



painaustralia

SHINGLES: IT'S NOT JUST A RASH

THE DEVASTATING IMPACT OF SHINGLES
AS REVEALED THROUGH OUR CONSUMER SURVEY

painaustralia



The shingles that I experienced was debilitating. It took much willpower not to scratch and the frustration of the nerve pain was never-ending. At times, I banged my head against the wall to distract myself. The lack of sleep and the nerve pain made working difficult, meaning that I had to take leave or regular breaks, making for long days. I am lucky that I have a job and an employer that has been very flexible and understanding. I do not wish shingles on my worst enemy!!!”

~Chronic Pain Consumer

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About Painaustralia

Painaustralia is Australia's leading pain advocacy body working to improve the quality of life of the 3.6 million people living with pain. We aim to raise awareness and minimise the stigma, social and economic burden of pain.



Introduction

Shingles is a health condition often mentioned in the community. We hear the term in conversations and occasionally see advertisements on TV, but how much do we really understand about what it is and the impact it can have on our loved ones?

One in three people will develop shingles in their lifetime, with the risk increasing with age.

Nearly all adults 50 years and over carry the inactive virus that causes shingles. Shingles is caused by the reactivation of the varicella zoster virus, the same virus that causes chicken pox in earlier life. It usually causes a very painful acute illness including a terrible rash, and in some cases leads to long term neurological symptoms.

Approximately 10 per cent of people aged 50–59 who have had shingles experience ongoing pain, known as postherpetic neuralgia (PHN), that can last for months or even years.

Shingles costs our community significantly due to its prevalence and associated health complications, lost productivity, hospital admissions, and the impact on carers and families.

One case of shingles in an Australian aged over 50 years old is estimated to cost the health system almost \$1000 in direct costs.

While hospitalisation costs for severe cases or those with complications like postherpetic neuralgia can exceed \$10,000 per admission, particularly for older adults who are more likely to experience these severe outcomes.

Given these substantial costs and risks, immunisation is an essential tool that saves lives and helps people of all ages live longer by protecting them from severe aspects of various conditions including shingles.

In Australia, shingles vaccinations were previously offered free under the National Immunisation Program (NIP) for people aged 70 and above. However, starting 1 November 2023, the Federal Government expanded eligibility, making the shingles vaccine free for individuals aged 65 and older, as well as certain vulnerable groups, under the NIP.

While Painaustralia welcomes this initiative, we still need more from the Federal Government. Consumers aged 50–65 remain ineligible for a government funded vaccine, leaving a significant gap in access due to the cost. For Australians in this age group who choose to have the vaccine course, it can cost up to \$500, a challenge for some and sadly prohibitive for many.

Painaustralia commends the Federal Government for its commitment to the NIP but urges it to make the shingles vaccine available for free to all Australians aged 50 and over. This would be a sensible and beneficial step for public health.

Last year, Painaustralia conducted a crucial survey on shingles, gathering insights from consumers across the country about their experiences with the condition. The responses to our nationwide social media survey highlight that those who have endured the debilitating pain and associated symptoms of shingles strongly support our call for increased access to the vaccine.



Shingles survey

Survey aim

To shed light on the impact of shingles, the associated pain and how the lives of consumers can be affected by this condition.

Painaustralia would like to express our gratitude to all the participants who took part in our survey. Their responses help to raise awareness about the impact of shingles, highlight the importance of vaccination, and reduce the stigma faced by those living with chronic pain conditions

Study participants

The survey was conducted in the first quarter of 2024 through a call-out on Painaustralia's social media sites with 111 people completing the survey. While the majority of those who took part in the survey had experienced shingles, 15 per cent who participated were responding about a family member. The majority of respondents were women (71 per cent). Respondents came from every state and territory in Australia.

Nerve pain, blisters, a rash, itchiness, sensitivity to touch and light, chills, tingling feelings, lethargy, fatigue, numbness, headache, an upset stomach, and fever were all reported symptoms experienced.

The majority of respondents (92 per cent) experienced nerve pain, 85 per cent had blisters, 84 per cent a painful rash and 69 per cent experienced some form of itchiness.

Overwhelmingly, and of concern, respondents reported that their symptoms were ongoing and, for some consumers the associated pain and other manifestations lasted many many months. 42 per cent of respondents reported that their symptoms were ongoing, 20 per cent said they experienced symptoms for up to three months, nine per cent for three to six months and 16 per cent had experienced symptoms that lasted up to four weeks.

One of the most debilitating effects of shingles is neuralgic pain that can often last for months after any rash caused by the virus has disappeared. This severely impacted the ability to work and participate in daily activities. Of those that experienced nerve pain, 45 per cent reported that they had been left with nerve pain that lasted longer than 12 months, 14 per cent said it lasted longer than six months and 21 per cent said they experienced it for three months.

