

JOINT SUPPORT



Arthritis NZ
Mateponapona
Aotearoa

Living well with arthritis



IN THIS ISSUE • AUTUMN/WINTER 2025

New approach
to gout
management

Key findings
from the Arthritis
Confidence Index

Advocacy team
champions arthritis
support

PHILIP'S Column

Welcome to our Autumn/Winter
2025 Joint Support



As the cooler months approach, I'm delighted to share some of the significant work being done to support people living with arthritis across New Zealand.

We're excited to present some of the key findings from our inaugural Arthritis Confidence Index survey launched on World Arthritis Day 2024. With over 1,200 respondents sharing their experiences, the survey has provided valuable insights into the challenges faced by people with arthritis, particularly around specialist wait times, financial strain, and mental health impacts. These findings are already being used to shape our advocacy efforts and support services moving forward.

Our advocacy team, Francesca Holloway and Dr. Valerie Milne, continue their work championing support for people with arthritis. Their approach includes engaging with government agencies, collaborating with partner organisations, and ensuring our Consumer Reference Group's lived experiences inform all our initiatives.

I'm particularly pleased to update you on our application to Medsafe regarding the reclassification of allopurinol. If approved, this change would enable pharmacists nationwide to supply allopurinol following an initial GP consultation, making this vital gout medication more accessible to the 250,000 New Zealanders living with gout.

This year we've also launched our very first podcast series, "Menopause and Arthritis," hosted by Jo Miller. This important initiative addresses the dual challenges many women face when managing both conditions simultaneously.

As always, our Arthritis Assist service remains available to provide personalised support with managing pain, staying active, and understanding your arthritis.

I hope you find this issue of Joint Support informative and encouraging. Your continued support enables us to work toward our vision of improving life for all New Zealanders affected by arthritis.

Warmest regards,

Philip Kearney
CEO Arthritis NZ



BLACKMORES®

Keep your life moving



Proud sponsors of Arthritis New Zealand

Good health changes everything

Always read the label. Use only as directed. If symptoms persist see your health professional. Vitamin and minerals are supplementary to and not a replacement for a balanced diet. Blackmores, Auckland.

Need help with your arthritis?

Arthritis Assist can support you with managing pain, staying active, and understanding your arthritis.



Call: 0800 663 463

Email: info@arthritis.org.nz



ADVOCACY TEAM CHAMPIONING arthritis support in NZ

by Patricia Thompson

Advocating for the needs of people living with arthritis is no small task, but **Francesca Holloway** and **Dr. Valerie Milne** are deeply committed to it. They are Arthritis NZ's advocacy team, and they work to ensure the organisation's voice is heard in important conversations about health policy and services.

From keeping track of current issues to collaborating with partner organisations and engaging directly with the government, their work plays a crucial role in improving outcomes for people with arthritis.

Their multi-faceted role includes ensuring the data and statistics Arthritis NZ uses are up to date to inform its work on behalf of people with arthritis. "We are responsible for ensuring we are using the right numbers," says Francesca, who is Advocacy Manager.

"There are so many forms of arthritis. People can have more than one form, and some have unusual forms. We work from several sources of data, including the New Zealand Health Survey, Te Tāhū Hauora Health Quality & Safety Commission and research projects funded by Arthritis NZ.

"We also work closely with organisations such as Age Concern, Physiotherapy New Zealand, Rare Disorders New Zealand and the New Zealand Rheumatology Association. We have formed a wide network linking organisations providing advocacy.

"Our focus is current issues, who are making submissions, whether we should make a joint submission or submit as a group, and we share key points we are making in submissions."

Valerie, who has rheumatoid arthritis and a PhD in patient access to rheumatology care, is the 'numbers whizz'. She follows arthritis developments and develops research programmes with Arthritis NZ's research manager and rheumatologists.

The team is also the organisation's link to central government and to Pharmac.

"I focus a lot on talking with different people, such as health spokespeople across the different parties," says Francesca. "We work with the whole of government to ensure we are up to date with what is happening in health policy."

