



Improving the life of every person affected by arthritis



ARTHRITIS
NEW ZEALAND
KAIPONAPONA AOTEAROA

JOINT *Support*

APRIL 2019



The economic impact of arthritis in New Zealand

Read Page 4 & 5



Children's Camp

This year's camp saw over 100 people treated to plenty of fun activities, arthritis education, and got the chance to meet other families and peers.

Read Page 8.

Keep moving

In this issue we share some important information and guidelines regarding arthritis and exercise – an important part in living well with arthritis.

Read Page 6.

New pain booklet

We have launched a new resource called Arthritis Pain. This booklet focuses on understanding influencers on pain, and treatments to assist pain.

Read Page 3.



A word from Philip



As this edition of Joint Support is being collated, we are preparing to make a presentation to the Health Select Committee at parliament on 10 April.

The Health Select Committee is a cross party group of MPs who consider all issues related to health. It scrutinises government legislation, can call for submissions and receive petitions. Currently the Health Select Committee is chaired by Labour Manurewa MP Louisa Wall.

In addition to our submission to the Health Select Committee we have also made a submission to the Finance and Expenditure Select Committee on the well-being budget measures for this year's budget, and this is the first occasion to our knowledge that Arthritis New Zealand has presented to it.

Our submission arises from the launch of the report by Deloitte Access Economics, the Economic Cost of Arthritis in New Zealand, last year. This report provides a wealth of information and data about the prevalence and cost of arthritis in this country – some of the key points from it are summarised on page 4.

It shows the enormous cost of arthritis, and includes direct health sector costs, indirect costs such as productivity and efficiency loss due to lost tax revenue, and informal and formal carer costs. An important addition to the research is the inclusion of the cost of loss of wellbeing for people with arthritis. Arthritis substantially reduces the amount of healthy years of life lived and it is interesting to note that rheumatoid arthritis contributes to a greater proportion of the loss of well-being.

The full report can be obtained from us. Phone 0800 663 463 to get a copy or visit our website to download it.

In our next issue of Joint Support we will include the key points from our submission to the Select Committees. We may not report on our submission points before they are heard by the Select Committee.

In addition to our submission, we meet with individual MPs from all political parties and in the lead up to the general election next year we will be asking people with arthritis to contact their MPs with questions we will provide. It is interesting to hear from some MPs that they have never heard from anyone in their electorate who has arthritis!

Let's change that.

Philip Kearney
Chief Executive

Improving the life of every person affected by arthritis

For more information about arthritis and living well, visit our website www.arthritis.org.nz

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**Contact us
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Call our toll-free number and ask to speak to an arthritis educator

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www.arthritis.org.nz**

New pain booklet launched

We are proud to announce our new information resource, Arthritis Pain, which replaces the previous Joint Protection and Managing your Pain booklets to help people who experience joint pain to understand more about the multiple influences that contribute to chronic or long term pain.

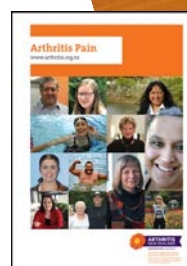
The booklet was launched on 7 March 2019 by Arthritis New Zealand arthritis educator and co-author Robyn Tuohy.

This resource focuses on understanding things that influence pain, and treatments to assist with arthritis pain management.

“When we talk with clients, the most common symptom that they identify and want advice about is how to treat their pain. Often they describe their pain as limiting many of their activities such as walking, getting up from a chair, getting dressed, no longer being able to garden, do hobbies, or stand for long periods. They have poor sleep, and some are no longer able to join in with friends and family who are more active than they are,” said Tuohy.

At Arthritis New Zealand, we recognise that dealing with long term pain can be challenging, and that medication is often not enough, or there is a reluctance to take pain medication. Perhaps other non-drug approaches to treating pain have not been fully explored. Some of the reasons could be because there is a lack of time with a health provider, or there are expectations and beliefs around arthritis and pain - that it is something you have “to put up with”, so arthritis pain is not discussed.

In the new booklet we have used current pain



Robyn Tuohy, arthritis educator and co-author

research that views pain as being complex and influenced by multiple factors. We provide knowledge about treatment strategies and provide a pathway for people with arthritis pain to understand their pain as being treatable, so over time they gain in confidence around the approaches that work for them.

