

A conversation about gout...

In New Zealand, the majority of people with gout have higher than optimal serum urate levels. A primary reason for this is a lack of understanding of what gout is and of the need for ongoing treatment. Effective communication and educating patients about their condition improves their long-term outcomes. We interviewed Leanne Te Karu, a Pharmacist Prescriber from Taupo with a special interest in managing patients with gout, about why she thinks the message is not getting through. We discuss her approach to helping increase people's knowledge of gout, and include simple strategies to improve communication, enhance understanding and improve the health and quality of life of people with gout.

The challenges of managing gout

"It's such a bizarre thing that gout is something that, on the whole, is so easily treatable, so easily preventable and yet we as health professionals do so poorly." — Leanne Te Karu

In New Zealand, surveys of health data sets estimate that at least 4% of adults aged over 20 years have gout, with higher rates in Māori (at least 6%) and Pacific peoples (at least 8%).^{1,2} Prevalence also increases with age, and is higher in males and in people living in lower socioeconomic areas; it is estimated that one-third of Māori and Pacific males aged over 65 years have gout.¹ It is likely that a significant number of people with gout are currently not identified, which would make estimates of prevalence even higher.³

A significant proportion of people with gout in New Zealand are poorly managed; it has been reported that studies in New Zealand have found that only approximately 50% of patients with gout had received a serum urate test in the previous year.⁴

A study involving patients with gout in South Auckland found that only 20% of those who were tested regularly had a serum urate level at or below target at any time in the previous year.⁵

One of the main barriers to managing gout is that patients often have a limited understanding of their condition and the medicines they take to control it, which can negatively affect self-management and medicine adherence.^{6,7}

Stoicism, embarrassment, a belief that gout is self-inflicted, fear that they will be "told off" by the clinician and that gout is a normal part of ageing are all commonly cited as reasons for poorer long-term outcomes.^{6,8} In contrast, increased knowledge (as perceived by the patient) about gout is positively correlated with improved management.⁹

However, the process of educating and engaging people with gout, as with many long-term conditions, is challenging.

This article is based on an interview with gout and clinical pharmacy researcher **Leanne Te Karu**. Leanne has worked across many facets of the health sector including hospital, community pharmacy, academia, marae and primary care. She is a Pharmacist Prescriber based in Taupo and runs a clinic in Turangi. She was a founder of the Māori Pharmacists' Association and has had a long-standing involvement in increasing health equality, particularly in Māori and lower socioeconomic communities.

Three steps to improving communication

Most people with gout will benefit from improved education about their condition and their treatments. However, this process is complicated by the differences in the level of patient's knowledge, literacy, education and interest. Because of this, information and material provided to patients must be individualised and appropriate for them. The following three-step approach may be helpful when discussing complex information with a patient:

- Assess the patient's current understanding of the topic
- Build on that knowledge
- Check that the patient has understood the information you intended to convey

This then creates a loop, with gaps in understanding forming the basis of the further education, after an attempt to convey information.

Assess the patient's current knowledge

"We need to ascertain what people know first. It starts with checking what people know, so that you have a platform to go forward from." — Leanne Te Karu

Start by asking the patient what they have been told about gout or how they would normally manage an acute attack. This can create an opportunity to ascertain what the patient knows and their level of understanding without the patient feeling like they are being tested.

Build on that knowledge

"It is essential that we deal to those fallacies about gout: that it's purely about food; that it's all your fault... and the myths about allopurinol being ineffective or 'bad'" — Leanne Te Karu

Once the clinician understands the level of knowledge the patient has, they can fill in any gaps, discuss incorrect beliefs and suggest practical approaches to self-management. Education should cover what gout is, the difference between acute and preventative treatments and the lifestyle aspects of gout management.

Check that the patient has understood

"Before the end of the consultation we need to do a final check to ensure we have imparted the messages we intended. The important part is that we take ownership of any potential gaps in knowledge i.e. the responsibility is ours

as health professionals. You can try various approaches, e.g. saying 'Ok, so I've done a lot of talking today. I just need to make sure that I'm doing my job correctly and that I've explained it clearly and what you got out of it?'"

