



Don't suffer in silence with your kidney disease itch

Get help and support to make your itch heard.

Visit www.letyouritchbeheard.com.au

to find out more.



EVERYTHING YOU NEED TO KNOW ABOUT YOUR KIDNEY DISEASE ITCH

What is kidney disease itching?

Extreme itching is a disruptive symptom associated with kidney disease that can make you scratch uncontrollably and damage your own skin, which can lead to bleeding and infections.¹ It is often described as an itch beneath the surface, which no amount of scratching can satisfy.^{2,3} At first, you might think it is a bee sting or an allergic reaction.²

Since everyone feels their kidney disease itch differently, it can be hard to identify. For some, the itch is constant, but for others it flares up during the day or night.⁴ Some people find their whole body is itchy, while others are affected on their face, back and dialysis arm. Things like extreme temperatures, stress, exercise and water can be a trigger.⁵

“It is just so bad that I am scratching till really, I have got no skin left.”
– patient in Australia with kidney disease itching.⁶

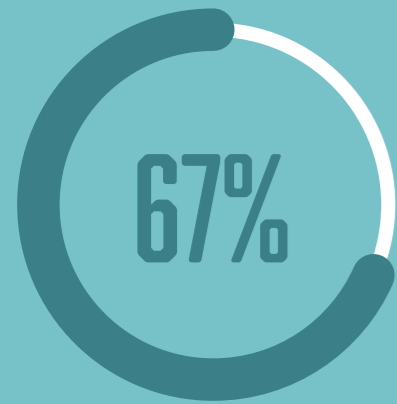
So much more than ‘just an itch’, kidney disease itching is linked to a number of health conditions.^{4,7,8} That’s why it’s important to speak out and get help if you are suffering.

The medical term for kidney disease itching is
‘chronic kidney disease-associated pruritus’.⁵



How common is CKD-associated pruritus?

Living with kidney disease itching can feel overwhelming, but remember that you are not alone.



of CKD patients on dialysis...



of CKD patients not on dialysis...

...experience itching.^{8,9}



What causes kidney disease itching?

The exact cause of kidney disease itching is not known, but several factors play a part.⁵



Nerves misfiring

Kidney disease can change the signals that nerves send from your skin to your brain. If your nerves send too many signals or signals for no reason, it can cause itching.⁵



Pain signal problem

Chemicals that naturally occur in the body called opioids play a role in how your brain receives pain signals. Kidney disease can cause an imbalance in the opioid system in your body which can interfere with your pain signals and cause excessive itching.⁵



Immune system overacting

Kidney disease can cause an imbalance in your immune system which can lead to inflammation in your skin. This can cause chronic itching.⁵



Dialysis not working well

If you are on dialysis and it is not working well, this can cause toxins to build up under your skin and cause itching.⁵

How is CKD-associated pruritus diagnosed?

If your itch is affecting your life, speak to your doctor right away. They will examine your skin, ask about your medical history and they may order blood tests, allergy checks and scans.¹

Itching can be caused by lots of different things and no single test can confirm whether it is related to kidney disease. That's why your doctor will use a process of elimination to find the root cause of your itch.¹⁰ If nothing can be found, you will likely be diagnosed with chronic kidney disease-associated pruritus.^{1,5}

KIDNEY DISEASE ITCHING IS MORE THAN JUST AN ITCH

On the surface, it's just an itch. But underneath it's so much more. Here are some of the ways your kidney disease itch can affect your life.



HOW IT MIGHT AFFECT YOUR SLEEP

Since kidney disease itching tends to be worse at night, sleep problems are quite common.^{7,8}



Up to 1 in 2 people with a moderate to severe itch have difficulty sleeping.^{7,8}

This can make you feel tired during the day, affecting work, social and family life.⁴

“OFTEN I AM LYING AWAKE FOR NIGHTS IN A ROW WITHOUT BEING ABLE TO SLEEP.”

46-year-old living with kidney disease itching for over 1 year.¹¹

Sleep is essential because it helps your mind and body to repair and recharge, so you are ready for the day ahead. It's important to prioritise sleep and talk to your doctor if you are struggling.¹²

HOW IT MIGHT AFFECT YOUR RELATIONSHIPS

If you feel embarrassed about scratching in front of others or worried that people will pass judgement on the appearance of your skin, you are not alone.^{4,13}



One third of people with severe itching say that it affects their social life, leaving them feeling lonely and isolated.^{4,13}

“BEFORE, I WAS A SOCIAL BUTTERFLY. NOWADAYS, IF I'M HAVING A BAD ITCH DAY AND SOMEONE INVITES ME OUT FOR DINNER, I TURN THEM DOWN. IT'S KILLING MY SOCIAL LIFE AND KEEPING ME ISOLATED.”

