

Arthritis Matters

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Issue 68 | March 2021

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packs five days into one

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BRICKBATS to child-resistant pill bottles

PAIN MANAGEMENT: advice from a neurosurgeon



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NEW SOUTH WALES

www.arthritisnsw.org.au

ABOUT US

Arthritis NSW is a member-based health charity founded in 1967 to help improve the quality of life of people affected by arthritis and other musculoskeletal conditions. We work to empower the individual to manage their own condition and health towards achieving their personal meaning of our vision, **Freedom from Arthritis**.

The organisation is a trusted source of evidence-based and up-to-date information on arthritis and its treatment, with resources and education delivered across a number of platforms including our website at arthritisnsw.org.au, publications such as *Arthritis Matters* and community awareness sessions in metropolitan and country areas. Our health services team develops and delivers exercise programs tailored to the needs of people affected by arthritis, such as the popular Warm Water Exercise Classes. We deliver annual camps for children affected by juvenile arthritis: Camp Twinkletoes for children under eight years old and their families, and Camp Footloose for children and young people aged nine to 18 years.

We engage with the community through our membership program, a network of support groups, publications such as *Arthritis Matters*, eNewsletter subscriptions, social media platforms such as Facebook, and our toll-free Arthritis Infoline which connects callers with health professionals.

You can subscribe to our FREE eNewsletter on our website.



BENEFITS OF MEMBERSHIP

Understanding | Support | Community

We would love to have you as a **Member** of Arthritis NSW. This involves payment of a modest annual Membership fee which not only helps us to develop and deliver our services, but also provides you with a number of unique member-only benefits. You will receive up to date information via our magazine *Arthritis Matters*, twice a year and attractive discounts on all classes and events.

For more information on becoming a Member, please visit:

arthritisnsw.org.au/membership/about/

Call: 02 9857 3300 Email: info@arthritisnsw.org.au

- ✓ Be heard
- ✓ Be informed
- ✓ Be supported
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Arthritis Matters

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For arthritis information
Arthritis Infoline

1800 011 041
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On the cover: Children at Camp Footloose ready to launch their kayak on Lake Narrabeen during the one day event in October 2020: From left clockwise: Charlotte Nicholson, Sophia Gordon, Thomas Nicholson, Abigail Hall, Lauren Welch.

Advertising

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For enquiries or to advertise in *Arthritis Matters*: 02 9857 3300 or info@arthritisnsw.org.au

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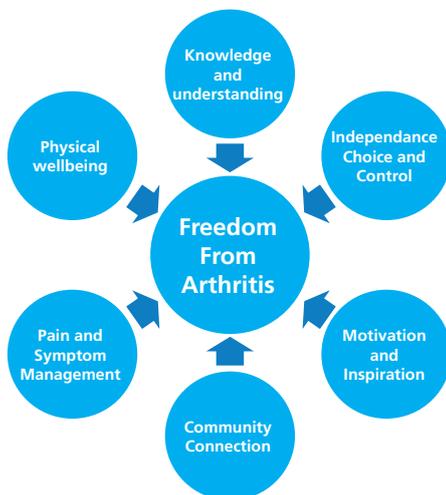
Articulating your goals



‘When I first heard about ANSW I was quite desperate, knew both knees had arthritis I was at the end of my rope’ (Molly then enrolled in ANSW exercise classes). ‘For me, doing any exercise is just really great for my day – it’s fabulous. It’s the physical and emotional lift. You are more alert and can cope with whatever may be coming your way – you’re more resilient.’

The Arthritis NSW team has been spending time recently connecting with clients to understand their goals, and assess whether we are helping to achieve them. This theme of understanding client goals, and if and how we might meet them (and how we might do better!) flows through

The image below displays the ANSW outcomes domains which contribute to the overall vision of ‘Freedom from Arthritis’



the ANSW Strategic Plan. You might remember an article on this Plan in the October 2020 issue of *Arthritis Matters*. I’m pleased to say we have made a start on its key elements.

Firstly, we are close to implementing the means to measure changes that clients experience (outcomes measurement). For many clients this will involve completing a questionnaire before and/or after a session, a call, or a term of exercise classes. This will be rolled out through 2021, and will help us to better help you meet your goals. We have grouped the consistent changes that clients told us they seek:

- participants’ freedom to do the things they value is increased or maintained
- participants understand their condition more comprehensively
- participants maintain a sense of independence, choice, control and resilience
- participants’ motivation to participate in activities that improve or maintain their condition is increased
- participants feel they are part of a community and connected to and supported by one another
- participants experience decreased pain
- participants’ mobility and strength are improved or maintained.

Mobile NDIS services

Through 2021 we hope to extend the ever popular services (exercise classes, kids’ camps, phone and digital support), while introducing new services, including therapeutic services such as occupational therapy and exercise physiology. These will be offered to people who are qualified under the NDIS, or who are able to access them through health insurance or private funding. In time we intend to extend into dietary, psychology and other therapeutic services.

Initially the services we will provide under the NDIS include:

1. Exercise physiology

- assessment (history, health measurements – pre & post)
- exercise prescription and supervision
- support and guidance with behaviour change (eg. reducing barriers and goal setting)
- reporting (as required).

2. Occupational therapy

- assessment
- functional capacity assessments and reporting
- equipment prescription and environmental modifications
- education on managing pain, sleep, joint protection and hand function.

Initially these services are being delivered in the area from Parramatta to the CBD, lower north shore and inner west. These same services are available for people to self-fund, or to fund through health insurance etc.

For bookings call 02 9857 3300. You can be sure you will be booking the best possible support from THE ARTHRITIS EXPERTS.

Whether it’s through providing service to people with chronic arthritis under the NDIS, or our more traditional services, as always I thank you, as donors, members, clients, volunteers and supporters for changing the lives of thousands of people with arthritis. Thank you!

Alex Green
CEO
Arthritis NSW

Introducing mobile NDIS services

Arthritis NSW (ANSW) is excited to announce the introduction of our mobile National Disability Insurance Scheme (NDIS) services for adults with rheumatoid arthritis.



Our NDIS services include Occupational Therapy and Exercise Physiology for self and plan-managed participants who live within a 10km radius of Ryde. In addition to offering mobile services that come to you, there are also telehealth options available if you prefer to have your consultation with our health professionals online.

Our services are backed by more than 50 years supporting people living with rheumatoid arthritis. You will receive support from qualified professionals in their respective fields, and you will also have access to the vast information and supports offered by Arthritis NSW – the arthritis experts.

What we offer

We are offering the following NDIS services for self and plan-managed individuals with rheumatoid arthritis.

1. Exercise Physiology Services

– Assessment (*History, Health Measurements – Pre and Post*), Exercise Prescription and Supervision, Support and Guidance with Behaviour change (e.g. *reducing barriers and goal setting*) and Reporting (as required). Available: 5 days a week

2. Occupational Therapy Services

– Assessment, Functional Capacity

Assessments and Reporting, Equipment Prescription and Environmental Modifications, Education on managing pain, sleep, joint protection and hand function. Available: Tuesdays and Thursdays

Locations covered

If you require support but live outside of our service radius, ANSW will consider any request for support on a case by case nature. So please enquire, though additional travel costs may apply.

