

# JOINT SUPPORT

ARTHRITIS NEW ZEALAND MAGAZINE JUNE 2018



*Improving the life of every person affected by arthritis*

## Shopping trolley success

Arthritis New Zealand advocate Lorraine Knight has been campaigning for change at the supermarket.



While shopping at her local Pak 'n' Save, she realised there was a shortage of small trolleys, which are much easier for her to manage.

“The big trolleys are very hard to control. I have severe problems from arthritis and can't grip properly and have little strength in my hands. The small trolleys are quickly snapped up by many shoppers, and it can make the shopping experience time-consuming and frustrating for people like me.”

Lorraine raised the issue with Foodstuffs New Zealand, asking them to make sure there were plenty of small trolleys on hand. Meanwhile at Arthritis New Zealand, we realised Lorraine had uncovered a real problem for many people with arthritis. Our Facebook post drew numerous comments about how the smaller trolleys are much easier to handle.

Foodstuffs responded promptly by circulating a memo to its stores instructing staff to bring large and small trolleys in from the carpark at the same time. They acknowledged that the large trolleys can be difficult to use, not just for people with arthritis but for older people as well.

Lorraine is happy with the way her feedback was handled, and is already fired up about her next campaign – hard-to-open packaging, especially cans, bottles of dishwasher powder and anything encased in hard plastic.

Advocacy for her is about communicating with the relevant people to bring about change, because unless they're informed, they may not be aware of customers' problems.

“Small actions can make a big difference for people with and without arthritis,” she says.



**ARTHRITIS  
NEW ZEALAND**

KAIPONAPONA AOTEAROA

## A word from Philip

I have been in this role for six months now and it has been a real pleasure to meet and talk to supporters all around the country. The issues and concerns I hear are fairly similar: the importance of access to good services and support; the recognition that arthritis is a serious health issue; and understanding that arthritis affects people of all ages. These are consistent themes and discussion points.

Volunteers are vital to our ongoing success and I am continually impressed by the dedication and commitment displayed by our volunteers. Support for volunteers and their activities is a key focus for me and I am always happy to hear from you and discuss local activities and needs.

Thank you for your input into our Joint Support reader survey. The results (summarised below), clearly show that you value this magazine and it is important to maintain the print version alongside

digital options. You have told us that you want a wide variety of stories that cover all aspects of living with and managing arthritis, so we will continue to provide these in future editions.

Inside this issue you will find an article by Kylie Frost about the everyday task of cooking dinner and how difficult it can be when packaging is hard to open. This is very much part of our accessible packaging focus and highlights our role in advocating around key issues on behalf of all those impacted by arthritis.



I hope you find the other articles interesting and enjoyable too. If you have ideas and suggestions about what you would like to read in Joint Support, give us a call on 0800 663 463 or email [info@arthritis.org.nz](mailto:info@arthritis.org.nz). We are always keen to hear from our readers.

Ngā mihi nui

**Philip Kearney**  
Chief Executive

## Reader survey results

Thank you to all those who filled out our Joint Support reader survey in the last issue. We received 294 responses, most of them in paper form and only 49 (17 percent) via digital means.

It's clear that the majority of our readers are in the 'older' bracket as 96 percent of those who returned a paper form are over the age of 55. Perhaps not surprisingly then, osteoarthritis is

the most common form of arthritis among readers, followed by gout and rheumatoid arthritis.

We have noted that some of you find the print size and glossy paper hard to read.

The survey results show that most of

you would like to continue receiving the magazine by post rather than by email or online. Articles on pain management, and stories about people with arthritis are viewed as the most valuable; readers would also like to see more information about medications (and supplements), research, products, diet, nutrition and exercise.

Many of you wanted to know about local services, events, exercise classes or support. This is difficult to provide in a magazine that is produced only three or four times a year and covers the whole country. Local activities and support groups are all listed on the website. If you

can't access the website, do call us on 0800 663 463 during business hours to find out what is on in your area.

Don't forget that you can also speak with an arthritis educator about anything to do with your arthritis by phoning **0800 663 463**.

It's good to know that so many of you enjoy reading Joint Support. Your feedback was gratefully received and we hope you continue to gain benefit from the magazine.



## Living with juvenile arthritis

Children's Camp exceeded expectations for Rotorua teenager India Heron and her mother Belinda.