Presenting to the Health Select Committee is an important part of their work. The Health Select Committee is a small group of MPs who look at petitions, proposed laws, changes to existing laws, opinions, ideas, and submissions from organisations and members of the public. They then feed this information back to Parliament to help them make health decisions. When doing submissions, the advocacy team work with government agencies, including the Ministry of Disabled People and the Ministry of Social Development.



Dr. Valerie Milne

“One of our big focuses is the difficulty people have in getting to see a GP or getting a prescription renewed. It is especially difficult if they move locations to find a doctor whose books are open, especially in rural areas,” explains Francesca.

Their work also extends into other areas, such as what is happening with ACC or housing and how that will affect people with arthritis. All of that information and their work with sister organisations inform their submissions.

Their role also involves providing direct support or advice, often for people who have been referred from other parts of the organisation, such as the Arthritis Assist team.

“For instance, it might be a question about immigration,” says Francesca. “People moving to New Zealand who want to know how they will access medication.”

The Arthritis NZ Consumer Reference Group

They also work with Arthritis NZ’s Consumer Reference Group (CRG), which consists of individuals with lived experience of arthritis who offer insights and perspectives that inform the organisation’s decision-making.

That includes feedback on services, resources and advocacy. Members also discuss issues among themselves and may suggest ideas to the advocacy team of other parts of the organisation.

“The group was set up as a way of ensuring consumers have a voice,” says Francesca. “It provides a very important dataset of people with different arthritis conditions who we can go to as needed.

“People like **Sandra Forsyth**, who has lived with chronic conditions since 2010 and is passionate about peer support, medical/patient literacy and equity of access to health services. Sandra works with many groups providing a voice for health consumers and was recently appointed to Health New Zealand Te Whatu Ora’s new regional council for Hawke’s Bay.



Francesca Holloway

“It means when an issue arises that is related to the service we provide, then we can go to the group for feedback - for instance, our MyRA support program for people with rheumatoid arthritis.

“That was independently redeveloped from Arthritis Australia’s MyRA website and tailored for New Zealand users, and the Consumer Reference Group provided important input on that.

“We are currently preparing a factsheet and will ask for their feedback. I am also preparing material for use with the government and will go to them to ensure it is easy to understand and follow.

“It is so important to have that input from people with lived experience. A lot of people don’t see arthritis as a disability, but it can be very disabling,” concludes Francesca.

If you are interested in learning more about the CRG and how you can participate in it, email **info@arthritis.org.nz** or call **0800 663 463**.

THE ARTHRITIS CONFIDENCE INDEX SURVEY HIGHLIGHTS

challenges faced by people with arthritis

Arthritis NZ's inaugural Arthritis Confidence Index (ACI) survey reveals key insights into the experiences of people living with arthritis in New Zealand. The ACI covered the six-month period between April and September 2024 and gathered responses from 1,220 participants.

The findings highlight that osteoarthritis is the most common condition reported, affecting 73% of respondents, followed by rheumatoid arthritis (24%). Notably, the wait time to see a specialist was the most important personal health issue.

Financial strain emerged as a major concern, with many relying on personal savings or working despite being unwell. Additionally, 58% said their mental health had been adversely affected by their arthritis.

Exercise proved challenging for many, with 24% facing severe barriers or being unable to exercise. Access to GP care was also a concern, with rising costs and long wait times reported.

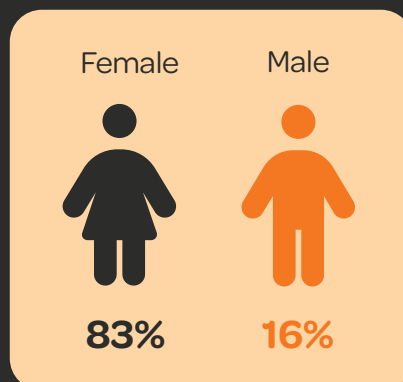
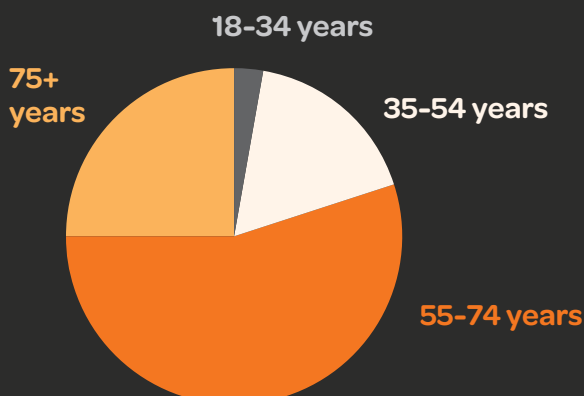
Despite these challenges, some participants expressed confidence in managing their condition, and Arthritis NZ remains committed to using the survey insights to advocate for improved healthcare access and support services.