Our health professionals

Andrew graduated from the University of NSW in 2012 and has been working as an accredited exercise physiologist ever since with a diverse range of individuals in clinical and fitness settings. He is passionate about helping others to become more aware of the role exercise plays in positively impacting their health and enjoys guiding others to better self-management and implementing life-long behavioural change. He is also the Health Services Manager at Arthritis NSW and has been with the organisation since 2016. *Specialities:* behaviour change, goal setting, pain management, arthritis management.

Lauren completed a Masters of Occupational Therapy at the University of Sydney in 2016. She operates her own private practice specialising in rehabilitation in the home for persons with disabilities and those ageing at home. Her strengths are helping people overcome barriers to participation in daily living activities by empowering the individual, modifying the environment and using evidence-based interventions. Prior to her work in occupational therapy hospital and community work, Lauren was a physical education teacher for seven years. She has a keen interest in optimising quality of life outcomes and promotes healthy lifestyle habits. *Specialities:* rehabilitation, upper limb therapy, sleep hygiene, problem solving.



Andrew Cairns



Lauren Beahan

Looking ahead in 2021

Our 16 support groups are very pleased to be meeting again this year after 2020's enforced hiatus, where most managed to keep in touch with their members to ensure their wellbeing.

Group leaders report that everyone has been delighted to reconnect, some even squeezed in their annual Christmas parties.

One such group was Holroyd Support Group which kept in contact and even managed a few meetings at the Merrylands Bowling Club later in 2020. They had reason to celebrate after the Arthritis NSW annual general meeting get-together with the awarding of Life Membership to Robyn Collette, who has been Treasurer of the Holroyd Branch since 2014. Her group nominated her for her tireless fundraising activities.

After some time reflecting on how they could best help Central Coast locals people living with arthritis, the Long Jetty Arthritis Support Group has transitioned into a coffee and chat group where they will meet at a local café and informally share stories and updates going forward.

Warilla Branch Support Group resumed committee meetings in October. Their first formal gathering was their Christmas party where member John Brooks received his Life Membership Award. The group is looking forward in 2021 to doing a membership drive to expand their numbers, focusing on building friendships, and running crafts and bake stalls at Bunnings and Warilla Grove shopping centre to raise money for the ANSW children's camps. They are running their group bus trips again with the first mystery bus trip departing in March.

The 10–15 members of the Penrith Support Group kept in touch by phone and caught up for lunch when lockdown restrictions lifted. In December, they organised a Christmas lunch and recently secured new meeting rooms for 2021 at the Penrith RSL. Group Secretary Jan Riddell reports that some of their members won't be returning however they are hoping their new meeting venue will attract more members.

The Macarthur Support Group were ready to go in 2020 with a great and varied speaker program and were able to run two events in February and March before lockdown. They also ran a member survey in March to plan group activities with a more than 50 per cent response rate.

The group Secretary Bettina Herron kept the members in contact with each other with a regular group email newsletter with ideas and links with ANSW and Arthritis Australia including online exercise classes, cooking and craft activities, COVID updates, health and fitness ideas and local cafes doing takeaway food. One of the group convenors kept in touch with members without email.

They are now monitoring health advice and plan to meet soon in COVID-safe venues to enjoy social contacts and waiting on their meeting venue to re-open so they can start their monthly speaker program.



Robyn Collette with her Life Membership award.



ANSW CEO Alex Green presents John Brooks with his Life Membership Award.

I am so proud of all our support groups for maintaining contact with each other during the 2020 lockdown and ongoing restrictions. Let's hope that 2021 brings us together again to meet, share and support each other more than ever.

Jo Boik
Business Development Manager
Arthritis NSW

JAFA makes headway on JIA goals

More funding has been made available for a part time paediatric rheumatologist to likely begin in mid-2021, according to the Founder and Director of the Juvenile Arthritis Foundation Australia (JAFA) Ruth Colagiuri.

Associate Professor Colagiuri said that JAFA received the go ahead for the funding from NSW Health Minister Brad Hazzard in January and that the position would be based with the Sydney Children's Hospital Network.

'This is a great result after a 15 month campaign for increased funding

for more services and a wonderful way to start 2021,' said Professor Colagiuri. 'JAFA will continue to lobby government for an increase in other services such as paediatric nursing, physiotherapy and psychology to support families with children with juvenile arthritis.'

National register

In other good news, JAFA is now working with the Australian Paediatric Rheumatology Group (APRG) to develop a national register of juvenile arthritis patients to be rolled out mid-2021. Work is underway to develop

the content for a short, anonymous questionnaire which will be used to gather data from families.

'The register will help JAFA and the APRG understand the scope of juvenile arthritis in Australia and help researchers to better investigate the condition,' said Professor Colagiuri. 'We particularly want to know the extent of the time that lapses between presentation of initial symptoms and diagnosis, so we can reduce that interval. The register will also help us make the case to government to provide more support to families.'

Camp Footloose Day 2020

Against challenging and uncertain odds, Arthritis NSW held a Camp Footloose JIA Day on 3 October 2020. Ten girls and two boys joined ANSW staff at the Sydney Academy of Sports (Narrabeen) for a day of fun activities and the opportunity to catch up with each other and share their experiences in this unique year.

The morning began with a round of archery, where the young ones tapped into their inner Robin Hood and Katniss Everdeen, then we took to the crystal clear waters of the lagoon for a 1.5 hour kayak (including nature meditation).

Over lunch, the children laughed and caught up and shared stories from their experiences of 2020. For the afternoon session, we sat down and had an ANSW facilitated "Camp Footloose Planning session". This session was designed to put the children in the driving seat and share their thoughts on how future Camp Footloose should look and feel. There was a great level of participation from all ages and their feedback and recommendations are already being added to the planning of the 2021 event.

It was wonderful to witness the children's indomitable resilience and to hear their laughter and see the smiles and realise just how much they've come to value their camp experience and their very own JIA community.

Andrew Cairns
Health Services Manager
Arthritis NSW



L-R: Lauren Welsh, Sophia Gordon and Mikala McDermott enjoy kayaking on Lake Narrabeen at Camp Footloose 2020.

Planning is well underway for Camp Twinkletoes on 17 April 2021. If you would like to join Arthritis NSW for this day of immersive learning on juvenile arthritis from health professionals, while your children are supervised in fun activities by trained carers, visit arthritisnsw.org.au/children-arthritis/camps-for-kids/camp-twinkletoes to register your interest.