The Arthritis Pain booklet describes best-practice conservative treatment options for arthritis pain, which includes physical, emotional and social approaches to provide a pain treatment framework.

These options may take time, and will need patience and persistence, while at the same time provide practical guidance to increase hope, motivation and, importantly, a way towards recovery and decreasing pain.

We encourage anyone who has patients or knows someone with arthritis to provide them with this booklet or let them know that this resource is available from Arthritis New Zealand.

A very successful charity golf tournament

On 8 March a very successful charity golf tournament was held in Whangarei. Organised by Whangarei Lions 24 teams competed including a team from Arthritis New Zealand. The two recipient charities were Arthritis New Zealand and Alzheimer's and the day was a wonderful combination of raising funds for worthy causes and people enjoying the great day. Thank you to everyone that helped make this day enjoyable and successful.



The economic impact of arthritis in New Zealand

Health sector costs
\$993m

Other financial costs
\$3.3b

Loss of wellbeing
\$7.9b

In September 2018 we launched a major report on the economic cost of arthritis in New Zealand in parliament.

The findings in the report have major implications for how arthritis is managed in the health system. It shows that arthritis is a growing health issue for people of working age and it also has a significant impact on Māori and Pacific.

There are around 670 000 people with arthritis in New Zealand, and 49% of those are of working age. Days lost due to sick leave amount to a total of about one million workdays lost in 2018 due to arthritis in New Zealand. The number of people with arthritis is projected to reach one million by 2040.

The total economic and wellbeing costs are estimated to be \$12.2 billion in 2018, of which over \$1.2 billion are production losses from the working age group that directly impact New Zealand's gross domestic product, and a further \$1 billion is spent on healthcare. Almost \$8 billion is lost through reduced quality of life from disability and premature mortality.

Osteoarthritis is the most prevalent form of arthritis in New Zealand, followed by gout arthritis and rheumatoid arthritis. Gout arthritis is relatively more prevalent in the Māori and Pacific populations. The prevalence of gout arthritis in the young Māori population is higher than for the non-Māori population, suggesting that gout arthritis is a significant health issue for the Māori population as it is associated with heart disease, diabetes and joint damage.