The next ACI survey is planned for later this year.

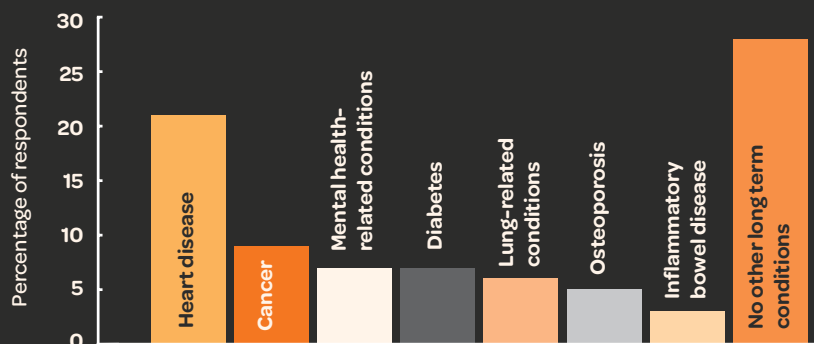
Age & gender:

80% of respondents are over 55 years of age;

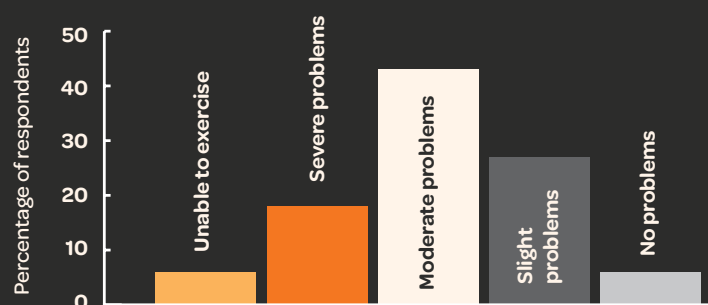
83% female, 16% male



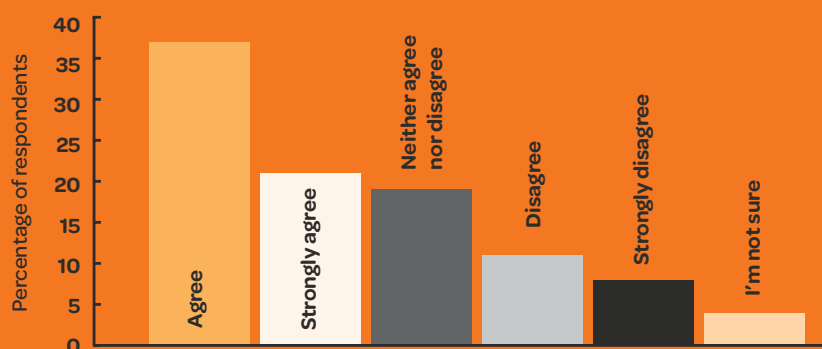
Heart disease is the most common other long-term condition people with arthritis have (21%)



24% face severe barriers to exercise



58% say their mental health had been adversely affected by their arthritis



NEW APPROACH to gout management

by Patricia Thompson

Pharmacists nationwide could help people manage their gout under a collaborative model with the family doctor.

Arthritis NZ is awaiting the outcome of its application to Medsafe, which would allow pharmacies nationwide to supply allopurinol without a prescription.

Allopurinol is the most widely used gout medication that is effective at preventing gout. When people run out of this medicine or are on a dose that is too low, they can have gout attacks, which are often extremely painful.

The application seeks to change the classification of allopurinol so it can be supplied by community pharmacists without a prescription – following an initial GP consultation and prescription.