— Leanne Te Karu

As Leanne states, the final part of the conversation is ensuring that the patient has understood. This could be done by asking the patient what they will say if their partner or a family member asks them about gout and how it is treated. This forms an important part of the conversation, as information that sounds clear to a health professional will not always be clear to a patient.

Health professionals have a responsibility for the health literacy of their patients

"We don't often talk about the health literacy skills of the health professional. The onus has invariably and historically sat with the patient in front us. More emphasis needs to be placed on ensuring we are providing understandable messages and checking for that understanding."

— Leanne Te Karu

Helping patients to understand what gout is requires a certain level of communication skill on the part of the clinician. While this is seemingly obvious, the current level of poor management, outcomes and medicine adherence clearly indicates that there is a gap in what patients should know about gout, and what they do know.

Given the wide range in levels of comprehension and literacy in patients, being able to adapt language to the individual patient is important. When talking about any health issue, patients will respond better when they perceive their healthcare professional to be understanding and understandable. A good strategy is to relate information to the patient's background and past experiences, provide practical information and avoid jargon.

Cultural competency facilitates building health literacy

"Health literacy needs to be thought of as a component of cultural competency. The overarching umbrella must be that people feel safe enough to share all that is relevant. In terms of gout, whanau often have stories, perceptions and experiences that are intergenerational. Again, at the heart of our practice is our responsibility to be culturally competent to ensure people feel safe to approach you, to share with you and to feel they have been understood."

— Leanne Te Karu

The Medical Council of New Zealand states that: “Cultural competence requires an awareness of cultural diversity and the ability to function effectively, and respectfully, when working with and treating people of different cultural backgrounds. Cultural competence means a doctor has the attitudes, skills and knowledge needed to achieve this.”¹⁰

Leanne stresses that cultural competency is an essential part of any attempt to improve a patient’s understanding of their health and is fundamental to the entire interaction.

Gout can be easily diagnosed, prevented and treated. Clear clinical pathways have been developed that are built on robust best practice evidence. Yet there are still people with poorly controlled and managed gout. Leanne believes that engagement is the missing link.

Dissolving the myths about gout

There is significant misinformation about gout in the community and many “myths” surrounding its pathogenesis, treatment and prognosis.

Myth 1 – It’s all about diet

“[We need to be really clear] that it’s not all about food. I think that’s a huge myth out there that we have to dispel, because that prevents people coming forward; they think they’re going to be judged about their diet – both food and drink intake. People often try to avoid all known triggers and still they experience flares. This can lead to blame both from self and whānau. It also reinforces a stereotype with younger ones who then delay seeking treatment.”

— Leanne Te Karu

Many people hold the belief that gout is primarily a lifestyle disease. As Leanne states, this is not the full story. Genetic predisposition, usually due to inefficient renal urate clearance, is thought to account for a significant proportion of the prevalence of gout; it is reported that up to 60% of gout may be attributed to genetics.¹¹ One-in-four people with gout have a known family history of gout.¹¹ Māori and Pacific peoples in particular appear to be genetically predisposed to developing gout.^{8, 12}

It is accepted that alcohol (particularly beer), purine-rich meats (e.g. red meat and offal), seafood (particularly shellfish and oily fish) and fructose and sucrose-sweetened drinks contribute to increased serum urate levels. Dietary and lifestyle changes are important and can achieve a lowering of serum urate levels,



but for most patients, pharmacological treatment of gout will play a more significant role in controlling hyperuricaemia.¹³

Dietary and lifestyle changes can be difficult for patients to adhere to and understand. As Leanne states, often the known triggers of gout are relatively healthy foods, e.g. tomatoes, kaimoana (seafood) and oranges which can still be enjoyed in moderation once target serum urate has been achieved. Sometimes this can be motivation for maintaining treatment when people realise they can enjoy such foods again.

Myth 2 – You cannot exercise if you have gout

"I agree there are conflicting messages out there, because we know that in an acute stage if you exercise your serum urate levels are going to go up, so we don't want that to happen, but we do want you to have an active lifestyle overall."

— Leanne Te Karu

In the short-term, aerobic exercise may temporarily increase serum urate levels.¹⁴ This should be carefully explained to patients to avoid discouraging them from exercising. Of course, exercise will be physically difficult or impossible for many patients during an attack due to pain and limited mobility.