per year
\$12.2 billion

Overall cost of arthritis in New Zealand

1 million people in 2040

49% - people with



Osteoarthritis



Gout arthritis

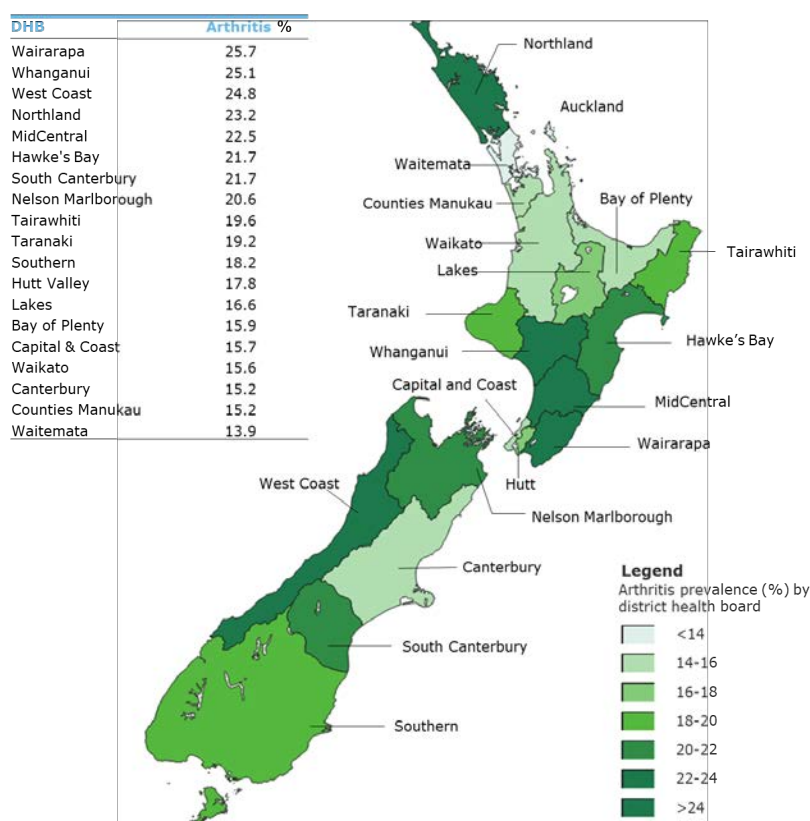
Rheumatoid arthritis

most prevalent

Arthritis New Zealand has proposed some solutions to government for more effective management of arthritis so that lives can improve, and costs reduced. A focus on cost-effective interventions for arthritis such as those targeted at reducing obesity, continued investment in research and development, and self-management education, are important to minimise costs and improve wellbeing.

One strong focus for the future will be gout arthritis. There are clearly some areas of New Zealand such as Tairāwhiti, Northland and Counties Manukau, where the prevalence of gout arthritis demands immediate attention. We have an audacious goal of significantly improving the percentage of people on a managed programme for their gout arthritis. Such a move will not only greatly improve the management of this condition but can also produce savings. In fact we estimate that over 5 years savings in healthcare costs and the reduction in loss of well-being could total \$244 million.

Arthritis prevalence by region



40

with arthritis of working age

\$1.2 billion a year – production losses

Exercising with arthritis

Exercise information is always available from Arthritis New Zealand. Regular exercise is one of the most important things you can do to manage your arthritis and improve your quality of life. Exercise will reduce pain, keep you moving, restore flexibility and protect your joints against further damage.

In this article, we highlight some useful information on exercise.

Benefits of exercise:

- Improves sleep
- Lifts mood and mental wellbeing
- Reduces stress levels
- Lifts confidence and self-esteem
- Helps with weight management
- Promotes good heart and lung health
- Lowers blood pressure and cholesterol
- Manages blood sugar levels (diabetes)
- Improves strength and balance
- Gives you more energy

So why isn't everyone with arthritis exercising? The top 7 concerns our educators hear from people with arthritis are:

1. I am afraid exercise will make my pain worse or aggravate my condition.
2. I don't know what to do or how to get started.
3. I lack the motivation to do it on my own.
4. It is hard to get going when I am in pain.
5. I don't have the time.
6. I don't have the energy when I feel tired
7. I have tried before and didn't stick with it.

*These questions are answered in the full exercise information that is available.

Of course, it is possible for some of your everyday activities to count as 'exercise' – mowing lawns or sweeping or vacuuming, for example can all be effective cardio workouts.

There are four types of exercise that are important in a general exercise programme and for people living with arthritis – all of which bring slightly different benefits:

Cardio - anything that raises your heart rate and makes you breathe more heavily. You need to engage the muscles in your legs or arms or both. You will know if you are doing cardio exercise if you are 'huffing and puffing' and your body temperature increases.

Resistance - moving against a resistance provided by your own body weight and gravity, bands or weights like dumb bells, barbells, kettlebells, weight bags, and plates. Isometric exercise can also be useful as part of a resistance programme.

Mobility - maintaining a good range-of-motion (ROM) in joints.

Balance - the complex combination of our visual, vestibular (inner ear) and proprioception systems that work together to keep us upright and to move at will.

Motivation

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 more positive and get a good night's sleep.

At times motivation to exercise can be difficult, especially if you're aching all over. Here are some tips and tricks that have helped others living with arthritis:

- **List why** you should exercise versus why you want to. Take a piece of paper and make two columns. In one column list all the reasons you should exercise and in the other all the reasons you want to exercise. Ideally the 'want' column will be more emotionally connected.
- **Be flexible** with your exercise routine. Some days will be better than others. Know what you can do and have a plan B on the days when you are sore.
- **Set realistic goals** and review them according to how circumstances change for you. 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. Keep a visible record of these exercise goals and achievements.
- **Reward yourself** when you hit a goal or target.
- **Imagine yourself exercising** as you plan to and then conjure up the feeling of satisfaction you will feel and the positive effects on your body when you have done it.
- **Start short.** Make a deal with yourself that you only have to do a short amount (say 5-10 minutes) and then after this time ask yourself if you can do more... chances are that you will have warmed up sufficiently to go on for longer.