Arthritis NZ CEO **Philip Kearney** says enabling pharmacists to take on gout management programmes would significantly increase the regular use of allopurinol; help ensure the right dose is taken and provide opportunities for community education.

Community trials

Community pharmacy gout management projects in different parts of the country, supported by Arthritis NZ, have been very successful. In Porirua, a programme increased allopurinol use by 80%.

“Allopurinol is a frontline medication for gout arthritis in New Zealand, used in 85 to 90% of cases,” says Philip.

It is a preventive medicine that reduces uric acid in the body to bring it under 0.36mmol/L (millimoles per litre), the optimal level of where it should be. Allopurinol needs to be titrated to bring a patient to the levels of medication that work for them, which involves regular blood tests to get to the right level of medication. Once the optimal level of medication is reached, it is important to continue medication daily for life – and not just to prevent the agonising pain of gout.

Philip says many causes for lack of adherence to medication could be addressed through community pharmacy management and education programmes. These include the difficulty in getting GP appointments for follow-up prescriptions helping people get to the right dose of allopurinol for them, and the misconceptions about gout.

“Adherence is a big challenge. Often, people get better and stop medicating. It’s not as simple as just going back on allopurinol, and the pain goes away. You have to start from scratch and get your uric acid back to the required level.

“Some people don’t like the idea of taking medications every day. Also, there can be shame or a stigma attached to gout because many people think that it’s self-inflicted.

“Allopurinol is a proven method of managing gout and enables patients to go back to eating, within reason, foods they would avoid due to gout, such as certain seafood which are good for overall health. Taking allopurinol regularly is a win-win.”

A further barrier is that people currently have to get repeat prescriptions from their GP. Philip says enabling pharmacists to supply allopurinol without prescription, provide follow-up urate testing, and support patients to understand better and manage gout medication would support uptake and adherence.

“Taking allopurinol at the right dose every day makes such a difference to people’s lives, and that’s why it is so important to remove barriers and to provide education, so patients and their whānau understand gout and people are encouraged to take their allopurinol – it’s that supportive element.

“Pharmacies are a key touchpoint for people. They are open longer hours than GPs, including weekends in many cases, and they don’t need an appointment. So it would be easier for people to access allopurinol.”

Working together

Medsafe is the agency responsible for regulating medicines in New Zealand. In preparing the submission for reclassification of allopurinol, Arthritis NZ worked with pharmacist **Dr Natalie Gauld** and with the support of Green Cross Health. Gauld (awarded with an ONZM for her work with pharmacy and health) has extensive experience running a community gout programme and had previously submitted on the issue.

Consultation was also undertaken with organisations, including the Pharmaceutical Society, Pharmacy Guild, NZ College of GPs, PHARMAC, Susan Reid and Gout Action Aotearoa, and other key stakeholders.

If the reclassification is approved, work will begin to develop the model of care, education programmes, provision of equipment, and financial arrangements to support pharmacies in their work.

“

“Allopurinol is a proven method of managing gout and enables patients to go back to eating, within reason, foods they would avoid due to gout, such as certain seafood which are good for overall health. Taking allopurinol regularly is a win-win.”

“We are hopeful reclassification will happen,” says Philip. “That will be the first step, but there will still be a long way to go.

“It will be about starting to work together to enable change – because we know if we can change things, it will have a material impact on communities. It has to be community-driven. We will be there to support it, but to be most effective, the community must lead it.”

About gout and allopurinol

Gout arthritis is a naturally occurring inherited disease, but there are widespread misconceptions that it is caused by diet or lifestyle. While it is more common in men, women get gout too.

Up to 250,000 New Zealanders have gout, but just 43% are on managed programmes to reduce the excess uric acid, which causes flares and extreme pain.

Arthritis NZ aims to increase the number of people with gout who are on urate-lowering programmes such as allopurinol to 55% of those diagnosed with gout – an increase of 23,000 people.

Allopurinol is a low-cost medication. Research by Deloitte on behalf of Arthritis NZ calculated that achieving the 23,000 target would result in savings of around \$210 million annually – taking into account factors such as gout-related hospitalisation and absenteeism from work.