A little gratitude goes a long way

COVID-19 Impact

What a year 2020 was. It might be one you'd rather forget, but before you do, it's important to review the year that was and acknowledge and understand the health impacts of COVID-19. Confronting both the physical and mental health impacts of COVID-19 may be difficult, but if left unchecked, they could go on to cause many lasting problems long after the virus is under control. Addressing the subsequent side effects of such an event can inform positive reactionary actions, such as, streamlining treatment/s, behaviour changes, and future prevention strategies, policies and procedures.

A recent study by Flanagan et al. (2020), *The Impact of COVID-19 Stay-At-Home Orders on Health Behaviors in Adults*, highlights the effects of lockdown on physical and mental health. It seems pandemics are not only viral! The study included 7753 participants and shows how COVID-19 is having many indirect, negative consequences on both our physical and mental health. When reading through the effects, reflect on your own lockdown experience and compare it to the study's findings – how did you fair during lockdown?

Results snap shot

44% of people reported worsened sleep quality.

There was a significant increase in sedentary behaviour.

43% of people reported an increase in unhealthy snacking, including alcohol intake.

27% of people reported significant weight gain.

There was a significant decrease in physical activity.

Anxiety levels nearly doubled.

Results in depth

Dietary behaviours and physical activity patterns

Eating behaviours were significantly changed with COVID. There was an increase in positive eating behaviours eg. a decline in eating meals from restaurants and consuming pre-prepared food, an increase in cooking meals at home, a lower frequency of breakfast skipping, lower frequency of consuming fried foods, and an increased frequency of eating fruit. Reported negative eating behaviour changes included increased consumption of sweets and sugar-sweetened beverages.

A perceived shift toward unhealthy eating was accompanied by increases in sedentary behaviours, declines in physical activity, later bedtimes, and nearly twice the increase in reported anxiety compared with those eating healthier diets.

Sleep and mental health

Sleep onset and wake time significantly changed; sleep onset and wake time occurred later. Changes to sleep quality varied; 43.8% reported worsened sleep quality, while 10.2% reported improved sleep quality.

Most participants reported being concerned or moderately concerned for their own physical health (75.0%) or the health of a family member (87.5%) as it relates to COVID-19. Overall anxiety significantly increased, and 20% of participants reported symptomatic anxiety, an increase of 14% compared with before the pandemic.

COVID-19 health consequences and arthritis

As we know, arthritis is a broad term used to describe a variety of musculoskeletal conditions that affect the soft tissues of our joints. For the most part, management strategies for arthritis focus on physical activity, diet, getting good sleep, and mental health issues such as anxiety. It is important to note that the main (non-pharmacological) management strategies for arthritis are those that have been significantly affected by the COVID-19 pandemic. For this reason, it is important to look ahead and create some goals or new habits to help get your physical activity, diet, sleep or mental health back on track – especially if you feel your arthritis has worsened since the pandemic and lockdowns started.

Physical health: Exercise

If you feel your sedentary behaviour has increased and your physical activity has decreased – well, as per the above research findings, you are not alone! The many changes and restrictions that have occurred have definitely changed the way we exercise, however, even while restrictions are lifting there are still many things you can do to move more at or around home. For example, going for a walk, a bush walk, using hills or stairs near you to help increase intensity, participating in exercise classes online, cleaning the house or car (= great physical activity!), use the ANSW Get Moving! and Get Moving! PLUS free exercise library on our website to exercise at home.



Exercising at home could look something like (in line with your fitness or functional level):

- choose 3–5 *exercises you can comfortably do at home eg. sit-to-stand, wall push ups, and banded shoulder press
- choose a repetition (how many times you repeat the exercise) and set (how many times you'll repeat the repetition range) range eg. 10 reps, 2 sets
- set yourself a goal of completing the exercises 2–3 times/day eg. once in the morning and once in the afternoon. Change up the exercises daily for variety and add a walk around the block every other day and you'll be on your way back to forming good habits, managing your arthritis and pain, and shedding the 'COVID curves'.

*Check out the *Get Moving* and *Get Moving Plus* exercise library on our website to find what works for you.

If you can get out of the house now, and resume class exercise, please remember to observe social distancing and other applicable requirements.

Physical health: Diet

While the research indicates that more people were eating/cooking meals from home instead of eating take away foods, there was an increase in unhealthy snacking and subsequent weight gain. Reflect on your daily food intake and ask yourself the following questions:

- What's in my pantry to snack on? Is it healthy or unhealthy?
- What are my portion sizes like? Have they increased?
- Am I getting enough protein, vegetables and fruit?
- Has my alcohol intake increased?

After reflecting on the above questions, do you need to make some changes? Keeping our diet in check is important, not only for our cardiovascular and metabolic health, but for the health of our joints. If you're in need of inspiration, consider taking a page out of the Mediterranean diet. The Mediterranean diet is associated with lower cardiovascular disease, diabetes and obesity rates, and due to its anti-inflammatory properties, it has potential to reduce the impact arthritis has on joints (*Tosti, 2018*).

Mental health

Research indicates that symptoms of anxiety and depression are higher among those with arthritis that those who don't have arthritis (Guglielmo, 2018). In conjunction with the findings from the aforementioned study, it may well be the case that the mental health of those with arthritis is severely suffering. Firstly, if you feel your mental health has suffered or worsened over the pandemic, you are encouraged to reach out for help. Please find some helpful contacts at the end of this article. Secondly, in such unprecedented times, it's important to practice gratitude and self-compassion.

Gratitude. Those that practice gratitude, eg. gratitude writing, thinking and expression, have lower levels of negative emotions, feelings and have better mental health in general (Wong, 2018). Taking just five minutes a day to reflect on what you are grateful for may will bolster and improve your mental health. This practice requires us to take a moment and to be still while thinking about the things in our lives that we are grateful for. This practice may make very difficult times somewhat bearable; put things in perspective; and allow us to appreciate what we do have. How do you finish this sentence? 'I am grateful for...'

Self-compassion. When faced with difficult life struggles, or confronting personal mistakes, failures, and inadequacies, self-compassion responds with kindness rather than harsh self-judgment, recognising that imperfection is part of the shared human experience (Neff, 2015). Some more than others have been affected by the current pandemic, however, it's important to acknowledge and accept any emotional suffering. Allow time to process and acknowledge your feelings and allow others to do the same. Practicing compassion and mindfulness helps develop emotional resilience and wellbeing – something that we may all need going forward after such an eventful 2020.

Helpful contacts

Mental Health Line: 1800 011 511

Lifeline: 13 11 14

Beyond Blue: 1300 224 636

Kat Keane

Health Educator
Arthritis NSW

References

Flanagan, E. W., Beyl, R. A., Fearnbach, S. N., Altazan, A. D., Martin, C. K., & Redman, L. M. (2020). The impact of COVID-19 stay-at-home orders on health behaviors in adults. *Obesity*. <https://doi.org/10.1002/oby.23066>

Guglielmo, D., Hootman, J. M., Boring, M. A., Murphy, L. B., Theis, K. A., Croft, J. B., Barbour, K. E., Katz, P. P., & Helmick, C. G. (2018). Symptoms of Anxiety and Depression Among Adults with Arthritis - United States, 2015-2017. *MMWR. Morbidity and mortality weekly report*, 67(39), 1081–1087. <https://doi.org/10.15585/mmwr.mm6739a2>

Wong, Y. J., Owen, J., Gabana, N. T., Brown, J. W., McInnis, S., Toth, P., & Gilman, L. (2018). Does gratitude writing improve the mental health of psychotherapy clients? Evidence from a randomized controlled trial. *Psychotherapy Research*, 28(2), 192–202.

