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About Psoriasis Uncovered New Zealand 2011*

Psoriasis Uncovered was a joint initiative between Psoriasis Association Southland and AbbVie to assess the impact of living with psoriasis in New Zealand. Its aim was to understand and document the needs of people with psoriasis and improve awareness and understanding of one of the most common skin conditions in the world. The Psoriasis Uncovered survey was based on a sample size of 308 participants who completed an anonymous questionnaire either on paper or online over an eight-week period (31st October 2011 – 16th December 2011). People living with psoriasis in New Zealand were invited to participate in the survey via information available in dermatology clinics, the Southland Psoriasis Association, a link on the DermNet website, and advertisements in metro newspapers.

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Disclaimer: Some photographs and models used in this booklet are for illustrative purposes only and are not psoriasis sufferers. This booklet has been independently developed and produced by Psoriasis Association Southland with an educational grant provided by AbbVie.

Psoriasis: More than a skin thing

YOUR GUIDE FOR LIVING WITH PLAQUE PSORIASIS

3



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Psoriasis Association Southland is the main support network for people in New Zealand affected by psoriasis and psoriasis-related conditions.

About Psoriasis Association Southland

Psoriasis Association Southland aims to:

- Educate sufferers, their families and the public about psoriasis and its treatments
- Support sufferers and their families
- Distribute new information and research results
- Establish regional support groups
- Encourage research into new treatments and potential cures.

To support these aims, Psoriasis Association Southland fundraises at the local level and maintains contact with government departments, health authorities, pharmaceutical companies and psoriasis support groups worldwide.

We welcome your involvement with Psoriasis Association Southland and encourage you to consider membership.

For more information, please visit www.psoriasis.org.nz

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Foreword from Patricia Officer Young

President, Psoriasis Association Southland



This booklet is the third in a series developed by Psoriasis Association Southland in partnership with AbbVie to mark the 35th anniversary of Psoriasis Association Southland.

Booklet three, Psoriasis: More than a skin thing, provides information, tips and facts about living with psoriasis and associated conditions in New Zealand.

We encourage you to review the set of three easy-to-read booklets on plaque psoriasis. We trust the information provided assists you in your journey with the management and treatment of your psoriasis.

The three booklets are available from Psoriasis Association Southland and can be downloaded for free from the Psoriasis Association Southland website: www.psoriasis.org.nz.

How might I expect my psoriasis to make me feel?

The impact of psoriasis is more than just skin deep. Due to the long-term and visual nature of psoriasis, it can have profound emotional, social and psychological consequences for your life. It is critical that you are aware of these potential problems, to help you prepare for and tackle them.

It is completely normal to experience strong emotional reactions to having psoriasis, particularly during flare-ups. You may feel:



Fast facts: Emotions

94%

of New Zealanders surveyed with psoriasis suffer from embarrassment because of their condition.*

77%

of New Zealanders surveyed with psoriasis hide it from other people.*

94%

of New Zealanders surveyed who hide their psoriasis worry about the general public's reaction, fearing judgement (43%) and discrimination (33%).*

* From Psoriasis Uncovered 2011 - a survey of 308 New Zealanders with psoriasis¹

My psoriasis extended over my face and scalp. I suffered from low self-esteem. I went to great lengths to hide my condition; from family, friends, my wife and employees – I even hid it from myself, refusing to look in mirrors unless I had to. I found it limited my job choice and I now work with animals, away from members of the general public. I threw myself into keeping fit and kept myself on a strict regime. I'm now on medication which has brought it under control, but I also strongly believe in the benefits of lifestyle, such as meditation, relaxation and minimising stress.

IAIN, 43, PSORIASIS SUFFERER, COROMANDEL





I was diagnosed officially at 16, when I started to suffer from Psoriatic Arthritis and movement became painful in addition to my skin problem. I couldn't play sport or socialise like an average teenage boy and was in fact near housebound for close to a decade. I had psoriasis for so long that I developed a habit of not wearing shorts or singlets in public; I was always covered up.

GRAHAM, 30, PSORIASIS SUFFERER, KERIKERI

What difficulties might I experience within my relationships?

You may have problems relating to other people because of misunderstandings surrounding your condition. You may feel like hiding your condition, due to embarrassment or a fear of having to explain or talk about it. Sexual relationships and intimacy may also suffer.