Survey insights

Long-lasting pain and its impact on daily activities and participation with family and friends was the overarching focus of respondents.

The survey found:

14%

Of respondents had their quality of sleep impacted.

11%

Felt mentally unwell; being either sad, depressed, anxious or less motivated.

10%

Were unable to participate in family, recreational and or social activities.

9%

Were unable to be physically active including being able to walk the dog.

9%

Were unable to do everyday activities such as cooking, grocery shopping or taking the kids to school.

9%

Were unable to travel either by car, or take public transport.

6%

Were unable to be physically intimate.

4%

Were unable to manage their personal care and needed help to shower, get dressed or go to the toilet.

Financial impacts of shingles

A consistent theme among respondents was the severe pain and long-lasting symptoms of shingles, which often led to financial hardship due to lost work or unpaid sick leave. Many also highlighted the prohibitive cost of treatment and medications as a significant burden.

Fifty-three per cent of respondents said having shingles impacted their ability to work in some form, whether it meant having to repeatedly take more sick leave, work less hours or being unable to work at all. Five per cent of respondents said shingles had led to them taking early retirement.

Respondents told us:



34%

Felt they had become a burden to the community.

21%

Were out of pocket due to medical appointment and medication.

17%

Couldn't pay their bills and had to rely on community and government support.

13%

Were unable to meet the demand of cost of living and pay their day-to-day expenses.

9%

Said the burden of meeting cost of living and financial costs had shifted to their partners.



My life has completely changed due to shingles and the ongoing neuropathy. **I am always in pain, burning, sore** - being on Lyrica has affected my walk, my vision, my ability to concentrate amongst many other things.

I live by the hour, by each day, hoping I can have a better quality of life. I have worked hard physically all my life in the horse industry and had broken bones. This **Shingles pain is my biggest challenge** and recently been told I have this nerve pain for life that affects my head and face every moment day and night is extremely hard. I wish there was a remedy but **at least there can be a vaccination for others.**

CONSUMER VOICE

I am still suffering the post shingles pain, cannot touch affected area, **taking a shower is hell and a good night's sleep is not possible.**

I am currently on 75mg PREGABALIN, one in the morning and one at night. This has helped somewhat but the stabbing **pains I still feel take my breath away.**

When I got shingles, I had never heard of them before. I had an itchy rash down my neck, shoulder and across my back and the pain was **red hot burning nerve pain.** I remember feeling very ill, uncomfortable, exhausted and had a headache to the point of nausea. It felt awful. **Shocking to me at the time.**

Once you get shingles it re-occurs regularly and **seems to raise its head after other illnesses when your system is fatigued.** I'm scared this will get worse as I age. I've probably had shingles 10-15 times, at least 2-3 times a year for past 10 years. I'm now 54 and worried how difficult it will become once I'm in my late 60-70. **Being immunised at 50 will help so many people not get this awful disease.**





CONSUMER

Not being able to work for some time and unable to **physically and mentally** work full time and the huge cost of medications.

I'm casual so lost pay.

Unable to work or look for a job for 3 months whilst ill with, and post Shingles suffered **tiredness and concentration issues** to apply for jobs. My husband is on Aged Pension, thus **finances were tight** with household and utility expenses.

Job absences causing **strain on budget** due to unpaid leave.

Nervoderm lignocaine **pain patches** have spent approx \$1,000.

I had to drop down from full-time to part-time hours, and then **I had to leave my job** entirely. This has left my husband and I reliant entirely on his salary.

Unable to work, cook, clean, pick kids up, drop them to activities... needed help and my husband had to take time off as well.

My medical bills ran in the thousands.

She can barely work

and it is costing her \$600 a month for medicine.

She couldn't do her casual work and **hasn't worked for 6 months.**

Expensive, time-consuming, medical and chemist visits to town.

I was unable to contribute to monthly finances, with **my partner having to work fewer hours** to help care for me.

Not knowing if she could work, leading to **loss of income** as she is in a small business, countless Dr appointments and different medications. All costing time and then eventually **financial stress.**

Cost of Nervoderm patches.

Couldn't even think about paying bills, reporting to centrelink fortnightly, over counter stuff costs a fortune, **couldn't even think properly** how to even pay at the cash register for food.

I couldn't work because the location of my pain meant I couldn't wear anything with a collar. Driving was difficult because of the neck support - **anything** that touched the hair on the back of my head, **hurt**, including the wind.

Unable to work continuously, causing great **loss of wages.**



Call for increased shingles vaccine uptake

Due to the financial burden, intense pain, and the profound impact on their families, survey respondents consistently expressed a strong desire for greater uptake of the shingles vaccine.

The majority of respondents wanted the vaccine to be more affordable and accessible to people over the age of 50 through the Government's National Immunisation Program.

Consumers said the benefits of vaccines were:



Prevention is better than cure.



Personal protection.