Like other children with arthritis, India, 13, was able to try new activities and make new friends, knowing that they understood what she was going through.

In spite of a painful flare just before camp, she was able to try rock-climbing, kayaking, flying Kiwi and the flying fox. She also enjoyed relaxing in the hot pools and hearing from older young people about their experiences with arthritis.

*"India loved it and felt very relaxed. She learnt a lot about herself and the disease – that she can push her limits in a safe environment and it will be OK. The youth panel was really beneficial."*

– Belinda, India's mum



India Heron on the flying fox at the recent children's camp.

Belinda said the highlights for her were meeting other parents and learning from health professionals. She said the camp was very well run and "beautifully encouraging".

*"It was an incredible thing and we were very fortunate to be part of it."*

India's arthritis began with a swollen knee. At first, it didn't appear to be serious but before long her right knee was twice its normal size and she was limping in pain.

Medical tests ruled out a sprain or a tumour. After the fluid was drained, India had steroid injections to manage the inflammation.

A couple of months later the diagnosis was confirmed as JIA, or juvenile idiopathic arthritis – the most common form of arthritis in children. Both India's knees were soon affected, then her ankles, hips, wrists, elbows, fingers and toes.

Since diagnosis about 18 months ago, India has responded well to arthritis and pain medication. Physiotherapy and hydrotherapy also help. She and Belinda are still in touch with other families from camp and are keen to go again next year.



13 year old India and her mum Belinda.

## Tiny fish helps find a cure for gout

A tiny transparent fish is helping researchers find a way to treat painful gout arthritis attacks.

Zebrafish are a popular aquarium species. They also have many characteristics that make them a useful model for studying human genetics and disease. They're small and robust, reproduce quickly, grow fast and the young fish are transparent, which means their internal structures and processes can be easily observed.

Using highly specialised microscopes, researchers at the University of Auckland have been able to detect how the zebrafish's immune system responds to urate crystals and drives inflammation – the main cause of gout attacks.

Acute gout attacks occur when uric acid in the blood forms crystals that build up in and around the joints, activating the immune system and leading to inflammation and extreme pain. Researchers have previously relied on examining tissue samples that only provide a static 'snapshot' of the disease. This is the first time the process has been observed in a whole animal.

Dr Chris Hall of the Faculty of Medical and Health Sciences led the study with several colleagues, including Professor Nicola Dalbeth, an academic rheumatologist and internationally recognised expert in gout research.

"We have shown that our discovery translates to the human disease and that blocking this mechanism of immune cell activation represents a new strategy to alleviate gouty inflammation," Dr Hall says.



Dr Chris Hall and his zebrafish.

The study is particularly significant in New Zealand where gout arthritis is more prevalent than in any other country. Māori and Pacific people are more likely to have gout arthritis than other ethnic groups but are less likely to receive the most effective long term preventive medicines.

Source: University of Auckland

[www.fmhs.auckland.ac.nz/en/faculty/about/news-and-events/news/2018/3/tiny-fish-leading-the-way-in-a-cure-for-gout.html](http://www.fmhs.auckland.ac.nz/en/faculty/about/news-and-events/news/2018/3/tiny-fish-leading-the-way-in-a-cure-for-gout.html)

## Hami's story

Many people do not know that gout is a form of arthritis, and the second most common type in New Zealand, particularly affecting Māori and Pacific Island people.

Hami's story is typical. Several members of his family had gout arthritis and he also had osteoarthritis, which had led to knee and hip replacements. Hami had his first gout attack ten years ago when his big toe suddenly became swollen and extremely sore. Four years later, he was having two or three gout attacks a year that also involved his right ankle, foot and elbow, but he was not diagnosed with gout arthritis by his GP until 2014.

Hami was already taking an anti-inflammatory for his osteoarthritis and this continued to be prescribed for his gout, until a gastric bleed forced him to stop using it. Then he started on allopurinol which he now takes every day.

He also changed his diet and lifestyle by cutting out sugary drinks, reducing alcohol and red meat, and drinking more water.

Hami lost 5kg in weight and was very pleased when all his joints felt much better, although he was surprised it took so long to get on top of this problem.