Patient living with kidney disease itching for 1 year.²

Remember that perception is personal and how other people see you isn't the same as how you view yourself. So, whilst you may be aware of your itch, other people may not even notice.¹⁴

HOW IT MIGHT AFFECT YOUR MENTAL HEALTH

Living with kidney disease can put a strain on your mental health – almost 20% of dialysis patients experience depression.¹⁵



Dealing with your CKD itching on top of this can make things worse, especially if you have been struggling to get support. Combined with lack of sleep and isolation, you might start feeling depressed.^{7,8,13}

“EMOTIONALLY AND MENTALLY IT'S VERY DRAINING AND DEPRESSING.”

Patient living with kidney disease itching for 1 year.³

Everybody feels down sometimes, but depression is an extreme and persistent low mood.¹⁶ It can affect how you think, feel, behave, and stop you from enjoying life.¹⁶

If you are struggling with your mental health, talk to your doctor for advice and support.

SPEAK OUT, BE HEARD

If your chronic itching is affecting your life, don't suffer in silence. Help is out there, if you ask for it.

Talk to your doctor

Speak to your doctor about your excessive itching. Write down a list of your symptoms and take a friend or family member to your appointment for support. No one should face kidney disease itching alone, so keep discussing your itch until you are heard.

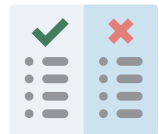
Here are some questions to ask your doctor.¹⁷



Are there any ways the itching from kidney disease can be relieved?



What are the pros and cons of each treatment?



How do I choose an approach to manage my itching that is right for me?



What happens if the itching treatment does not work?



Remember that the support you need can be just one conversation away.

Open up to friends and family

Opening up about your CKD itching can feel uncomfortable at first, but you might be surprised how understanding your friends and family are.

Speak to people who understand

You might see the same people during your dialysis sessions. Why not open up and see how they are coping? After all, no one can understand what you're going through more than those who are experiencing the same thing.

Connect with the kidney disease community

There is a community of people – just like you – sharing their itch experiences in patient associations and on social media. Connecting with them might help you to cope and feel less alone. Use **#letyouritchbeheard** to find others who may be suffering with kidney disease related itch, or to share your story online.





HOW TO CALM YOUR KIDNEY DISEASE ITCHING

While your doctor will always be there to look after you, there are lots of ways you can relieve itching from kidney disease at home.

AVOID SCRATCHING. INSTEAD, PAT

It is tempting to scratch and the urge can be overwhelming at times, but this can break your delicate skin and cause bleeding or infections, so try to pat the itchy areas instead.¹⁸

STICK TO SHORT BATHS AND SHOWERS

Your skin makes its own moisturising barrier, but soaking in water can strip off that layer. To keep your skin's natural oils intact, try to take short bath or showers.¹⁸

STAY AWAY FROM HOT WATER

Try not to bathe more than once a day and use warm instead of hot water. This will stop your skin from drying out.¹⁸

LIMIT SOAPS AND FOAMING BODY WASHES

Many foaming body washes and soaps remove the natural oils from your skin (even those that claim to be suitable for dry skin). Instead try choosing moisturising creams or prescription bath oils.¹⁸ Ask your doctor or pharmacist for recommendations on the best products.

USE ICE FOR A QUICK FIX

Cool temperatures can give you temporary relief.¹⁹ Try laying a cold flannel soaked in moisturising cream on your skin, or apply moisturiser that has been kept in the refrigerator.¹⁸

KEEP COOL NIGHT AND DAY

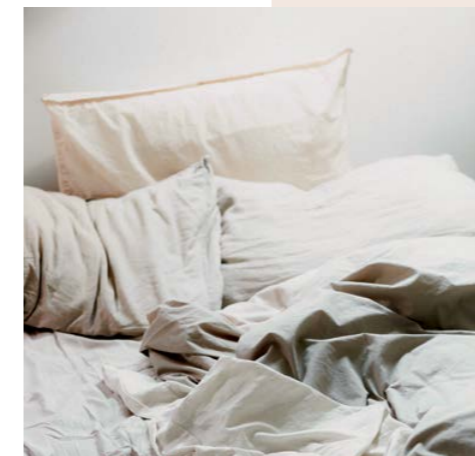
Hot temperatures can make your itch worse, so it can help to keep cool at night with lightweight bedding and loose clothing that won't make you sweat. If you feel hot during the day, use a fan to cool down.¹⁸

BE GENEROUS WITH MOISTURISER

If you have dry skin, your itch will feel worse. Using moisturising creams liberally can help to prevent dryness and scarring.¹⁸

MEDICATION FOR ITCHING PRESCRIBED BY YOUR DOCTOR

Kidney disease itching can be difficult to treat, but there are a few prescription medicines that may help some people. For more information about prescription medicines for itching, speak to your doctor.