Neff K.D., Dahm K.A. (2015) Self-Compassion: What It Is, What It Does, and How It Relates to Mindfulness. In: Ostafin B., Robinson M., Meier B. (eds) Handbook of Mindfulness and Self-Regulation. Springer, New York, NY. https://doi.org/10.1007/978-1-4939-2263-5_10

Tosti, V., Bertozzi, B., & Fontana, L. (2018). Health benefits of the Mediterranean diet: metabolic and molecular mechanisms. *The Journals of Gerontology: Series A*, 73(3), 318–326.

AN INTRUSION YOU CAN'T IGNORE

Retired teacher educator Christine Perrott describes arthritis as an unwelcome guest that moved in with her and her late husband Roy many years ago. Her story is below.



I'm a retired teacher educator who has lived on the Northern Tablelands most of my life, going to primary school in Guyra and then Presbyterian Ladies College Armidale. I did all my university degrees through University of New England (UNE): Bach Arts, Dip Ed, Master of Ed Honours and PhD in Education and Linguistics. I worked at Armidale Teachers College and later at UNE.

I married my husband Roy, a local grazier (*pictured opp page*) and spent much of my married life in the huge, cold, early 20th century Edwardian/Victorian home, 'Chevy Chase' about 8km out of Armidale. Now I live in Armidale on South Hill near the St Patricks Orphanage building. Roy died 10 years ago.

I have two sons in their 50s (*pictured opp page*), and four grandchildren. Just one grandchild is still at school, two are at university and one is apprenticed to a builder.

I enjoy classical music, reading novels and biographies, intricate garment knitting, movies, cryptic crossword puzzles, travel, and catching up with friends and family.

I volunteer with Helping Children and Families Assoc. (HCFA) and I assist postgraduate students with their theses (free). I'm on the Management Committee of North and NorthWest Community Legal Service, Vice President of Friends of The Old Teachers College and a member of Duval Residential College

Senior Common Room. I've written two books, *Classroom Talk and Pupil Learning* and *Patient Fortitude*.

Rheumatoid arthritis

Arthritis has been an unwelcome guest in my home for many years, visiting in different guises. Roy was struck down with rheumatoid arthritis in his 60s. He called it 'move-atoid' arthritis for the way his pains moved round his body. After many operations and a long hospital stay he was in a wheelchair for four years before he died aged 80 years.

I was thankful to be spared, but I didn't realise that a different form of arthritis, osteoarthritis was lurking in my low density bones.

The first obvious sign was when one day I came inside after pulling hoses around to set Roy up to water the garden from his wheelchair. 'I don't like the feel of my back,' I remarked. The next morning I was in excruciating pain and could hardly get out of bed; it was a compression fracture of my T12 vertebrae. Then my shoulders began to ache, sometimes crackling and popping. Also, it was common for my arm to collapse as I lifted a glass to drink, slopping liquid everywhere. I managed by taking things easy, sitting down when my back pain got bad and choosing appropriate chairs. Life was fine with good friends, interesting voluntary work, movies, travel, family, concerts, reading and a beautiful view and colourful garden maintained with regular help. Fortnightly physio visits and daily exercising helped.

Then I had a fall and fractured my L1 vertebrae which joined company with T12 to provide constant lower back pain. Doing jobs with extended arms like vacuuming, raking, sweeping, cutting up vegetables was agony and made my back ache terribly.



Polymyalgia rheumatica

One morning, when getting out of bed, I found my arms were stiff as if I'd been water skiing all the day before after a year's absence from the sport. *What on earth did I do yesterday to bring this on?* I thought, confident I would be back to normal after a night's sleep. Not so! I still have this stiffness and it's slowly worsening. It is polymyalgia rheumatica.* At least it has an impressive title, but I could do without the constant pain especially when I move about and prepare meals. Pulling up my pants is excruciating. Unfortunately, most painkilling medication disagrees with my digestion. I have also tried acupuncture, 12 fortnightly sessions, but to no avail.

However, one needs to carry on and get enjoyment from life. I try my best to remain stable and slow the deterioration by continuing to be active. I love to cook and have developed ways of including many vegetables in my stir fries, risotto, stews, frittata, fried rice, and salads as well as the old faithful soup. A mix of fresh fruits with yoghurt is an easy and tasty way to include fruits in the diet.

A new bed

I recently started having difficulty getting safely out of bed in the night. While sitting up watching TV, I have no problem. When lying down after sleeping, it's a big problem. I had to roll to the edge and use my wonky arms to sit up so I could get up. I became terrified of rolling out and not being able to then stand, not to mention the pain involved.

I needed a new mattress, so I made a very Irish decision and got a new bed. This bed sits me up using a remote control and I can easily vacate it with less pain and no anxiety. This was a masterful decision!

So, here I am eating sensibly, sleeping well, moving as much as possible and waiting impatiently for resumption of many of my favourite activities cancelled because of COVID-19. In the meantime I enjoy those that are available and take to heart the sensible advice provided in *Arthritis Matters*.

I just wish my unwelcome guest would leave.

*For more on Polymyalgia Rheumatica go to page 22.

That's a Wrap: Worst packaging for 2020

Arthritis Australia's Accessible Design Division runs an annual social media campaign to glean detailed stories about the best and worst packaging used by arthritis consumers.

The campaign provides critical insights into the experiences of our arthritis community and helps the Division target problematic packaging formats. Packaging has been a focus area of the Division because hard-to-open packaging impacts those with arthritis more significantly, which can negatively impact their emotional wellbeing, sense of independence and their overall health.

Results for 2020

The Worst Packaging category continues to be the most popular nomination category of the campaign, where consumers share their stories with us about wielding knives and having loved ones or pharmacists help them open wrap-rage inducing packaging. The worst offenders of 2020 were:

5. Clamshell packaging
4. Ring-pull tin cans
3. Milk bottles – with twist lids and the half-moon seals
2. Medicine packaging – push through tablet trays, also known as blister packs
1. Medicine packaging – push down and turn child-resistant bottles

TGA testing

This year the Division is also excited to announce that the Therapeutic Goods Administration (TGA) has allowed them to have medicine packaging join their *Easy to Open* certification program. This means they will be testing medication packaging and certifying those that are accessible to the arthritis community.



No Best Packaging

Sadly, for the Best Packaging category, no winner was crowned this year. Although the Division received nominations that could be described as better than a horrible alternative, when investigating the packaging the products didn't meet the minimum accessibility standards to be crowned the Best.