To raise awareness, we are now using the term 'gout arthritis' to describe the condition and we are working with DHBs to identify how we can support more gout arthritis education programmes that will relieve suffering for people like Hami.

## Kylie's story:

# Packaging limits dinner choices

It is 6 o'clock at night and I have finally finished work for the day. I head to the fridge to check what I can cook for dinner. In another life I was a chef and loved to cook. Now I dread it.

Oh goody, mince again. Maybe lasagne? The thought fills me with dread. Not because it is a hard meal, more because of the difficulty I now have in making it. First, the ingredients.

### Mince

The mince is easy. A knife will open the packet. After that it gets harder. The flavour mix isn't too hard to open. (Flavour mix! I know, but work ran late and the kids are complaining they are hungry.) This time there is already a little tear in the package I can make use of. Holding my arms up to brown the mince is hard on my shoulders and standing in one spot hurts. But dinner won't cook itself.

### Pasta

Next comes the pasta. I gave up on the bags a long time ago. Every time I tried to open them the pasta spilled all over the floor. Now, I use the big sheets in the box instead – easier to get out.

### Sauce

Then come the two jars of sauce. As a chef and someone who has to watch their diet, I know sauce in jars is really bad for me, especially as I am allergic to onions and most store-brought sauces have powdered onion in them. I know I will suffer tomorrow but all the chopping, whisking and time involved in making sauce from scratch is simply too much now. I need to get one of the kids to open the jars. Occasionally, I can still do it myself but it isn't worth the sore hands afterwards.

### Salad

Finally the lasagne is in the oven and I grab a packet of store-bought salad – my husband's favourite. Hmmmmm, where are my scissors? They've disappeared. One of the kids was using them, but when I ask, do you think they can remember where they are?

Oh well, no salad. Without my scissors I simply cannot open the packet. Lasagne by itself will have to do.



**Kylie Frost has ankylosing spondylitis. Two years ago she could barely walk; now, she runs marathons and triathlons, determined to keep moving and "too stubborn to quit". Like many others living with arthritis, Kylie struggles to open packaging of all kinds.**

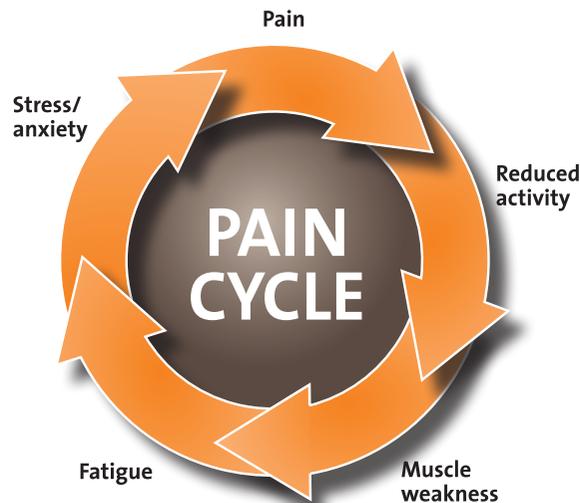


## What a pain!

Living with pain can be the hardest part of having arthritis. It's easy to start avoiding activities because they're painful or because you think they may be damaging your joints. You may start losing confidence and feel that life is no longer enjoyable.

Pain is a normal, complex human experience. Short term acute pain is very useful – it's a signal that you need to protect whatever part of your body is hurting. Chronic pain that lasts longer than three months is a different story. It doesn't always signal continuing harm or damage; it may just mean that the nerve pathways have become sensitised and your brain is overprotecting you.

The degree of pain does not necessarily relate to the severity of injury or joint damage. Pain doesn't show up on X-rays or scans! And chronic pain may not respond to standard medical treatment.



We also know that stress, fatigue or depression often make pain worse and create what can feel like a never-ending cycle of pain.

The good news is that this cycle can be broken. The first step is acceptance, which doesn't mean giving up. It's about recognising that you can take control and learn how to manage pain yourself. Everybody is different, so be prepared to try various techniques until you find what works best for you.

Pain may limit some of the things you do but it doesn't have to control your life.

### Tips for managing pain

- Gentle exercise and stretching
- Maintain a healthy weight and eat healthy foods
- Protect joints by using devices such as walking sticks and supportive, cushioned footwear
- Mind-based approaches (deep breathing, relaxation, mindfulness, distraction)
- Relieve stress: pace yourself, prioritise, plan, watch your posture
- Use medications, topical creams and gels
- Apply heat or cold – whichever brings relief
- Complementary therapies such as acupuncture, massage, yoga, aromatherapy.