- **Move to music.** Distract yourself by playing some motivating music that inspires you to want to move.
- **Lay out your exercise clothes** in clear view so you get into it in the morning without having to hunt for clothes.
- **Make a date.** Just as you would for any appointment or meeting, diarise your exercise and only forgo it under extreme circumstances.
- **Phone a friend.** Speaking to or exchanging texts with someone who supports you is often the little nudge you need when it is tough to get going.
- **Embrace social media.** Join a Facebook page with others that understand your situation. Knowing that others living with arthritis can and have overcome the same issues you have is very powerful in helping you stay connected and motivated.

How to start

If you are new to exercise or are beginning after an injury, illness or flare up, our advice is start low, make it slow and keep it short.

Start low – by this we mean the weight or loading that you use. If you are using weights start with something that after 10-12 reps is beginning to feel challenging but not impossible.

Make it slow – perform your exercises or stretches slowly and with control to ensure your technique is correct.

Keep it short – this is the activity duration. Start with a time that does not leave you overly fatigued – and build up by no more than 10-20% a time. For example if you start with a 15 minute walk – doubling it to do 30 next time is too much – 20 would be more appropriate. By building up the intensity and duration in small increments you will be much less likely to experience pain and discomfort.



Keep a record - This is invaluable to track progress, see patterns that you can learn from and provide you with motivation when you see how you have improved over time.

We hope that you find the exercise information useful. If you'd like to view all of this information, phone 0800 663 463 to have a copy sent to you, or visit our website at www.arthritis.org.nz

Forms of exercise to consider:

Walking

Simple, easy, able to do anywhere, anytime.

Running

As for walking you can do this anywhere, anytime.

Cycling outside

Great for OA in knees. Non-weight bearing and low impact so less stress on joints.

Cycling indoors

A class situation which is more motivating. Can adjust intensity.

Aqua Swimming

Non-weight bearing so very supportive of joints. Good cardio opportunity.

Aqua Classes

Non-weight bearing so very supportive of joints.

Gym

Equipment provides for both cardio and resistance exercise. Balance and flexibility work can be included. Able to personalise and progress at your own rate.

Seated classes

Suitable for those with limited mobility. Can include strength work with bands and weights.

Circuit classes

Able to work at your own pace. Cardio, resistance and balance work all provided for.

Yoga

Balance, strength and flexibility provided for. Good focus on breathing.

Tai Chi

Balance and strength plus a cognitive component inherent in learning moves. Gentle and flowing.

Pilates

Good for core strength and alignment. Slow and controlled.

Zumba

Cardio component. Music and class situation motivating.

Dance

Cardio (depending on dance) Cognitive component inherent in learning moves.



2019 Camp for children with arthritis

The 2019 Arthritis New Zealand Children's Camp was a roaring success. Over 100 people attended the weekend-long event that took place from Friday 1 March to Sunday 3 March in Matamata. The children discussed their challenges of living with arthritis and shared their solutions with each other in support group sessions. In these groups, they found friends and peers who have a similar diagnosis and are walking the same path. The other side of camp was to give the children a jam-packed weekend full of activities. These included games inside the gym and out in the sun, including the flying kiwi, flying fox, mini golf, Burma trail, foam slide, archery, wall climbing, kayaking, building rafts and racing them, top town, swimming, and heaps more. While the children had the time of their lives, parents were treated to in-depth informative sessions presented by members of the New Zealand Paediatric Rheumatology Service: Physiotherapist Rachel Callear, nurse specialist Nicola Gray, and paediatric rheumatologist Priscilla Campbell-Stokes. This year's camp was the ninth consecutive Children's Camp and saw a record number of people attend.



Thank you to all the volunteers who helped make this possible.

A highlight of the 2019 Arthritis New Zealand Children's Camp were the stories and advice shared by a panel of youth leaders (teens with arthritis).

The teen and youth leaders had one extra day before camp and were taught about leadership to help run activities during camp. All of the youth leaders are teenagers and each one has a form of arthritis. The panel consisted of five brave teenagers; Madi, Evelyn, Jayden, TP and Tessa, who chose to share their story and answer any questions that the parents of young children with arthritis had.