As with many medications, it is important to ensure that allopurinol is taken daily rather than just when symptoms are present.

MEET OUR

Menopause and Arthritis podcast host

by Patricia Thompson

On 7 March this year, we launched our very first podcast series titled Menopause and Arthritis. This podcast series will cover the dual challenge of managing menopause and arthritis for women in New Zealand. The host, **Jo Miller**, is a part-time Arthritis Assist employee who provides mental health support to people with arthritis.



Jo is studying health psychology at Massey University and has a particular interest in women's health and aging, including exploring the connection between arthritis and menopause. We caught up for a Q&A to find out more.

Q: Tell me about you

Jo: I had a career in marketing and communications but wanted to do something more purposeful and mindful and to give back to people. So, I began studying and ended up focusing on women's health. I have submitted the ethics application for my Master's thesis, which is looking at the lived experience of women going through menopause with rheumatoid arthritis (RA).

Q: Women are more likely to develop arthritis, particularly osteoarthritis and RA, during and after menopause. Why is that?

Jo: There is a correlation that seems to be related to female hormones – for example, women are three times more likely to develop RA than men - but there hasn't been enough research yet to identify why.

Q: What should women do if they develop joint pain during menopause?

Jo: During menopause, women's hormone levels of oestrogen and progesterone gradually decline. Some of the symptoms, such as joint pain, can be similar to arthritis. If you have those symptoms, see your GP or health provider and be prepared to ask the right questions. Talk about what has changed for you and what hasn't. Is it menopause, or could it be arthritis? Will hormone replacement therapy (HRT) help as an option for treatment?

Q: What led you to focus on this area of health?

Jo: I wanted to increase awareness so women understand more about the changes happening to their bodies and whether their symptoms are menopausal or might be arthritis. Then, you can discuss the best options and treatments for managing either or both. That might also include looking at lifestyle, exercise, diet, and complementary therapies.



Scan here to
listen or watch
on YouTube



Scan here
to listen on
Spotify.

Q: At what age might menopause symptoms appear?

Jo: On average, any time from the early 40s through into the 50s, and they can last a long time. It is often when women are very busy juggling children and jobs. From hot flushes to pain, it can impact home life, relationships and work. The important thing is to seek advice from a healthcare professional and ensure you get the right diagnosis and treatment.

Q: What inspired your research topic?

Jo: RA is very painful and menopause adds another layer of complexity for women already managing arthritis. Symptoms can overlap, making it even harder to manage the condition. Women can really suffer, even when the arthritis is in remission. My research is about looking at women with lived experience and how they navigate that stage of life with a chronic condition like RA, and how to support them during that period.

Q: What will the research involve?

Jo: I will recruit 12 women from around the country, who are in the 45-55 year old age group, experiencing menopausal symptoms and with a diagnosis of RA. I will be using a 'cooperative inquiry' approach where they will talk about their experiences with each other in groups. It will probably involve about three meetings for each.

Q: Tell me about the podcast?

Jo: It provides expert insights and real-life strategies. We asked our arthritis community what burning questions they have, and we are structuring the series with different topics that will cover the questions. I'll be chatting with experts, health professionals, and advocates to uncover practical advice and real stories.

The podcast is available to stream on YouTube and Spotify, just search for Menopause and Arthritis or use the QR codes provided above.

MOMENTS that matter

A collection of photos from various events and community work that Arthritis NZ has done during the last few months.



ABOVE:
Arthritis NZ staff Jo Bunt, Zechariah Reuelu and Rebecca Murphy were out improving health outcomes for Pacific and Māori communities at the **2025 Pasifika Festival**.



ABOVE:
Arthritis NZ's Zechariah Reuelu using the foot model he designed to demonstrate how gout crystals form to people at the **2025 Pasifika Festival**.

Arthritis NZ staff Tory Garnham (centre) and Zechariah Reuelu (right) with Porirua community pharmacist Ajay Kumar (left) at **Te Rā o Te Raukura 2025**, a community health expo held at Te Whiti Park in Lower Hutt.