IMPORTANT QUESTIONS TO THINK ABOUT BEFORE TALKING WITH YOUR DOCTOR

Below are some questions to consider before speaking with your kidney care team to help you reflect on your kidney disease itch and how it impacts you. Feel free to answer the questions in the spaces provided and tear off this page before going to your next clinic visit to help guide your conversation.

When did my kidney disease itching start?

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Over the last few weeks/months, has my itching become better or worse?

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Which areas of my body are affected?

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.....

Please tear here

How does kidney disease itching affect my life? (Think about how it might affect your sleep, social life and mental, as well as physical health)

What have I tried, if anything, to soothe my itching? What effect has it had?

Any other thoughts



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to find out more.



Please tear here

KIDNEY DISEASE ITCHING TERMS EXPLAINED



There are lots of medical terms that you might read or hear which relate to your kidney disease itch. Here are the most common ones.

Chronic	A condition that is long-term and that usually comes on slowly. ²⁰
Dialysis	A medical process which removes toxic waste products from the body when the kidneys are not working properly. ²¹
Immune System	The body's natural defence system which protects it from infection. ²⁰
Nerves	Long, thin fibres that carry information and signals between the brain and other parts of the body. ²¹
Pruritus	An unpleasant itching sensation that causes intense scratching. ¹
Toxins	Poisons found in the blood which are usually removed by the kidneys. ²⁰

A big thank you to the people living with CKD-aP who collaborated with us to develop this leaflet and make it as relevant as possible.

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Although every effort has been taken to ensure the accuracy of information in this booklet, it is not intended to be a substitute for professional medical advice, diagnosis, or treatment. If you have any unanswered questions about chronic kidney disease-associated pruritus or your treatment, please speak to your specialist medical team.

References: 1. BMJ Best Practice. Assessment of pruritus. 2018. Available at: <https://bestpractice.bmj.com/topics/en-gb/612>. Last accessed November 2021. 2. Data on file 001. 3. Data on file 002. 4. Rayner H, Larkina M, Wang M, et al. *Clin J Am Soc Nephrol*. 2017;12:2000–2007. 5. Verdusco HA, Shirazian S. *Kidney Int Rep*. 2020;5(9):1387–1402. 6. EKPf. Living with chronic kidney disease associated pruritus. 2021. Available at: <https://ekpf.eu/wp-content/uploads/2021/11/prurito.pdf>. Last accessed November 2021. 7. Pisoni R, Wikström B, Elder S, et al. *Nephrol Dial Transplant*. 2006;21:3495–3505. 8. Sukul N, Karaboyas A, Csomor PA, et al. *Kidney Med*. 2020;3(1):42–53. 9. Sukul N, Speyer E, Tu C, et al. *Clin J Am Soc Nephrol*. 2019;14(5):673–681. 10. Shirazian S, Aina O, Park Y, et al. *Int J Nephrol Renovasc Dis*. 2017;10:11–26. 11. Data on file 003. 12. National Heart, Lung, and Blood Institute. Sleep Deprivation and Deficiency. Available at: <https://www.nhlbi.nih.gov/health-topics/sleep-deprivation-and-deficiency>. Last accessed November 2021. 13. Silverberg JJ, Kantor RW, Dalal P, et al. *AM J Clin Dermatol*. 2018;19(5):759–769. 14. Pronin E. *Science*. 2008;320(5880):1177–1180. 15. Lopes A, Bragg J, Young A, et al. *Kidney International*. 2002;62:199–207. 16. InformedHealth.org. Depression: Overview. June 2020. Available at: <https://www.ncbi.nlm.nih.gov/books/NBK279285/>. Last accessed November 2021. 17. Think Kidneys. Ask Three Questions. Available at: <https://www.thinkkidneys.nhs.uk/ckd/tools-for-change/ask-three-questions/>. Last accessed November 2021. 18. British Association of Dermatologists. Pruritus Patient Information Leaflet. 2017. Available at: <https://www.bad.org.uk/shared/get-file.ashx?id=121&itemtype=document>. Last accessed November 2021. 19. Palkar R, Ongun S, Catich E, et al. *J Invest Dermatol*. 2018;138(6):1391–1399. 20. National Kidney Federation. Glossary of Renal Related Terms. Available at: <https://www.kidney.org.uk/glossary-of-renal-related-terms>. Last accessed November 2021. 21. Collins English Dictionary. Nerve. Available at: <https://www.collinsdictionary.com/dictionary/english/nerve>. Last accessed November 2021.