### The four Ps

These strategies will help you manage your energy levels and your pain:

**Pacing** – Do you do too much on 'good' days and spend 'bad' days recovering? Pacing is about taking a 'little and often' approach, not tackling activities all at once. Know your limits (or set a timer), change jobs frequently and take regular breaks.

**Planning** – work out what you need to do each day or week but remember to be flexible. Plan rest times, break tasks into smaller chunks and decide what you can delegate to others.

**Priorities** – set realistic goals and don't be too hard on yourself. Work out what you have to do today, what you could do today and what you would like to do today but is not essential. Learn to say no, and ask for help when you need it.

**Posture** – poor posture increases fatigue. Good posture protects your joints and reduces tension on muscles. Try to be aware of your body and don't hold any one position for too long. Keep moving!



## Pain medications

It can be tempting to rely solely on pills to take away the pain of arthritis, but medications are most useful when used alongside other self-management tools. It's important to discuss the different options with your doctor so that you take the right medicine in the right dose at the right time.

Many pain relievers hinder the production of prostaglandins which the body releases in response to illness or injury. Prostaglandins promote healing by sending blood and nutrients to the site, creating what we call inflammation.

Not all prostaglandins cause problems however. They have many functions and are found all over the body, which is why medications that hinder their production may have side effects.

### Paracetamol

Paracetamol is a simple pain reliever that can ease mild to moderate pain. It affects prostaglandin production and makes the body less aware of pain. Paracetamol is generally well tolerated, although some people are allergic to it, and an overdose can damage the liver, so it's important to take it correctly.

### NSAIDS (Non-steroidal anti-inflammatory drugs)

These reduce inflammation, joint swelling and stiffness. They can also relieve pain that is not controlled by analgesics alone. Common names include ibuprofen, diclofenac, naproxen

and tenoxicam (brand names are different). NSAIDS block the enzymes that are responsible for making prostaglandins, but they can have serious side effects, especially for the stomach, kidneys and lungs, so they need to be used carefully and should be taken with food.

### Opioids

These are used for severe or chronic pain, although there is increasing reluctance internationally to prescribe them for arthritis pain; non-opioids combined with self-management techniques may be just as effective. Opioids range in strength from drugs like codeine to tramadol, morphine, and pethidine. They work by attaching to specific proteins in various parts of the body and preventing pain messages from reaching the brain. Side effects include constipation, nausea, vomiting, and drowsiness. Dependence and addiction do not usually occur if these drugs are prescribed properly.

**For more on pain and medications, see the webinar "Managing Pain" on our website [www.arthritis.org.nz/webinars/](http://www.arthritis.org.nz/webinars/)**

### Mind your medicines

- Understand why you are taking the medicine and what the possible side effects are.
- Always read the labels and take your medicines as directed.
- Keep a personal record of all your medicines with you, including doses and allergies.
- Be careful if you also take over-the-counter medicines, including natural products, as some can cause problems if taken together.
- Do not share your medicines with friends or relatives. The drugs you are taking may be harmful to them.
- Talk to your doctor or pharmacist if you're not sure about anything.



Arthritis New Zealand is grateful to be supported by:



## Keep those joints moving

Exercise and physical activity are among the most important things you can do to manage your arthritis. Regular exercise can reduce pain, prevent your symptoms from worsening and improve your everyday function. Exercise can also help you feel better and get a good night's sleep.

Motivation can be difficult, especially if you're aching all over. Finding a physical activity that works for you and that you enjoy will make a big difference to how motivated you feel.

Here are a few tips:

- Be flexible with your exercise routine. Some days will be better than others. Know what you can do and choose other options on the days when joints are sore.
- Set realistic goals. It doesn't matter if they're very simple to start with. Gaining a sense of achievement, no matter how small, will keep you motivated to continue.
- Pace yourself. It's better to exercise in short bite-sized chunks, rather than going hard out and ending up exhausted.
- Protect your joints from strain and injury by using walking sticks, braces and cushioned, supportive footwear.