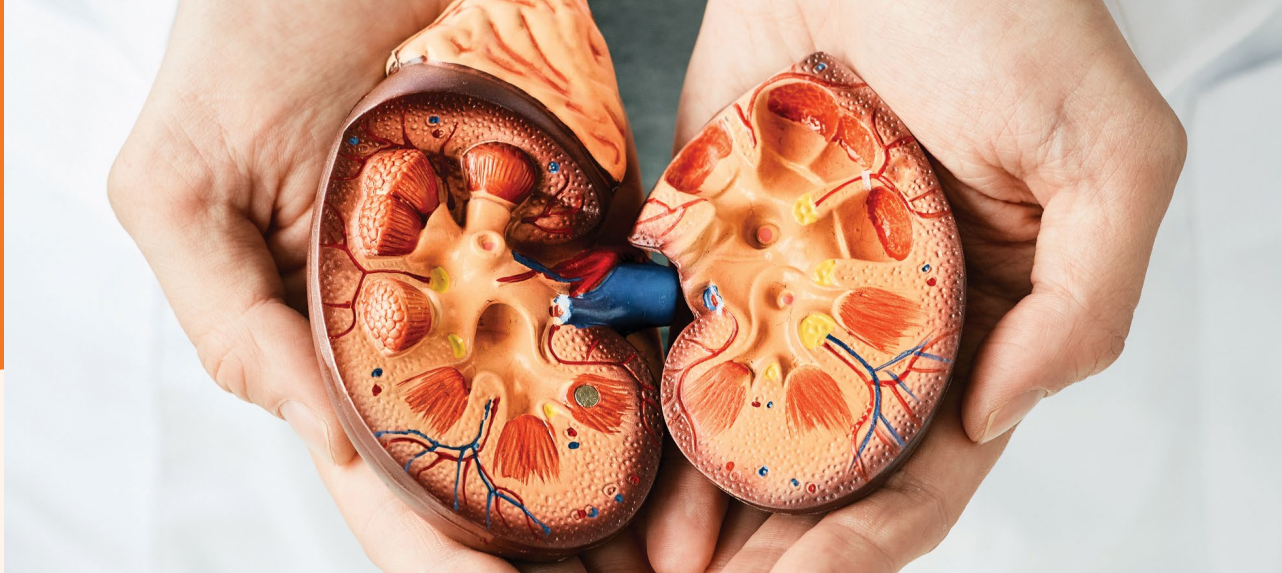


The attendees of the **Arthritis NZ Teens Camp** which was held at El Rancho in Wellington.



Our most recent event, **Families Camp 2025** held in Matamata.





GOUT AND kidney disease

by Dr. Valerie Milne

Gout and chronic kidney diseases create a vicious cycle: kidney disease can cause gout, and gout can worsen kidney disease. Early screening, lifestyle changes, and careful medication management are essential to preventing complications.

Gout occurs when high levels of uric acid in the blood form crystals in and around the joints, causing painful arthritis attacks. However, these crystals don't just affect the joints. They can also accumulate in the kidneys, contributing to kidney stones and long-term kidney damage.

At the same time, chronic kidney disease reduces the kidneys' ability to remove uric acid from the body, leading to higher levels of uric acid in the blood and an increased risk of gout attacks. Research shows that people with gout are significantly more likely to develop chronic kidney disease, likely due to chronic inflammation and uric acid buildup.

Managing both conditions together presents challenges, especially when it comes to medication. Anti-inflammatory medications, commonly used in gout, can harm weakened kidneys and require careful medical supervision. However, urate-lowering therapy (ULT) has the potential to help slow chronic kidney disease progression.

Risk factors for gout and kidney disease

Genetic factors underlie hyperuricemia (high uric acid levels) that lead to gout. Uric acid is produced when proteins called purines are metabolised from food, and most of it usually passes out of the body in the urine. As well as gout, high uric acid levels can also lead to chronic kidney disease and kidney stones. There are some manageable risk factors that also contribute to this condition. These factors include reducing the consumption of high-protein and high-sodium diets and sugary drinks. Reducing high sugar levels in the blood and hypertension (high blood pressure) can also improve a person's chances of reducing gout flares and some kidney conditions.

Dietary considerations

The relationship between diet and gout is well-documented. Some foods have been found to increase uric acid levels, while others may reduce the risk of high uric acid levels and gout flares.