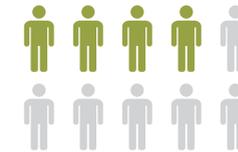
68%



CONCEALMENT

Of those New Zealanders surveyed who hide their psoriasis, two thirds (68%) hide it from friends, including close friends (33%), and a significant number even hide it from their partner (18%) and children (25%).*

38%



MISUNDERSTANDING

More than a third (38%) of the New Zealanders with psoriasis surveyed believed that their condition is not understood at all by the general public and the media.*

46%



COMMUNICATION DIFFICULTIES

Nearly half (46%) of New Zealanders surveyed who hide their psoriasis just don't want to talk about it.*

* From Psoriasis Uncovered 2011 - a survey of 308 New Zealanders with psoriasis¹



How might my psoriasis impact on my daily life?

Embarrassment due to your psoriasis may cause you to avoid certain activities such as swimming, sunbathing, playing sport or visiting the hairdresser.^{2,3} It may even make people feel unable to leave their homes.³

The physical pain and itching of psoriasis may keep you awake at night or disturb your sleep. This will have obvious consequences for your general vitality and feeling of well-being.⁴



Regardless of who I am with, I am always conscious of it, covering it up and worrying about scales and scratching. I fill the census in saying I have a social disability. It does affect the way I interact with people.

**HEATHER, 59, PSORIASIS SUFFERER,
CENTRAL NORTH ISLAND**

How might my work or career be affected?

Psoriasis may also affect your work and career, potentially limiting opportunities, influencing career choice, causing prejudice and interpersonal problems in the workplace and contributing to people losing their jobs or being turned down for posts.^{2,5}

66%



Two thirds (66%) of New Zealanders surveyed who conceal their psoriasis hide it from work colleagues and almost half (49%) hide it from their employer.*

19%



Nearly one in every five (19%) New Zealanders surveyed with psoriasis have not sought a particular job or area of work due to their condition, mainly because they are concerned about being able to cover up and also for hygiene reasons.*

\$1700



Of those New Zealanders surveyed with psoriasis who report lost wages due to their condition, the amount is significant — an estimated average of more than \$1,700 per year.*

* From Psoriasis Uncovered 2011 - a survey of 308 New Zealanders with psoriasis¹

Will I be able to cope?

Yes! There are several things you can do to minimise the impact of your psoriasis on your emotions, relationships, daily activities and work, and to help make life easier.

1

- Enlist support and encouragement from family, friends and colleagues.
- Try not to hide your psoriasis as it can cause you to feel isolated.
- Be honest and open about your feelings – it can help strengthen your close relationships.

2

- Start the day with positive thoughts and images.
- Imagine your skin is going to improve and think about the positive aspects of your life.

3

- Connect with others who have psoriasis by getting in touch with Psoriasis Association Southland.
- It can be comforting to talk to people who have similar experiences and feelings as you.

4

- Educate people about psoriasis to help dispel the myths associated with the disease and lessen your own anxiety about what others are thinking.
- Learn as much as you can about psoriasis. The more you know, the better you will be able to explain it to others. Seven in 10 New Zealanders surveyed with psoriasis feel like they would like to know more about their condition and believe that internet websites and forums, their Psoriasis Association and their GP are valuable sources of information.*

5

- Avoid making big commitments during times of psoriasis flare-ups.
- Give yourself plenty of opportunities to relax and unwind.
- Keep active and exercise.

6

- Talk to your GP or dermatologist regularly about how psoriasis is affecting your life physically, emotionally, socially and sexually.
- If they understand what you are going through, they will be able to recommend the most appropriate treatment to address your needs, as well as stress-relieving techniques to help you cope.

Are there any other potential issues I should be aware of?