The Division has, however, announced two honourable mentions from the consumer nominations which they noted still needed further improvement to not cause discomfort. The honourable mentions were:

1. Chemist Own paracetamol packaging – which was described as having a more flexible plastic tray and thinner foil to allow you

to apply pressure to push the medication out.

2. Mi battery branded clamshell packaging – which its nominator noted didn't require any tools to open the two halves.

The Division hopes 2021 will bring more nominations worthy of the Best Packaging category.

Alexander Brayshaw
Senior Technical and Design Lead
Arthritis Australia

For more on Arthritis Australia's Accessible Design Division visit: arthritisaustralia.com.au/accessible-design-division.

PAIN RELIEF COSTS LESS FOR AS PATIENTS

Thousands of Australians with Ankylosing Spondylitis now have access to a life changing treatment option through the Pharmaceutical Benefits Scheme (PBS) which would otherwise cost tens of thousands of dollars.

Ankylosing Spondylitis is an inflammatory disease primarily affecting the spine which causes inflammation of the sacroiliac and spinal joints.

This can cause some small bones in the spine to fuse, leading to reduced flexibility and possibly severe back and neck pain. People who live with these conditions have an increased risk of heart attack or stroke which can lead to disability, amputation or death.

In December 2020, Federal Health Minister Greg Hunt's office announced that access to Taltz® (ixekizumab) on the PBS would be expanded for patients with the debilitating condition.¹

Without the PBS subsidy, up to 8,000 patients would pay more than \$22,000 per year for this treatment.



Taltz contains the active ingredient ixekizumab, a monoclonal antibody which is a protein that recognises and binds specifically to certain proteins in the body. It works by neutralising the activity of the inflammatory protein IL-17A.²

The listing was recommended by the independent Pharmaceutical Benefits Advisory Committee.

1. health.gov.au/ministers/the-hon-greg-hunt-mp
2. ankylosingspondylitisnews.com

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Ask your local pharmacy:

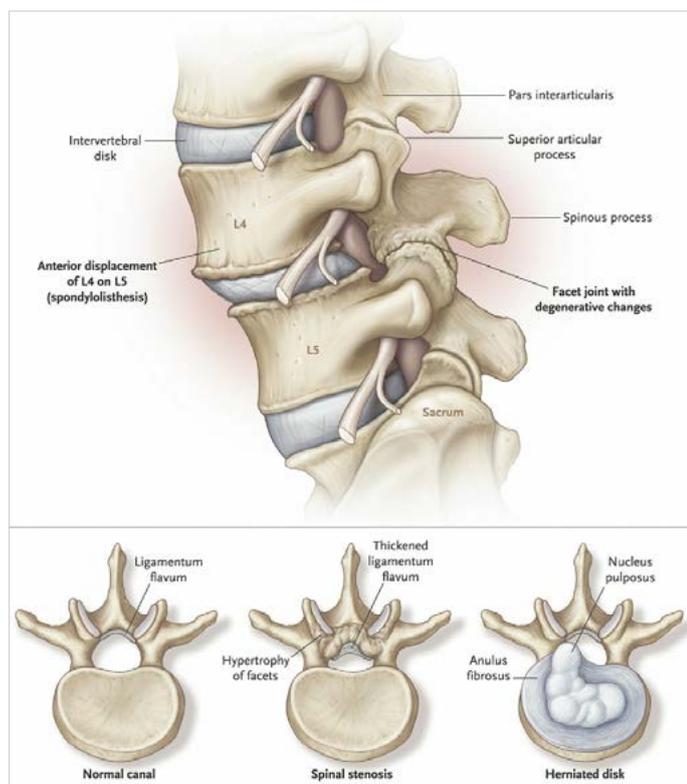


www.biofreeze.com.au

Modern management of lower back pain and sciatica

According to Sydney Neurosurgeon Dr Rodney Allan, more than 95 per cent of us will suffer from back pain during our adult life. Below he explains how more than 90 percent of us will get over it without requiring a visit to the neurosurgeon.

Wear and tear on the discs and joints in the back often produces pain – if this gets better with lying down, it’s often the discs causing the pain. Our spine is made up of ‘bones’ (vertebral bodies) and ‘discs’ (cartilage between the bones – with a hard outside and soft inside). There are also two joints at the back called facet joints. Any, or all of these, can cause pain.



Sometimes the soft inside of the disc can ‘herniate’ and press on the nerves as they travel past. This causes ‘sciatica’ – pain which typically goes down one or both legs.

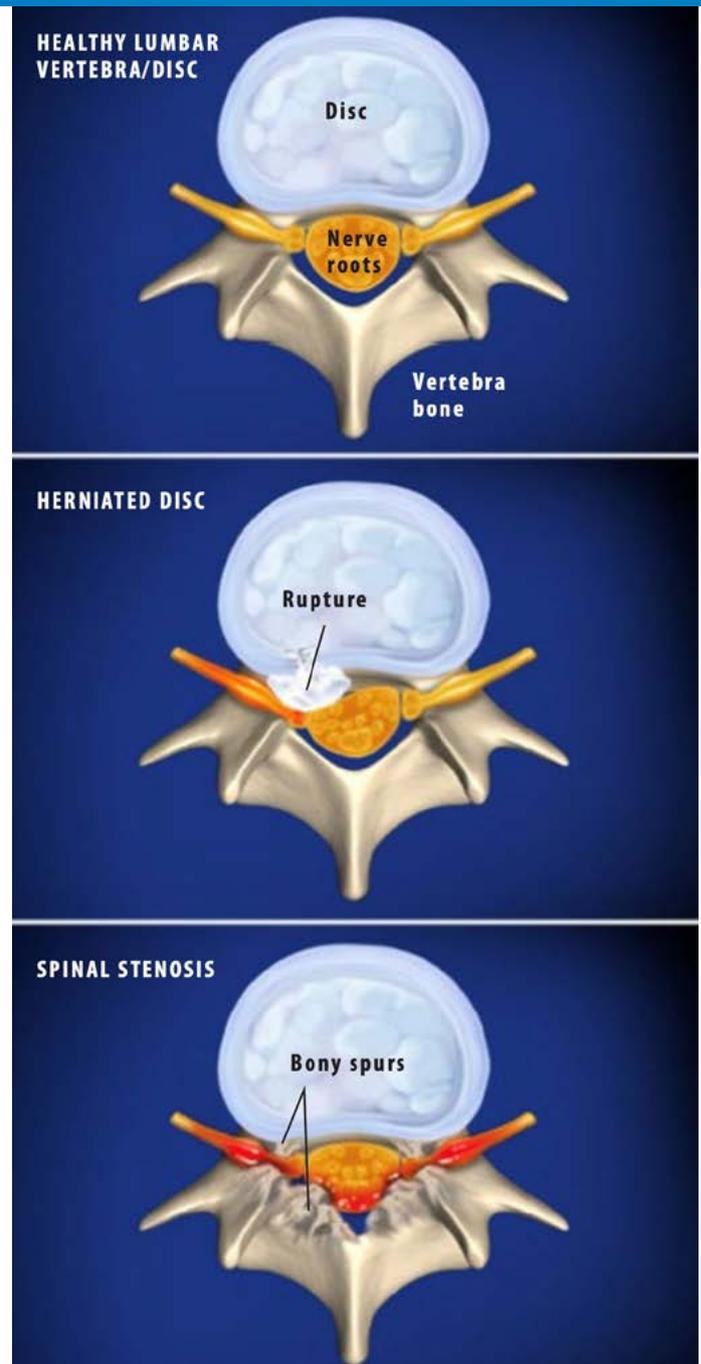
The diagram **to the right** shows how the nerves can be affected.