Explain that increased exercise between acute exacerbations will be beneficial in the long-term, particularly for those who are overweight or obese. Exercise is also beneficial in reducing the risk of developing many of the co-morbidities associated with gout, such as cardiovascular disease (CVD).

Once the patient's acute symptoms have resolved, if necessary, help them to develop an exercise plan. Ask the patient to suggest a level of activity they feel they can commit to on a daily basis and use this as a starting point. Over time, the patient's level of activity should ideally be at least thirty minutes per day, the minimum amount recommended for New Zealand adults.¹⁶

Leanne has found that many patients are open to participating in organised exercise programmes, e.g. a walking or swimming group. A large number of whānau are now involved in events such as "Iron Māori".

Leanne also cautions against stereotyping as some of the people she sees are very fit young men, with low body fat percentages, playing sport at representative levels. This is another reason that we need to de-stigmatise gout so all people feel able to seek health assistance.

Myth 3 – Allopurinol is a bad drug

"I believe that because historically we have not prescribed allopurinol as recommended we have perpetuated the myth that allopurinol is a 'bad drug'. By this I mean sometimes allopurinol is initiated at an increased dose with or without concurrent NSAIDs cover (more often than not – without) and people end up having a flare. We then do poorly at titrating dosage to reach target and people again get flares – they begin to wonder at the point of it all. I also find that sometimes people are not clear on the function of allopurinol and take it only while they have a flare. Again whose fault is it if they are not clear – certainly not theirs I would advocate." — Leanne Te Karu

Ensure patients understand that allopurinol is the mainstay of gout prevention, and the majority will need urate-lowering treatment for long-term control.¹⁷ It can be explained (in an appropriate way) that allopurinol inhibits the activity of an enzyme (xanthine oxidase) needed to create urate.¹³ If this enzyme is blocked, serum urate levels will fall and urate crystals will slowly dissolve over time.¹³

Many patients are hesitant to take allopurinol, as there is significant misinformation about the medicine in the community. One of the more widespread objections to allopurinol is that it will worsen the symptoms of gout. This belief has likely arisen due to the increased risk of gout exacerbations in the first six months of treatment when allopurinol is dosed or titrated sub-optimally, e.g. using a starting dose of 300 mg instead of titrating up from a lower dose.

Explain to the patient that allopurinol is a safe and highly effective medicine if taken consistently. It may cause flares when treatment begins, but as cover, most colchicine or NSAIDs (e.g. naproxen) is given concurrently, these should be manageable.¹⁷ This can be used as an opportunity to explain to the patient the need for titration and the necessity of taking the medicine every day, including during gout flares. Other strategies, such as using blister packs during the titration phase, can be considered to aid patients and to reduce medication errors.

If, despite optimal use of allopurinol, gout is still unable to be managed (or if allopurinol is not tolerated), further treatment options may be considered, e.g. probenecid, benzbromarone, febuxostat.