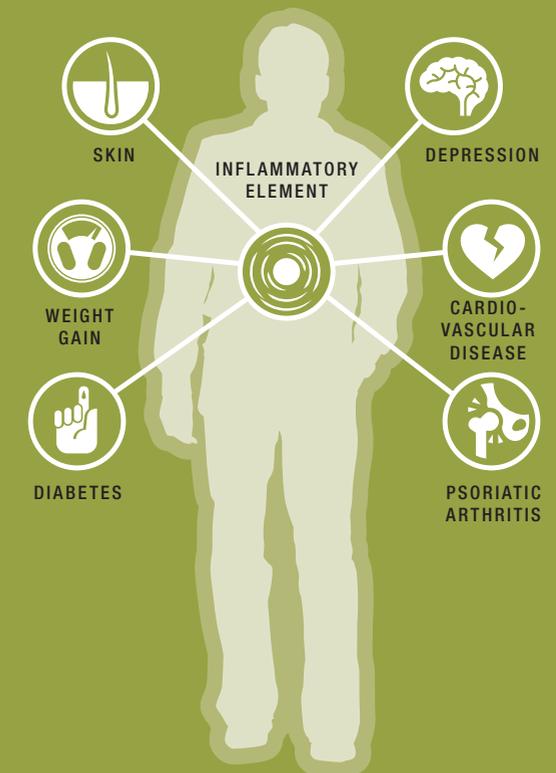
Some people with more severe cases of psoriasis may be at greater risk of developing other additional health conditions also known as 'comorbid diseases' or 'comorbidities'.

Psoriasis is a common complex inflammatory disease. It is this inflammatory element that may lead to other health conditions.^{6,7} Not everyone with psoriasis will develop these additional health conditions.

It is important that you are aware of the symptoms of these other health conditions so that you can discuss your concerns with your healthcare professional and receive the correct diagnosis and appropriate treatment to best manage your psoriasis.

If you have severe psoriasis, your doctor should carry out some measurements and tests each year to monitor your health. Tests may include monitoring your blood pressure, cholesterol and blood sugar levels, as well as measuring your height and weight.

The most important thing is not to be overwhelmed. Help is available for all associated conditions.



MENTAL HEALTH

Anxiety is a feeling of worry, nervousness, or unease, typically about an imminent event or something with an uncertain outcome. Clinical depression is a mood disorder in which feelings of sadness, loss, anger, or frustration interfere with everyday life for weeks or longer.

New Zealanders with psoriasis are reported to suffer from stress (35%), anxiety (24%), fatigue (21%), depression (18%) and trouble with memory (12%).* The prevalence of depression in patients with psoriasis may be as high as 60%, with severe cases leading some patients to contemplate suicide.^{2,6}

WHAT SHOULD I DO?

Talk to your doctor immediately if you ever have any signs of depression or suicidal thoughts. They will be able to help and may refer you to a psychiatrist, psychologist or counsellor.

Additional support and information are available from the Mental Health Foundation of New Zealand: www.mentalhealth.org.nz. You can also visit www.depression.org.nz or call the Depression Helpline on 0800 111 757.

DIABETES

Type 2 diabetes mellitus, the most common type of diabetes, is typically diagnosed at +40 years and can be prevented in a large number of people through lifestyle, a healthy diet and physical activity.

Several studies have shown that people with psoriasis have an increased risk of developing Type 2 diabetes mellitus.¹⁴ One in 20 New Zealanders surveyed with psoriasis also have diabetes.*

If you have psoriasis it does not necessarily mean you will develop diabetes.

WHAT SHOULD I DO?

If you have any concerns, ask your healthcare professional about screening for diabetes.

It is recommended that you talk to your healthcare professional for advice on maintaining a healthy diet and exercise regime.

If diabetes is diagnosed, your GP or dermatologist may refer you to an endocrinologist.

Additional support and information are available from Diabetes New Zealand: www.diabetes.org.nz

PSORIATIC ARTHRITIS

Over one in four (26%) New Zealanders surveyed with psoriasis also suffer from psoriatic arthritis (PsA).* Signs and symptoms of PsA include discomfort, stiffness, pain, throbbing, swelling, or tenderness in one or more joints.

If left untreated, a proportion of people with PsA may develop persistent inflammation with progressive joint damage that may lead to severe physical limitations and disability. Because PsA can be a very severe condition, early diagnosis is critical.⁸

Not everyone with psoriasis will develop PsA.

WHAT SHOULD I DO?

If you have any concerns, you should note them down and let your healthcare professional know as soon as possible. If PsA is diagnosed, you will be given treatment to alleviate the signs and symptoms of PsA, manage progression of the disease and maximise your quality of life.⁸ People with PsA may be co-managed by a rheumatologist and a dermatologist, particularly in the early stages of diagnosis. Your healthcare professional will determine the best course of action for you.