What should we worry about?

Most back and leg pain can be observed and treated simply.

Urgent attention is needed for:

- bladder or bowel control problems, eg. incontinence
- severe weakness
- loss of weight
- pain at night
- unbearable pain.



Best management

For new low back pain (lasting less than 12 weeks), try:

- heat
- massage
- physiotherapy.

Medications have a very limited role.

For chronic low back pain (lasting 12 weeks or more), try:

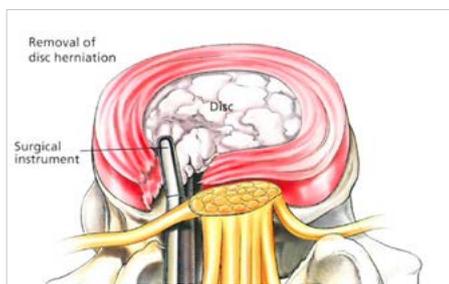
- exercise (including stretching, improving balance, and strengthening core muscles)
- physical therapy
- acupuncture.

- mindfulness-based programs intended to cope with or reduce stress.

Again medications have a limited role.

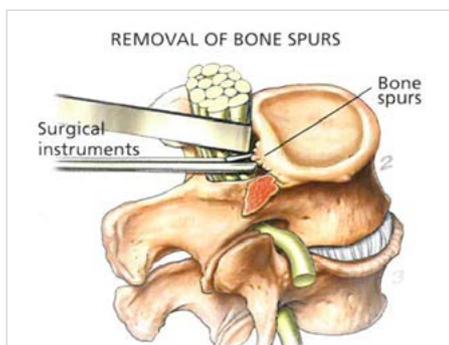
When is surgery helpful

Sciatica can be relieved with a small keyhole operation called a microdiscectomy – this is done through a one inch incision and patients can go home the next day. However 95 per cent will get better with waiting – so it's only a small group that benefit.



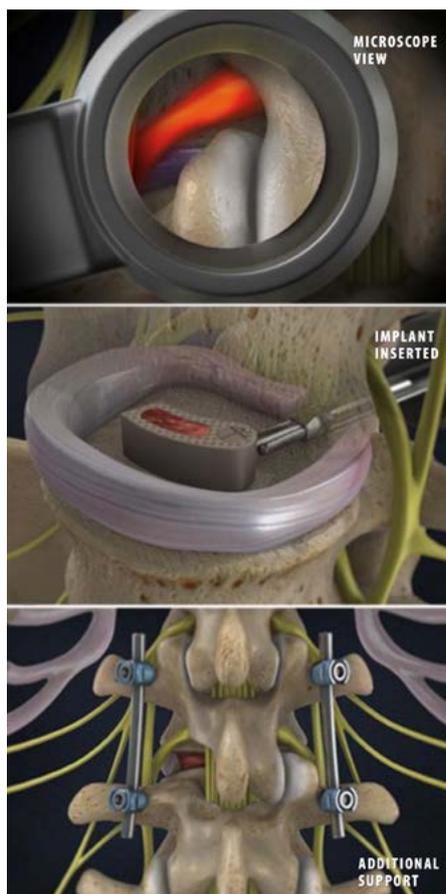
For back pain which doesn't resolve – sometimes injections of the anti-inflammatory cortisone into the source can help. This works for facet joints that cause pain. Physiotherapy is also very helpful as is exercise especially walking and swimming.

Some people get chronic leg pain or weakness – they may need an operation called a laminectomy to free up the nerves. Your GP can refer you to a neurosurgeon if this is you. An MRI will confirm the diagnosis.



Chronic lower back pain

Occasionally all simple measures fail and surgery can be considered. Fortunately, most operations can be performed using keyhole approaches now – sometimes with a robot to assist. For back pain, usually a fusion is the last resort but results can be excellent in carefully selected patients.



Because a fusion involves joining (fusing) two bones together there will always be a loss of mobility. That's why it's reserved for severe pain where nothing else is successful.

Neuromodulation

An exciting further option when someone isn't a candidate for other treatments, is to actually block the pain impulses from reaching the brain! This can be done with placement of an electrode in the spine through a small incision – it is called a spinal cord stimulator and connects to a box a bit like a pacemaker. The results can be truly outstanding with some patient's claiming that it allows them to be pain free for the first time in their lives!



Summary

- Simple treatments are best
 - Exercise
 - Physiotherapy
 - Avoidance of medications except if pain is severe
- Surgery can be effective but is rarely needed
- Surgery is usually keyhole for most conditions nowadays, so recovery is faster – but most neurosurgeons will only rarely need to operate for back pain, and only occasionally for sciatica
- If you are worried or the pain doesn't resolve your GP will be able to determine if there's a cause for concern.



Dr Rodney Allan (above) is an Australian neurosurgeon with additional advanced fellowship training in endovascular and cerebrovascular surgery. He is a consultant neurosurgeon at Royal Prince Alfred Hospital and has appointments at Royal Prince Alfred Hospital, the Chris O'Brien Lifehouse, North Shore Private Hospital and Central West Neurology and Neurosurgery, Orange.

GENTLE EXERCISE IS BACK!

Arthritis NSW is off to an exciting start in 2021 for our gentle exercise programs, after what could be called a tumultuous year. Our Warm Water classes are reopening at many locations, and it is lovely to see and hear of the many friendship groups coming back together in the pools and catching up on conversations and exercises that were put on hold for such a long time. We are thankful to all the staff at the respective pools who have worked hard to ensure that their facilities are COVID-safe and able to assist our many participants who have been eagerly awaiting the return to Warm Water class!

Best of Both Worlds

In addition to our regular Warm Water classes, we recently unveiled the Best of Both Worlds program which combines warm water classes with land-based exercise. All the instructors at our Bexley location are tertiary qualified and have been collectively working with various areas of the community for many years – and always with a smile on their faces! Our first Best of Both Worlds program is being held initially in Bexley at the Angelo Anestis Aquatic Centre twice a week on Tuesdays and Thursdays. If you would like to join or simply learn more,



The Wednesday morning class at Castle Hill.

contact our Health Services team on 02 9857 3300 as this will certainly be a very popular class! Additionally, if it does prove popular, the team at Bexley are very interested in providing this particular class at various locations so we are looking forward to working together on such a fun and exciting partnership.