Reduced healthcare costs.



Community well-being.





CONSUMER

VOICE

Anyone over 50 needs to benefit from Shingles vaccination, it affects everyone really badly.

I got **shingles** when I was 40, it had a **huge impact on my life** re pain, activity & work.

Because **it is a horrible thing,** and the pain was like nothing I've ever experienced.

Shingles is a debilitating disease that **takes away any quality of life** and in this case, it has gone on for just over a year.

A simple preventative measure which is available, why not use it? **Would save a great deal of pain** and inconvenience.

It's a miserable and debilitating disease. **Why make anybody suffer?**

To make vaccination available to everyone, because **the pain is indescribable.** I don't want anyone to suffer from it.

There should be no discrimination of age, PHN is a very serious situation & a great debilitation on everyday life.

The vaccine should be available definitely to those 50 and above and probably from a younger age. **The impact it can have on one's life is underestimated by those who have never experienced it.** I still have trouble sleeping because of having to position the back of my head so it doesn't get too hot or touch the pillow for too long. I experience more of an itch now in the heat, but it is annoying.

Make Shingles vaccination available Nation Wide & available to everyone like all other serious illnesses. eg measles etc

I have read some data that indicates more people in the age group 60 to 70 have suffered with a bout of Shingles, and so many I've spoken to are 60 to 65 years of age. Seems to me that **the age for free vaccination should be 60 years onwards.**

Shingles Vacc made **FREE to ALL vulnerable people** who had Chickenpox. I have long-term debilitating symptoms from my Shingles. Pain every time I lie down to sleep. Pain in a circle around my ribs, exacting where the Shingles blisters were first seen and diagnosed by my GP. Pain, I feel now as I type this Survey. **Preventable** Shingles? YES PLEASE. Get this done.



Tony's story

A part time PhD student and working as a hydrologist, 68-year-old Tony was used to being knee deep and wading through water and mud, keeping fit by running each day, and taking cardio and strength classes at the gym – that was until he was hit by shingles.

It wasn't the first time he had been recently diagnosed with a serious illness. A year earlier he had been told he had a rare cancer of the white blood cells called hairy cell leukemia. It is highly treatable but rarely cured and infection is one of the leading causes of illness and death.

He underwent chemotherapy later that year with the only side effects being some minor nausea for a few days. After his chemo treatment was completed, it was declared that he was in remission. Ironically it was the shingles some months later that impacted him so much more, leaving him bed bound and in intense pain – pain that lingered more than nine months after contracting the illness.

He discovered he had shingles when he woke one Sunday in August 2022. He had a severe blistering rash all over his torso and back and immediately attended a medical centre where he was instantly diagnosed with shingles. He was fortunate to receive the antiviral that day.

He then spent a week in bed, in enormous pain, could not wear any type of close-fitting clothes for months and even the doona "dreadfully hurt".

The shingles meant he could not work for several weeks, and for months he was unable to exercise, experienced severe fatigue, hot and cold spells, and his skin itched the entire time.



He took pregabalin but nothing helped to ease the continuous and incapacitating pain. "I was drained, with no energy and unable to do the simplest of things. I wanted to scratch myself the whole time, but I learnt very quickly that when I did the pain afterwards was actually worse." His torso and back have been left scarred from the shingles.

"For the first three months after getting shingles there were spells during the day of 10 to 15 minutes of really intense burning pain, every single day. It left me doubled over with pain and I couldn't do anything to alleviate the constant pain – sleeping was just impossible."

He knew very little about shingles before he contracted the condition, and he passionately believes the shingles vaccine should be made easily and subsidised to access.

His advice to consumers:

"If you can please get the vaccine because shingles can be debilitating, especially for people like me who are susceptible, we should make it widely available as possible."

Urgent need for greater awareness

Survey respondents strongly emphasised the need for greater awareness and improved communication within the community about the severe impact of shingles and the significant burden it places on people's lives.

They stressed that expanding social and media campaigns would increase public understanding of shingles, raise awareness, and encourage more individuals to get vaccinated.





The nerve pain down my whole left side is there all the time because of a delay in diagnosis of internal shingles. The pain gets so bad I am constantly scared it has come back. The numbness, tingling and nerve pain at the same time is confusing because there is **numbness and pain**. I wanted to get the chainsaw out and just cut the left of my body down to my leg off, go to the hospital and get them to remove that whole section of my body away. Plus, after care doesn't exist. Internal shingles I am worried about because having the shingles even breathing caused pain and now, I have trouble deep breathing and diaphragm movement doesn't happen naturally any more. The pain in my shoulder, elbow, wrist fingers and hip are something the doctors ignore. Get over it and live with it. **If I could have had a shingles vaccine at 50 I would never have had the pain I had and suffer now.** Lifelong damage because I couldn't afford the vaccine.