Evelyn - Aged 15, from Wellington "I was diagnosed at 12 with SLE lupus, which was a quick diagnosis and quite a shock. A month after I was diagnosed, I came to camp. That year I left camp feeling encouraged and surrounded by supportive people. We need to find a balance between study, rest and play. Reaching this balance can be challenging. To maintain energy, we might need more downtime than friends. Being active and getting enough sleep is important."

warm gears and a blanket waiting on the side lines. The most important thing to help you get through challenges is the love and support from family and friends who understand what you are going through."

Tessa - Aged 16, from Geraldine "I got diagnosed with JIA when I was 4 years old, and I don't remember a life without it. Coming from a small town, I struggled with feeling like I was the only one. We had to travel to see doctors and for joint injections. I work 10 hours a week after school. I like to gym and play hockey and love going to school. Having arthritis has taught me to be positive and how to be more resilient and overcome challenges."

Teens with arthritis share their experiences



Madi



Evelyn



Jayden



TP



Tessa

Madi - Aged 15, from Dunedin "I was diagnosed with adult rheumatoid arthritis when I was eight or nine years old. I was very sporty before the onset of arthritis. It knocked me back. I then decided to get back into sport by doing water-based sports like water polo. One thing that has helped me on my journey is informing people, such as telling my coach I need to sit out for a bit, or ask teachers if I can type on my laptop instead of write at times when my hands feel cramped. I am a St Johns Cadet and enjoy the marching, but I need to sit down often which is tough because this is such a passion of mine. I had to learn to find the balance and where my limits are. I know I have had to work harder than other children, but I think that gives me the drive I have today. The extra struggle has taught me a lot."

Jayden - Aged 17, from Wellington "I was diagnosed with JIA at the age of 3. In kindy, I struggled to walk and keep up with others, but as I got older I started playing sports and found I was able to keep up. The right medications helped me get better and stronger. I made it in to top teams from the age of 11 and further into high school. I used to enjoy athletics and football but in high school I decided to focus on my football. I push myself to keep going despite arthritis. I can keep up and keep going with the support of good doctors and family and friends."

TP - Aged 17, from Wellington "I got diagnosed with lupus in 2015 and I get arthritis in winter. I love to play rugby and I keep at it by telling my coaches my limits and knowing when to sit down. It also helps to have a hot drink,

Tips from the Teens:

- Work out what activity works for you.
- Focus on the positive – best to go to school/work and learn or be productive than stay home feeling miserable.
- Do a half day instead of no day.
- Do other things in place of the physical activities you can't do today – like play a boardgame at home.
- To fight fatigue, it's important to get into the sleep zone with meditation or something similar.
- Learn what helps to minimise your pain after exercise or sport.
- Don't be hard on yourself.
- This flare-up/pain won't last forever.



Snippets

Little book with big ideas

A new book, *Here we are, read us: Women, disability and writing*, creatively explores the sometimes complicated and often neglected relationship between writing and disability. The book features eight diverse, well-known and emerging women writers, one of which lives with the effects of childhood rheumatoid arthritis: Tusiata Avia, Steff Green, Helen Vivienne Fletcher, Charlotte Simmonds, Michele Leggott, Trish Harris, Te Awhina Arahanga and Robin Hyde (the only non-living writer). They are novelists, poets, essayists, playwrights, memoirists and bloggers. The important thing they have in common is that they all share the lived experience of disability.

In the book they talk about the intersection of disability and

writing, sharing the insights and experience that enrich their work.

Robyn Hunt, co-founder of Crip the Lit, says that disabled people have been a neglected audience. "Many of us have grown up without seeing ourselves and our lives realistically reflected in the books and media surrounding us. We want young disabled people to hear and be those voices."

The book was published by Crip the Lit with funding from Creative New Zealand, and was supported by Arts Access Aotearoa.

It will be available at no cost in hard copy including large print; and online as an audio book, an e-book with accessible downloadable files, and in braille from the Blind Foundation.

Arthritis Ambassador Updates

Some of you may be wondering what our past arthritis ambassadors are up to, so we have decided to include a few updates in each issue of Joint Support.

Mahe Drysdale - We continue to follow the news of Mahe as he strives to gain nomination for major events. His continued passion and commitment to rowing with arthritis is a testimony to what can be achieved.

Nehe Milner-Skudder - Rugby fans can't wait to see him on the field. Sad though that that he will depart NZ's shores at the end of 2019... but we will continue to follow his career and hopefully he will continue to support us with messaging.