- Be creative. Remember that caring for children, housework, and gardening are all excellent forms of exercise.
- Find an exercise buddy or a friend who will encourage you to keep going.
- If cost is a challenge, ask your GP about a Green Prescription or find out if you qualify for the disability allowance.

### Here are some suggestions from others with arthritis:

***"I go to aquacise classes three times per week. It really helps to keep me moving."***

***"Cycling is low impact on my joints and the muscle strength I have gained has made a massive difference to my general rheumatoid arthritis. I feel the best I've felt in 11 years."***

***"I have a dog who needs walking, a horse that needs riding and a farm to work on. I am very glad for all of these things."***

***"I gave up knitting because it hurt my shoulders and elbows. With treatment and circular knitting needles, I'm loving knitting again."***

***"I believe in the saying 'move it or lose it'. Getting going can be hard if I'm tired or sore. However I know I'll feel a lot better afterwards."***

## Exercises for thumb arthritis

Osteoarthritis of the thumb involves the joint at the very base of the thumb near the wrist, known as the basal thumb joint or 'CMC' (carpometacarpal).

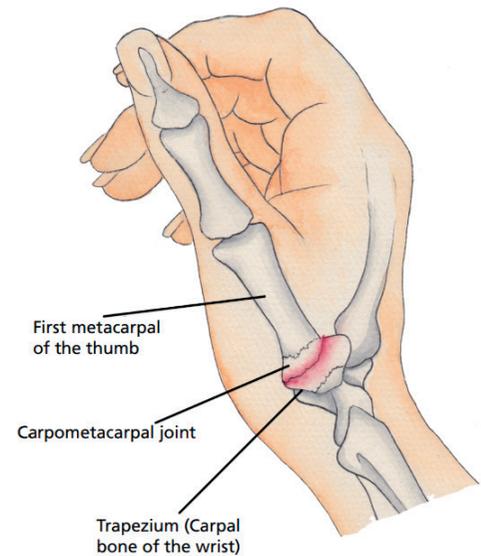
This joint looks a little like a saddle – scooped up at the front and back, and draped downwards at the edges. The bones need a strong but mobile joint capsule around them to support them, as well as muscles contracting in each direction to keep them stable.

Damage to the joint capsule or overstretching the surrounding muscles may lead to uneven movement and pressure on the joint that can cause arthritic changes.

Symptoms may include pain, reduced grip strength, stiffness, swelling, and deformity.

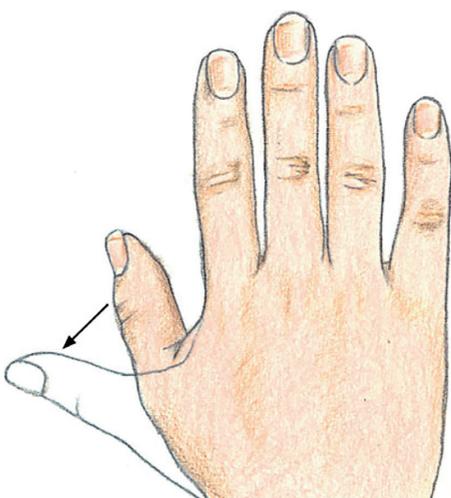
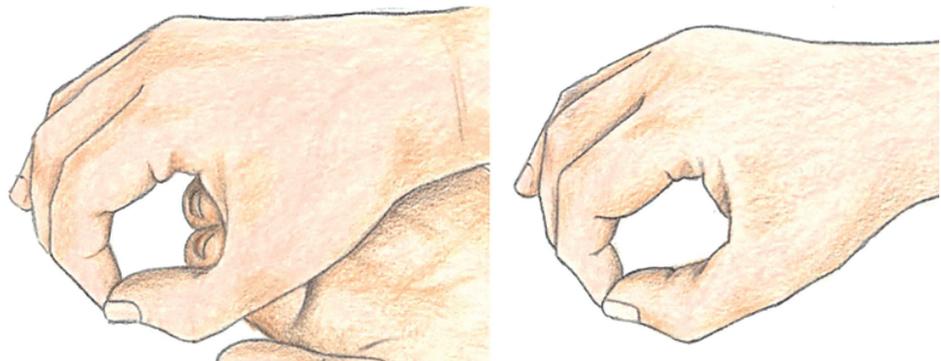
Splinting and exercises can provide effective relief for thumb joint osteoarthritis. The splint provides temporary 'scaffolding' to allow the joint to settle down and prevent excessive movement, while the exercises strengthen the surrounding muscles.