Presentations for gout can be used as an opportunity to address co-morbidity

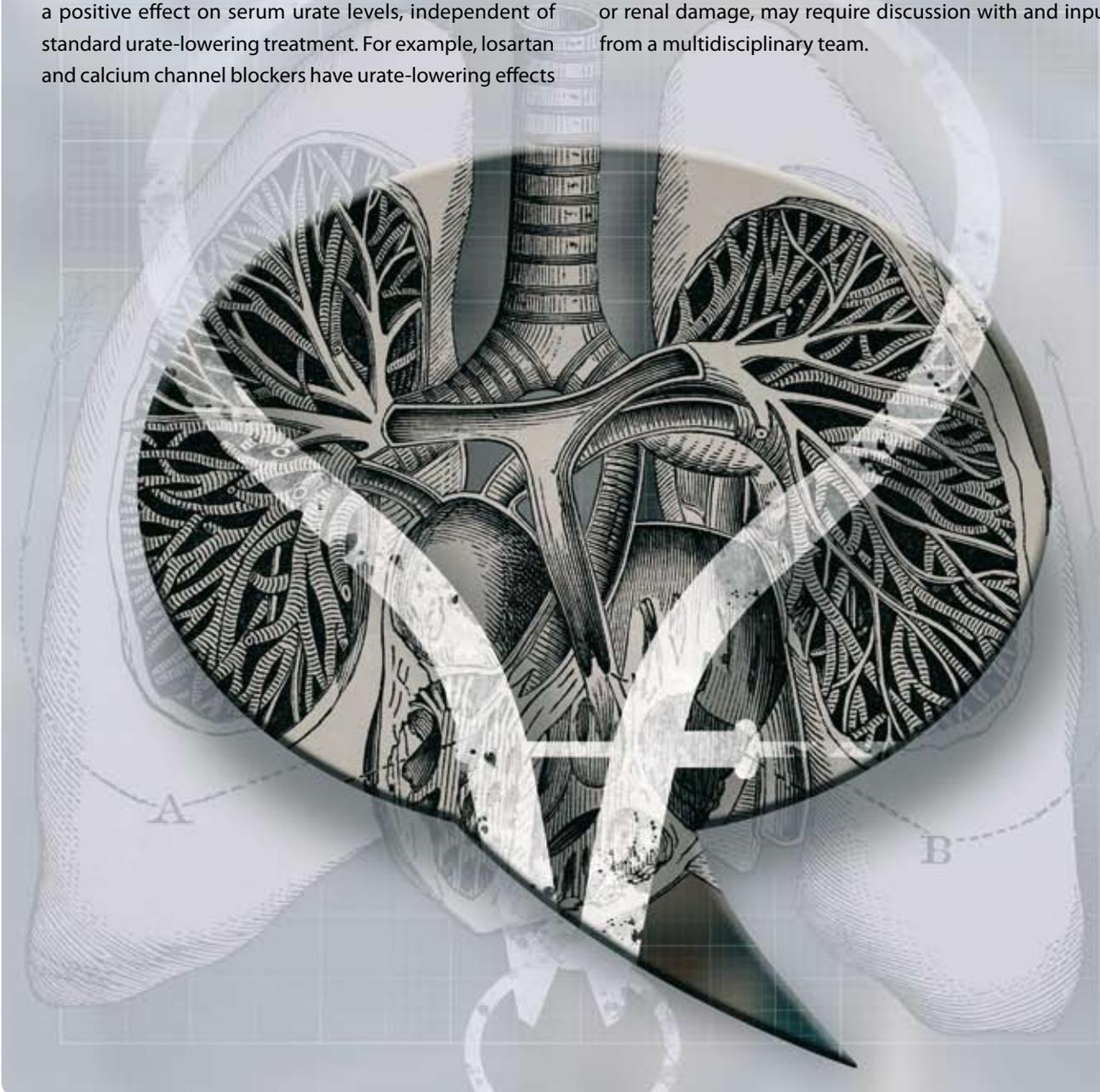
In New Zealand, it is estimated that 40% of people with gout have cardiovascular disease and/or diabetes.¹⁵ The European League Against Rheumatism (EULAR) recommendations state that associated co-morbidities, such as hyperlipidaemia, hypertension, hyperglycaemia, obesity and smoking, should be addressed in people with gout as part of their routine management.¹⁷

Apart from the obvious benefit of detecting and managing these conditions in their own right, there is evidence that the management of co-morbidities has a positive effect on serum urate levels, independent of standard urate-lowering treatment. For example, losartan and calcium channel blockers have urate-lowering effects

which may be useful in the treatment of hypertension in patients with gout.¹⁵ Atorvastatin also has urate-lowering properties and may be useful in patients with gout who require a statin.¹⁵

Conversely, several medicines that are used to treat associated co-morbidity can increase serum urate levels, such as diuretics and low dose aspirin.¹⁵

Management of patients with gout with multiple co-morbidities, such as heart failure, severe hypertension or renal damage, may require discussion with and input from a multidisciplinary team.