Geraldine Brophy - As a well-known actor, Geraldine is as busy in the arts world as ever. She is directing the CATS production which is currently touring New Zealand.

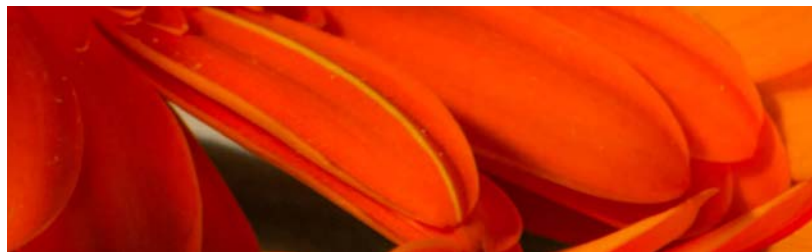
Appointment



Els Dutton, a member of the Arthritis New Zealand Board of Trustees has been appointed to the 10-person Community Advisory Group of Manaia PHO in Whangarei. Els is a longstanding volunteer with Arthritis New Zealand and has a wealth of knowledge and experience about the needs of people with arthritis in Northland.

Arthritis New Zealand is grateful to be supported by:





Federation elects substantive governance board

The Federation of Primary Health Aotearoa New Zealand, which promotes primary health as the central function and main focus of New Zealand's health system, has confirmed the outcome of the election to appoint its substantive governance board. The board, which has been elected from nominees put forward by the 39 inaugural members of the federation, will take over the reins of the organisation from the Establishment Board which has been overseeing the creation of the federation since its first meeting in April 2018.

"This feels like a significant moment for the advancement of primary health care in New Zealand and an enabler for breaking down the barriers which many of us have perceived to be getting in the way of true health and care integration for many years. I am excited about the potential of the federation," said Chair of Arthritis New Zealand, Associate Professor Peter Larmer.

PIDA Awards introduce new special award category for Accessible Packaging Design

The Australian Institute of Packaging and Packaging New Zealand have introduced a new Accessible Packaging Design category to the annual Packaging Innovation & Design Awards programme. The Accessible Packaging Design Special Award is designed to recognise packaging that is accessible, intuitive, easy-to-open and innovative and is in partnership with Arthritis Australia and Arthritis New Zealand.



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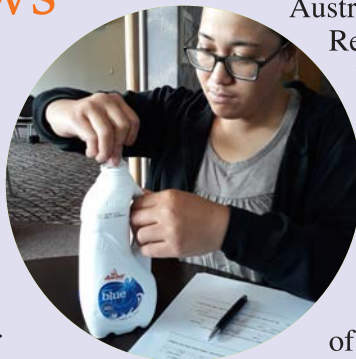
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Accessible packaging – some good news

Arthritis New Zealand and Packaging New Zealand have joined forces to establish guidelines for accessible packaging in New Zealand. These guidelines provide practical design advice to address the problems that many people face when opening ordinary everyday products such as those that have hard-to-pull seals, tear tabs that are too small and lids that cannot easily be gripped.

The ability to open packaging easily is an ongoing challenge for people with arthritis and has significant implications including easily accessing food and medicines. In extreme cases, people with arthritis may be unable to use certain packaged products altogether. However, it is not only people with arthritis who have difficulty opening certain packaged products. Our population is ageing and as a person ages they experience a decrease in dexterity and strength which can cause increased difficulty



managing hard-to-open packaging.

The guidelines were initially developed by Arthritis Australia working with the Georgia Tech Research Institute and HealthShare NSW.

They were a world first and provide scientifically verified standards for making packaging both functional and easy to open. They are available from Packaging New Zealand and Arthritis New Zealand.

Another step towards raising awareness of the significance of accessible packaging is the introduction of an Accessible Packaging Design Award in the annual Packaging Innovation and Design Awards run by the Australia Institute of Packaging and Packaging New Zealand. This award is intended to highlight the need for manufacturers and brand owners to recognise the increasing significance of improving the accessibility of product packaging (see page 11).

“Arthritis New Zealand wants to take constructive steps to encourage industry to make accessibility of packaging a must-have and this has led Arthritis New Zealand to co-sponsor this award,” said Mr Kearney.

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