Land-based only

If you are unable to make it to our Bexley venue but still interested in land-based exercises, we are recommencing with The Joint Movement program (TJM) and the return of our Strength & Balance classes. For those not familiar with Strength & Balance, it is a land-based class for all ages where instructors provide a variety of exercises to participants twice a week throughout the term. For those who have completed TJM and are looking for more exercises, this program is the perfect match! Both land-based exercise programs are still being held online via Zoom but once we have secured venues, we will return to face-to-face classes for the Strength & Balance Program. TJM continues through our partnership with Arthritis QLD and remains a free 10 week class for all participants over 65 years. If you have access to a computer but are unsure of how to use the Zoom video program, we are more than happy to explain how it works and to ensure you have a smooth and hassle-free experience. Both program exercise classes are 60 minute long and focus on gentle movements rather than an aerobic program. Please remember to bring a towel.

Glen Puxty
Program Administration Officer
Arthritis NSW

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What legacy will you leave behind?



Your gift is about making a difference in the lives of those impacted by arthritis and its effects.

With one in four adults and one in 1,000 children in the state affected by this condition, we have extended our community education reach into rural NSW. Our programs create awareness of ways to prevent arthritis and to spot symptoms early for better health outcomes. Our annual camps help reduce the isolation experienced by children living with juvenile arthritis and give them a safe space to have fun in a supportive environment. Our gentle exercise programs – warm water and strength and balance classes – help keep people active and moving, building muscle strength and core stability, which reduces overall pain.

Our work helps people to manage their condition on a daily basis.

Leaving a gift in your Will is a very personal decision, and perhaps the greatest commitment you can make to help create opportunities and contribute positively to life changing services and to make a difference in someone's life.

Thank you for your support and helping us to move closer to *Freedom from Arthritis*.

For further information about leaving a gift in your Will, or to have a confidential conversation, please call 02 9857 3300 or email: bequests@arthritisnsw.org.au or visit our website at arthritisnsw.org.au/support-us/planned-giving-bequests/

Great outcomes for all stages of life

In previous editions of *Arthritis Matters*, we have provided information on how health professionals themselves manage arthritis on both a personal and professional level. In this article, we look at the profiles of three members who have led different lives and lifestyles, yet have similar challenges with arthritis. I've been able to follow their stories for many years, and have been fascinated with how they successfully manage their conditions in varying ways. These members want different outcomes in life, and that has influenced their personal management approaches. I am confident of my ability to tell their stories accurately – two of our subjects are my parents, and one is a former professional referee whom I trained for several years and admired his determination to set and achieve goals.

These stories are particularly relevant now, as Arthritis NSW has been working on an outcomes framework to be introduced later in 2021. I've been using outcomes concepts when tracking the progress of my parents, Margaret and Ron Edwards from Queanbeyan. In the case of former NRL referee Glyn Henderson, we have used the concepts retrospectively to describe his achievement of goals. Glyn has more recently been feeling the aches, pains of working on a property in Jindabyne, and we have started a new approach to maintaining his strength and mobility.

New ground

ANSW is currently breaking new ground to ensure that members and participants benefit from programs and services. For those who have set desired goals in the past, or may in the future, the new Outcomes Framework will help to measure how happy we are with our achievements. The best thing about our framework is that it will be very practical, and adaptable to needs.

To give the new outcomes framework some real context, the stories below help illustrate our commitment to outcomes for individuals.

Ron Edwards



Introducing my dad, Ron Edwards, who has just celebrated his 85th birthday.

Dad loves golf and his garden, therefore his goals centre on being able to continue to drive, play golf and stay strong enough to maintain their 4-bedroom home on a large corner block. Dad's challenges were mainly neck stiffness that sometimes affected his driving and golf swing, along with a double knee replacement five years ago that sometimes affected his gardening and was sometimes just plain annoying! He did a range of exercises and stretches nearly every day and, in the two-week period around his birthday, he was able to drive to three games of golf and have his garden ready for birthday parties and Christmas! Being able to continue doing this – having **independence, choice and control** – is an outcome domain in the Arthritis NSW outcomes framework.

He strives to **know and understand** information about improving his **mobility or strength**, along with reduced discomfort in his knees. Achieving outcomes for Dad involved adding some more specific exercises to improve shoulder mobility and flexibility for golf, and adding some routines to keep his knees tracking within minimal irritation. Dad has sometimes tended to over-extend himself during exercise or around the house, and managed to pull his patella away from the replaced knee 'hardware' in 2017. With some corrective strength and flexibility work (see photos), his golf swing is pretty good and he experienced **less pain** (he calls it discomfort) in his knees – they are more 'annoying' than painful. He's back playing veteran's golf when he can, in addition to his regular Saturday game, as **connection** to the golf **community** and his mates is a major driving force.

Margaret Edwards



Introducing my mum, who turns 85 this year. Mum has always preferred a less hectic approach to life, especially since her hip and knee replacements 10 and 7 years ago

respectively. A couple of falls during 2018-19 encouraged her to start exercising, something that she's not fond of and hadn't done much of since giving up bowls in 2017. In March 2020, at the start of COVID, mum developed unusual pain and was initially diagnosed with polymyalgia. In April, things escalated and mum was hospitalised – they found an infection and lung embolism that caused hospitalisation for 10 days. On leaving hospital, she could only walk a few steps at a time before needing to rest. Once recovered, I became her regular personal trainer, and we informally set desired goals around more freedom in her breathing and getting back to 'normal' in her community life. Challenges included motivation to exercise as mum had never played sport other than bowls.

Our exercises with mum started slowly, with a few minutes at a time to mobilise her body after 10 days in hospital. Fortunately, mum's specialist was Professor Mark Hurwitz, who repeatedly told her to uncross her legs in the bed (scolding dad too), and to straighten up when sitting to keep blood flowing. This meant that she needed to do less work to mobilise, and we could focus on breathing and exercises that she'd been given by previous physiotherapists. We worked towards sit-to-stands and opening up the hip flexors to get blood flow to the knees. She also would remember Professor Hurwitz words later in recovery, and would get the newspaper in the morning, straighten up, and walk tall when she walked back up the driveway. This is complemented by 10 mins of strength and flexibility exercises, and adopting good positions when doing housework.

Mum certainly achieved her outcomes of having more energy and **motivation** to enjoy her home and garden. Her aches and pains improved, therefore it is likely that previous symptoms were related to the development of infections. Her **reduced pain** has been maintained since April, something that inspires her to keep exercising. She was able to attend Christmas parties, and her appointment with Dr Hurwitz in December showed continuing improvement.

