project a success.

EUR[•]O[•]PSO

ASK YOUR DERMATOLOGIST FOR A GET- TOGETHER.

ASK FOR CLEAR SKIN.

**If you are affected
by psoriasis, go and talk
to your dermatologist.**

Thanks to advances in dermatology, more people are taking back cuddles and kisses, short sleeves and nights out. And with one question, so could you.

Ask your dermatologist for clear skin today.