There needs to be **more education targeted at those most vulnerable to shingles**.

The number of fear-mongering drug company ads I have seen in waiting rooms over the past few years is appalling. The medical community also needs more education. I recently visited a pharmacy to obtain my PHN medication when an elderly lady came in with severe, obvious shingles. She asked for a cream to numb the pain. The pharmacist tried to give her capsaicin cream, telling her it was an anaesthetic. I intervened and directed her to visit her doctor immediately.

Even if it is not free for over 50s, **having it available free for those on a healthcare card and at an affordable price** for others would be great.

I don't think the general public understands what a big impact having shingles can have on you. GP's could perhaps suggest these vaccinations for people over 50 and a social media campaign would be good. **As the impacts can be long lived** (with people having to stay home from work etc), I think **it would be a better economic decision to allow people that would like to have the vax to have it for free**. It's currently quite expensive.

Please make the vaccine free to as many people as possible as fast as the government can arrange it.

Apart from specific Pain Specialists, the medical profession seemed unaware of the severity of the PHN pain. **We tried all available channels** to mitigate this pain but without much success.

It never occurred to me that I could get shingles. I had been vaccinated against them but when I was undergoing Chemotherapy it happened. If the Oncologists had told me this was a possibility, I might have thought twice about having Chemo. **Believe me, the experience of Shingles was far worse than Radiology and Chemotherapy combined.** I am still living with the pain 13 months on, and nothing looks like changing.



Strengthening protection against shingles

The survey reveals that while some awareness of shingles and its impact exists, there is still a long way to go before the community fully grasps the severity of this debilitating condition. Despite recent improvements in vaccine availability and affordability, it is crucial to recognise that shingles can affect people of working age—particularly those in the prime of their careers—not just the elderly or those over 70, as is commonly assumed. The financial and health costs of shingles can be overwhelming, with prolonged pain and symptoms that significantly impact quality of life.

Increased dialogue and greater awareness is needed, not only within the broader community but also among healthcare professionals, particularly general practitioners. Expanding these conversations is essential to fostering a deeper understanding of shingles and its far-reaching consequences.

Painaustralia strongly supports efforts to lower the age eligibility for free shingles vaccination. We ask the Australian Federal Government to build upon its 2023 initiative for the shingles vaccine to be made accessible to all Australians aged 50 and over, ensuring broader protection and reducing the burden of this serious condition.



Robert and Libby's story



At 88, Robert Bakewell was a stalwart of the Phillip Island community—a former surveyor who had worked in New Guinea in his youth, an adventurer, and an active member of his local Probus club. He thrived on sharing stories of his travels and experiences, always full of energy and lived on his own. But in June 2022, everything changed when he contracted shingles.

His daughter Libby witnessed firsthand the devastating toll the illness took on her father over nine harrowing months. What began as some pain, feeling unwell and a rash spiralled into a relentless decline. He lost his ability to speak coherently, endured excruciating pain, eventually was unable to walk, and ultimately had to move into care. Shingles stole his independence—and Libby says eventually, his life.

Libby vividly remembers the phone call from her father on a Friday evening in June. He told her he wasn't feeling well, and they talked about going to the doctor on the Monday if he wasn't any better. By Sunday, a painful rash had developed around his neck, and by Monday morning, he was "in absolute agony". Concerned she travelled from Melbourne and took him to his GP, who diagnosed him with shingles and prescribed pain medication. But his condition didn't improve, instead it worsened rapidly.

Within a day, the rash spread aggressively across his chest, neck, ears, and scalp. "The pain was unbearable. He couldn't eat, and his strength faded," said Libby. Over the next few weeks his condition continued to deteriorate and deeply troubled, she took on the role of his carer, sacrificing her own work to help him and also move him into a care home. She watched helplessly as he wasted away, unable to do any of the things he once loved. The only small respite from the pain was CBD oil prescribed by his GP.

Even after the rash subsided, Robert never truly recovered. The pain remained, unrelenting. "He was in excruciating pain, lying on his bed, groaning," Libby recalled. His once-active life dwindled to nothing as he lost weight, was unable to feed himself and lost mobility. At first, he relied on a walking stick, then a walker, and finally a wheelchair. His weakened state led to a series of falls, further exacerbating his health issues. Robert passed away in March nine months after contracting shingles.





"Shingles ravaged his body. He never recovered, no matter what we did, we couldn't make him well," Libby said.

Before her father's illness, neither Libby nor Robert had understood just how serious shingles could be. "I had no idea it was this severe, no idea at all," she admitted. "It's not just a little rash that goes away."

Libby's advice to anyone who contracts shingles is not to underestimate this disease. "Do not minimise the symptoms, act fast and don't dismiss it or ignore it. The pain and complications can be severe and life-altering.

"Before shingles, dad went from being a vibrant, funny and energetic man to being completely incapacitated and he never recovered."



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