If your hands feel painful and stiff, try warming them up before you do the exercises. Remember that re-learning a movement pattern can take time and concentration, so be patient with yourself. The more you do it right, the less you'll have to think about it. The aim is to create a 'new normal' set of movements.



### Circular pinch →

This exercise trains your muscles to hold the thumb steady, without collapsing the middle joint. Touch your thumb and index finger together. Support the middle thumb joint with your opposite hand. Pinch your fingertips together lightly and remove the supporting hand while maintaining the circle position. Gradually increase the force of the pinch and then relax your fingers.

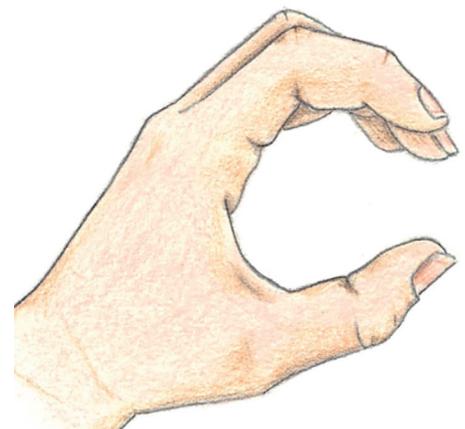


### ← Thumb stretch

Rest your hand on a table, palm down. Spread your thumb away from your hand, opening your palm wide. Hold for 5–10 seconds, and then return to the starting position.

### C exercise →

Place your thumb and fingers in the shape of the letter C, as though you are grasping a tennis ball. Hold this position, tensing your muscles lightly, for 5–10 seconds, and then relax.



Source: Alison Wilding, a qualified hand therapist and director of In Touch Hand Therapy, Christchurch.  
Exercises and photo credit: [www.painfreelivinglife.com](http://www.painfreelivinglife.com) and [www.careuk.com/sites/default/files/Bucks-Music\\_osteoarthritis.pdf](http://www.careuk.com/sites/default/files/Bucks-Music_osteoarthritis.pdf)

## Snippets from around the world

### Virus linked to chronic conditions

The Epstein-Barr virus (EBV) is best known for causing glandular fever but a new study shows it could also increase the risk for some people of developing seven other chronic diseases, including lupus, rheumatoid arthritis and juvenile idiopathic arthritis. EBV is one of the most common viruses in the world, infecting most people at some point in their lives, often without symptoms. Researchers from Cincinnati Children's Hospital discovered that the virus hijacks the body's immune cells and interacts with the DNA associated with these chronic conditions.

**Source: Cincinnati Children's Hospital Medical Center**  
[www.cincinnatichildrens.org/news/release/2018/mono-virus](http://www.cincinnatichildrens.org/news/release/2018/mono-virus)



### The one hour rule

Here's a tip for those 'flare' days when you don't want to face the day. Tell yourself that within one hour of waking up, you have to be out of bed. Even if you have to go back to bed later, that's OK. Just trying can have a domino effect. If you're up, you may as well have a shower, and then you may as well eat breakfast. Before you know it, you might even feel up to leaving the house. Give yourself those 60 minutes and you may surprise yourself.

**Source: Ellyse Rafferty, The Mighty**  
[themighty.com/2017/05/one-hour-rule-mental-illness-getting-out-of-bed/](http://themighty.com/2017/05/one-hour-rule-mental-illness-getting-out-of-bed/)

### Research on healthcare inequity

University of Waikato Research Fellow Dr Chunhuan Lao has been awarded a \$36,000 Lottery grant to examine inequity in access to hip and knee replacement surgery in New Zealand. The project will explore disparities in osteoarthritis-related surgery and mortality among different regional and ethnic groups. Existing research shows that Māori and Pasifika communities have less access to healthcare services compared to Pākehā, but inequity in access to joint replacement surgery has not been explored before. The team carrying out the research includes rheumatologist consultant Dr Douglas White, a member of our Board of Trustees.