Additional support and information are available from Arthritis New Zealand: www.arthritis.org.nz

WEIGHT GAIN

Research has established that people with psoriasis are at an increased risk of putting on weight. In fact, 29% of surveyed New Zealanders with psoriasis are overweight.*¹

People with psoriasis who have a higher body mass index tend to have more severe psoriasis, with weight loss associated with improvements in severity.^{14,15}

In a vicious cycle, psoriasis itself may lead to weight gain.¹⁶ This may be because psoriasis affects a person's appearance and can make them feel socially uncomfortable, which can in turn affect their morale and confidence and lead to comfort eating.

WHAT SHOULD I DO?

It is recommended that you talk to your healthcare professional for advice on maintaining a healthy diet and exercise regime. You may be referred to a dietician who can provide advice that is individualised to you.

The New Zealand Nutrition Foundation aims to encourage informed, healthy, enjoyable food choices as part of an active lifestyle. Further information is available at: www.nutritionfoundation.org.nz

CARDIOVASCULAR DISEASE (CV) RISK

CV risk is the likelihood of developing a disease or experiencing an event that involves the heart or blood vessels, such as blocked arteries or a heart attack.

People with severe psoriasis have an increased CV risk than those without the condition.⁹⁻¹² There may be an increased CV risk the longer your psoriasis is left uncontrolled.¹³ More than 1 in 5 (21%) surveyed New Zealanders with psoriasis have high blood pressure.* It is important to remember that CV problems in people with psoriasis are not common and not everyone with psoriasis will be at risk of developing CV disease.

WHAT SHOULD I DO?

If you have any concerns, it is important that you speak with your healthcare professional about CV risk assessments and a prevention plan.¹⁰ They will be able to give you advice on maintaining a healthy diet and exercise regime, and if you are a smoker, they can give you support to help you quit.

Your healthcare professional can also prescribe relevant medication if needed. Your GP or dermatologist may refer you to a cardiologist.

Additional support and information are available from the Heart Foundation: www.heartfoundation.org.nz

ALCOHOL CONSUMPTION & SMOKING

Some patients with psoriasis may have a predisposition to increased alcohol intake and smoking.¹⁴

Nearly one in 10 (8.7%) surveyed New Zealanders with psoriasis have started to drink more alcohol since they have been diagnosed with the condition.*

High daily alcohol intake may make people with psoriasis unresponsive to treatment.¹⁴

The intensity of smoking correlates with more severe disease – smoking more than 20 cigarettes per day more than doubles the severity of psoriasis.¹⁴

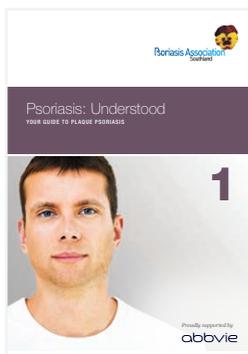
WHAT SHOULD I DO?

Any improvement in your mood with alcohol, smoking or other drugs will be temporary and may lead to or worsen your depression, psoriasis symptoms and associated conditions, such as an increased CV risk.^{2,14}

Talk to your healthcare professional immediately if you feel you may be consuming more alcohol or increasing your smoking habit because of your psoriasis. Quitline (www.quit.org.nz) and Alcoholics Anonymous (www.aa.org.nz) may be able to help. Your doctor will also be able to point you in the direction of support.

Behavioural therapy, support groups, and in some cases, medications may be helpful.¹⁵

In addition to this booklet, there are two further easy-to-read, information booklets that can be downloaded for free from the Psoriasis Association Southland website:
www.psoriasis.org.nz



1 PSORIASIS UNDERSTOOD

Explains what psoriasis is, causes, symptoms and treatment options



2 PSORIASIS CONTROLLED

A guide to biological treatments for plaque psoriasis



Psoriasis Skin Diary

Psoriasis Skin Diary is a mobile application (app) available for iPhone and iPad, designed specifically for Australians and New Zealanders with psoriasis.

The Psoriasis Skin Diary app provides a user friendly way for people to record how their skin is behaving and also better manage their psoriasis through a range of tools and personalisation features.

This app can help you track your symptoms so you can have a better conversation with your doctor. Tools include a Skin Diary with photo library and Skin Checklist. In addition, there are several personalisation features, such as appointment reminders, a personal profile form, password protection and a resource section.

You can download the Psoriasis Skin Diary app from iTunes for free. This app was developed by AbbVie in partnership with Psoriasis Australia and the Skin and Cancer Foundation of Victoria.

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