Foods that can increase uric acid levels:

- Seafood high in purines
- Organ meats (offal)
- Sugary soft drinks and processed foods
- Alcohol, particularly beer

Foods that may reduce uric acid levels:

- Low-fat dairy
- Non-citrus fruits, carrots, mushrooms, and eggs
- Peanuts, whole grains, and soy products
- Coffee and black tea
- Vitamin C (in moderate amounts) may help lower uric acid, though excessive doses could increase kidney stone risk
- Drinking more water (6 to 8 cups a day) is important to lower uric acid levels

Medications and impact on gout

Treating gout in people with chronic kidney disease and/or with other conditions requires careful management. Some medications used to treat conditions other than gout trigger or exacerbate gout by increasing uric acid levels and/or reducing the excretion of uric acid. These types of medicines include:

- Diuretics for treating hypertension
- Antiretroviral drugs
- Beta-blockers, ACE inhibitors, and other medications for heart health
- Immunosuppressants

ULT therapy and chronic kidney disease progression

Studies suggest nearly 25% of adults with chronic kidney disease at stage 3 or higher also have gout, and the management of gout in patients with chronic kidney disease presents some challenges because NSAIDs and colchicine should be used cautiously, and lower doses of ULT such as allopurinol may be required. The effect of glucocorticoids, used for gout flares, on kidney function is unclear.

Despite the concerns about ULT worsening kidney function, a recent study found that achieving urate levels low enough to prevent gout flares using ULT was not linked to an increased risk of severe kidney disease progression. Instead, patients who achieved this target had a slightly lower risk of developing

Urate-Lowering Therapy (ULT)

Gout attacks can be prevented with medicines that reduce uric acid levels, such as allopurinol, febuxostat, or probenecid.

- These preventive medicines need to be taken every day, even during a gout attack.
- If ULT medicines are stopped, even if only for a few days, uric acid levels rise and crystals form. This can cause a gout attack and joint damage,
- It may take 6 to 12 months of taking preventive medicines every day before your uric acid level is below the usual target of 0.36 mmol/L.

Source: <https://healthify.nz/medicines-a-z/g/gout-medications>

end-stage kidney disease. Therefore, using ULT medications, such as allopurinol, to reduce urate levels appears to be helpful for managing gout in chronic kidney disease patients.

Gout and kidney transplantation

Kidney transplant recipients are at a higher risk of high uric acid levels, and new-onset gout than people who have not had a kidney transplant, and gout is often more severe and harder to manage in transplant patients. Cyclosporine, a commonly used immunosuppressant, significantly increases the risk of high uric acid levels.

Individuals with gout are at higher risk for kidney stones and chronic kidney disease, making early screening essential. Dietary modifications, careful medication management, and appropriate ULT can help reduce the risk of complications.



Together we can transform lives and ensure all New Zealanders with arthritis can live well.

People we love are suffering from arthritis. Many forms of arthritis can be managed well with the right support, education, and resources.

By supporting Arthritis NZ you can help improve the lives of people with arthritis.



DEEPER UNDERSTANDING

We can provide personalised information packs, with the latest medical advice.



PRACTICAL SUPPORT

Advice for people about their arthritis through our Arthritis Assist service.



PAIN MANAGEMENT

Information about how to manage pain and feel better faster.



TO DONATE, SIMPLY SCAN
THE QR CODE, OR VISIT

www.arthritis.org.nz

You can also give our
friendly fundraising
team a call on
0800 663 463

If you would prefer, you can donate
by direct deposit or internet transfer
directly into our bank account.

If you donate via direct deposit, please
email us with your details so we can
send you a receipt.

ACCOUNT NAME: Arthritis New Zealand Mateponapona Aotearoa

ACCOUNT NUMBER: 03-0502-0468578-00

YOUR REFERENCE: First Name and Last Name

**P O Box 10 020, The Terrace,
Wellington 6143, New Zealand**

Phone: 0800 663 463
Email: info@arthritis.org.nz
Website: www.arthritis.org.nz



**Arthritis NZ
Mateponapona
Aotearoa**