**Source: The University of Waikato**  
[www.waikato.ac.nz/news-events/media/2018/lottery-grant-for-university-health-research-project](http://www.waikato.ac.nz/news-events/media/2018/lottery-grant-for-university-health-research-project)



# Members to friends

From 1 July this year our financial members will become friends of Arthritis New Zealand as we transition to become a charitable trust. Friends will continue to receive Joint Support on a regular basis.

Don't forget we also offer:

- A telephone service for advice and information about your arthritis. Call 0800 663 463 between 9.00am and 4.30pm Monday to Friday and ask to speak with an arthritis educator.
- Facebook – conversations about arthritis on Mondays (except public holidays) from 7.00pm to 9.00pm.
- Our monthly e-News with updates on events and activities. You can sign up for e-News on our website [www.arthritis.org.nz](http://www.arthritis.org.nz)



## Opt in to *Joint Support*

If you've picked up this magazine at an event, or been given it by a friend, you're welcome to opt in to receiving it yourself, either by post or email.

Joint Support comes packed with information and tips about how to live well with arthritis. Make sure you receive your copy regularly by opting in today!

Just fill out the coupon below with your details, return it to us and we'll make sure you go on the mailing list. Or you can phone us on **0800 663 463** or email [info@arthritis.org.nz](mailto:info@arthritis.org.nz)



### Yes! Please add me to the *Joint Support* mailing list.

**I would like to receive this magazine by:**

Post       Email

**My details:**

First name:   
Last name:   
Mailing address:   
  
Email address:

### I want to support New Zealanders affected by arthritis.

**Enclosed is my donation of:**

\$120     \$80     \$50  
 \$25    Other:

**I am paying by:**

Visa     Mastercard     Amex     Diners  
 Cheque enclosed (please make out to 'Arthritis New Zealand')

Card number:   
Expiry date:  M  M /  Y  Y  
Card holder:   
Signature:

**Please fill in this slip and post back to us:**

Freepost 157311  
Arthritis New Zealand  
PO Box 10020  
Wellington 6143

Did you know you can also donate online? Visit [www.arthritis.org.nz](http://www.arthritis.org.nz).

**Thank you for your generosity!**

# JOINT SUPPORT

## Contact Us

<b>Call free 0800 663 463</b>	Call this number and ask to speak with one of our trained Arthritis Educators who will talk with you about managing your arthritis. They can advise you on medications, exercise, joint protection, pain management and healthy food as well as refer you to other community support or exercise groups.	
<b>Make a donation</b>	Phone 0900 333 20 to make an automatic \$20 donation to support New Zealanders living with arthritis.	
<b>Visit <a href="http://www.arthritis.org.nz">www.arthritis.org.nz</a></b>	Visit our website for information about the different types of arthritis, latest news, blogs, downloadable brochures, and more.	
<b>Offices</b>	Auckland	Unit B, 383 Khyber Pass Road, Newmarket, Auckland 1023 Phone 09 523 8900
	Wellington	Level 2, 120 Featherston Street, PO Box 10 020, The Terrace, Wellington 6143 Phone 04 472 1427
	Christchurch	Unit 3, 15 Washington Way, Sydenham, Christchurch 8145 Phone 03 366 8383
<b>Facebook</b>		<a href="http://www.facebook.com/ArthritisNewZealand">www.facebook.com/ArthritisNewZealand</a>
<b>Twitter</b>		<a href="http://www.twitter.com/arthritisnz">www.twitter.com/arthritisnz</a>
<b>LinkedIn</b>		<a href="http://www.linkedin.com/company/arthritis-new-zealand">www.linkedin.com/company/arthritis-new-zealand</a>
<b>Publication details</b>	Products advertised and information provided in Joint Support does not imply endorsement by Arthritis New Zealand. Official magazine of Arthritis New Zealand ISSN 2324-1357 (Print) ISSN 2324-1365 (Online) <a href="mailto:info@arthritis.org.nz">info@arthritis.org.nz</a>	

## Be a Well Being

[Blackmoresnz.co.nz](http://Blackmoresnz.co.nz)



**BLACKMORES®** are proud supporters of



**ARTHRITIS  
NEW ZEALAND**

KAIPONAPONA AOTEAROA

Vitamins are supplementary to a balanced diet. Always read the label. Use only as directed. If symptoms persist see your healthcare professional. Blackmores NZ, Auckland.