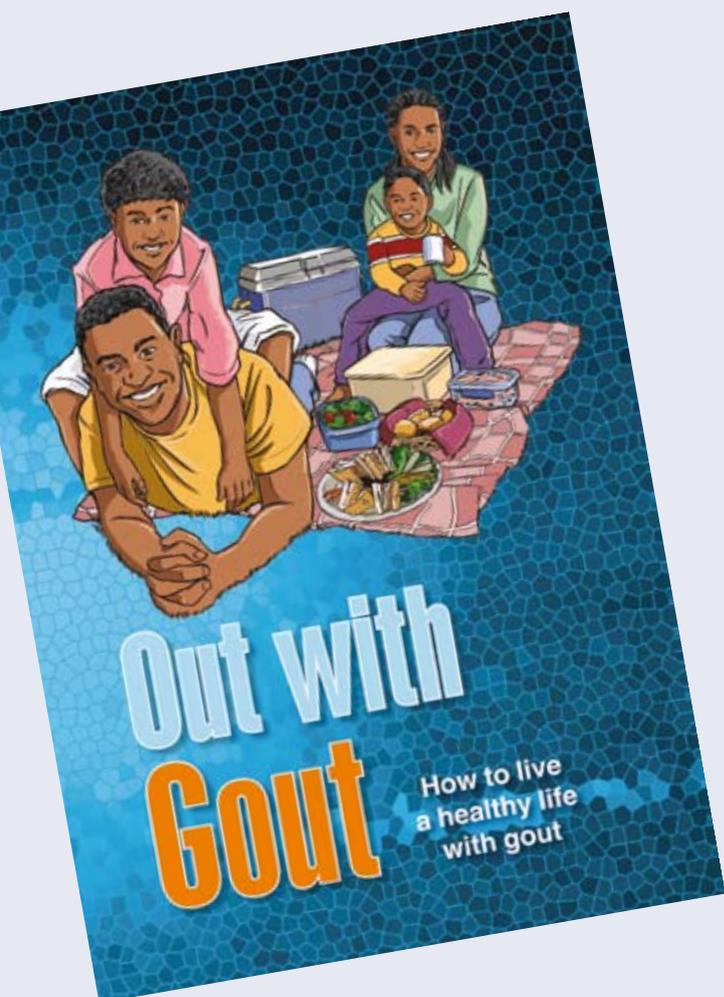


Resources for patients

The “Out with Gout” booklet, produced by PHARMAC can be recommended, or provided, to patients as a take-home resource. The booklet is culturally relevant to New Zealanders and is available in English and Te Reo Māori and can be ordered in other languages.

 The booklet is available from www.pharmac.health.nz/medicines/your-health/gout and alternate language translations can be ordered from: www.pharmaonline.co.nz

 For further patient resources, see: www.gouthappyfeet.com/gout-how-it-effects-you



Myth 4 – Gout is an acute joint disease

“It’s about [the patient] understanding that it’s not just about joint pain ... that gout is a chronic condition... that it’s actually about their kidneys, and about cardiovascular disease.” — Leanne Te Karu

For many patients, the pain and disability present during attacks will be the primary motivator for seeking treatment. However, this motivator is absent between exacerbations and in people who have reached their target urate level, which can then lead to them stopping their medicines. As Leanne phrased the problem: “[NSAIDs or prednisone] work during a flare... so why do I want to take a medicine everyday forever?”

This problem can be likened to an issue commonly encountered in people with asthma; regular use of a reliever medicine, but often suboptimal use of preventer medicine. As with asthma, understanding the role of each medicine is the key.

Helping patients understand what urate is, that NSAIDs only cover the symptoms and attempting to get patients actively involved in trying to lower their serum urate levels is crucial. Annual urate testing, which is necessary to monitor urate-lowering treatment efficacy and dosage, can be used to illustrate ongoing improvements in urate level and give justification for continuing allopurinol treatment.

Patients will benefit from knowing that gout is a chronic condition that requires long-term management to prevent joint erosion and permanent disability. Along with the long-term damage to the joints, gout is associated with other significant risks (see: “Presentations of gout should be used as an opportunity to address co-morbidity”). Hyperuricaemia, the primary risk factor for gout, is associated with an increased risk of:¹³

- Hypertension
- Renal damage
- Diabetes and insulin resistance syndrome
- Hyperlipidaemia
- Cardiovascular disease (CVD)
- Obesity

“It’s a little bit like diabetes... you are not always hypo or hyperglycaemic when you have diabetes, but you always have diabetes. [With gout], you always have this underlying tendency to have a gout flare if your urate level is too high.”

— Leanne Te Karu



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