Glyn Henderson



Introducing Glyn Henderson, 67, former NRL referee 1983-2003. Glyn Henderson had one lifelong outcome that he wanted to achieve; to be a touch judge for State of Origin and an NRL first grade Grand Final. Like many athletes, he'd had several injuries as both a player and referee. At the time he was the only Canberra-based NRL referee, and challenges included driving from Canberra to Sydney twice or three times per week.

In 2001 while in the first grade squad he 'blew' a calf muscle during a game. Glyn enlisted my services as a trainer to assist rehabilitation and get back into first grade. He undertook the hard training in Sydney, and his work with me was primarily massage and flexibility work to align muscles to endure the rigours of training. He was disciplined and completed 30 minutes of stretching every day, regaining his first grade place in 2002. In 2003, he irritated an adductor muscle (inner thigh) and x-rays showed knee 'bone on bone'. We changed his flexibility routine to focus

on hip and knees, facilitating a quick recovery. He was fortunate enough to achieve his lifelong goal as touch judge for the second and third State of Origin games, followed by the 2003 Grand Final. What makes this story particularly remarkable is that he turned 50 between the two games.

Seventeen years later, with regular flexibility work (see photo left), and staying active, he still only gets knee 'niggles'. I'm sharing Glyn's story to show that sometimes your goals are simple – this requires a more targeted approach and strong commitment to consistency and practice.

The ANSW framework and outcomes indicators are adaptable to your chosen goals, no matter what they may be. We have spoken with many ANSW members, stakeholders and staff and will start to pilot the components over coming months.

Work on the ANSW outcomes framework started in July 2020, with some initial conversations with people who use our services. This laid the groundwork for what is important to people and areas of focus. Over the past few months, we've had more formal conversations with both staff and participants to understand what outcomes look like, sound like, and what people feel when achieving personal gains. Sincere thanks to all our wonderful contributors to this process.

When we start to introduce outcomes into our programs, you may notice a different style of feedback questions to community education seminars and to resources such as the *Get Moving!* exercise series. We'll also ask questions in our enrolment forms related to your outcomes. Our staff and program instructors will also ask for your thoughts, either during programs or by phone, and we really encourage you to reply openly and honestly. We look forward to everyone sharing the outcomes journey and reaping the benefits!

Janine Robertson

Health Services Quality Manager
Arthritis NSW

Living with arthritis



Liz

A long time leader of the Long Jetty Arthritis Support Group, Liz has found that distraction is the best medicine to deal with pain.

'When I was in my early 40s, I noticed pain and swelling in my hands and elbows. Because the pain was bi-lateral

an inflammatory arthritis was suspected and I was given cortisone and sent to a rheumatologist. All the tests for rheumatoid arthritis and lupus came back negative. After consultations with a variety of specialists I was pretty much told that there was nothing to see here and go home and live with it! So I did.

'Of course the arthritis didn't go away and over the years I and my GP have accepted that what I have is osteoarthritis. Treatment has varied over time, but mostly I avoid painkillers of any sort. The person who has given me the most help is my osteopath, Lisa. I see her every six weeks and she gives me a tune up for my back, as I have scoliosis and lumbar degeneration that gives me back, neck and hip pain. My hands and feet I treat with Voltaren cream if they are really sore. Just occasionally I take Panadol or Neurophen depending on whether I feel the pain is inflammatory or not. Last year I had a cortisone injection in my hip for bursitis. On my doctor's advice I take fish oil and apple cider vinegar as a prophylactic.

'I find distraction is the best medicine. I walk, draw, paint, garden and do yoga when I'm not too sore, and I listen to music, read and write. Years ago a physio told me to join pool exercise classes and this led me to the Long Jetty Arthritis Group. I was eventually persuaded to take it over and ran it as a support group for 13 years.

'Now in my late 70s, I have been in semi isolation during the pandemic, but thanks to Skype and email I have been able to keep in touch with friends and family.'



Lyn

Lyn has osteoarthritis in her knees, right foot and both hands and believes that her career as an actor gave her techniques to deal with the pain.

'I was diagnosed with a dropped foot in 1999 and walked with a brace for about two years. My foot didn't move of its own volition for a long time

and, due to this inactivity, I developed arthritis.

'In 2010 I was diagnosed with arthritis in my knees and had both knees replaced in 2018. My doctor advised me to live with it as long as I could because replacement knees only last a certain amount of time. I had protected my knees for a long time because of the pain and so had less flexibility. I'm still working on flexibility. I walk a lot.

In 2013, my GP referred me to the Lifestyle Clinic at UNSW where the physiologists designed an exercise program based around weights and other exercises for my foot. I do two online weights classes with the clinic. I used to go to three classes a week before lockdown. I started the Best of Both Worlds at Bexley, (which includes both warm water classes and Strength & Balance classes) at the end of January.

'When I was 45, I began to experience pain in my fingers and knuckles. I can't make a tight fist. The best treatment is to keep moving and I typed a lot in my job before I retired in September. I worked at NIDA designing courses for the corporate world and taught the director and writer courses. I'm currently directing a play in community theatre at Rockdale. The arthritis affected my teaching style because I used to get up and down off the floor all the time and had to stop. But my career kept going.

'Chronic pain is exhausting and I've had it for 20 years. I stopped taking medication because it dulled my mind. But the mind is extraordinarily powerful and as an actor you use your mind a lot, so I've used acting techniques which helped me to suppress the pain. For example, I would be in quite a lot of pain and walking into a room to teach, I could change my focus and almost park the pain at the door. I put it on the backburner by changing my focus.'



Louise

Louise developed psoriatic arthritis (PsA) just over three years ago. She feels fortunate to not have psoriasis, however she does have two associated and painful conditions: costochondritis (extreme muscle pain around the rib cage and sternum) and hives.

'I went to my GP for an unrelated issue and mentioned that I had stiffness in my left index finger. She referred me to a rheumatologist. The pain and stiffness moved to my hands and arms. I was diagnosed with rheumatoid arthritis but as the condition progressed it was much more aligned to the behaviour of PsA and a re-diagnosis was made.

'I saw a hand specialist when I was diagnosed as I wasn't able to open jars or bottles or even bend most of my fingers. I had remedial massage and saw an osteopath, physiotherapist and an exercise physiologist to help relieve pain and keep my joints moving. I have been given a whole range of medications to manage this condition and avoid permanent damage to my joints.

'This condition and its offshoots have affected my life in so many ways, particularly the fatigue and the debilitating chronic pain. I have a naturally positive outlook on life and a wonderful husband and supportive family and friends but this is often a condition that you have to manage alone as it is so difficult for others to comprehend. I have to pace myself and to ensure I can do as much as possible.

'My career hasn't suffered but the energy I need to manage my work commitments is so much greater than before I had PsA. I am a Vocational Education Trainer and teach four 5hr classes per week. I use all my energy in those five hours each day and have nothing left.

'All my research to find the best ways to help myself has pointed to the same things – have a good team of medical people around you and keep moving.

'After months of pills and steroids, I have been on biologic injections fortnightly for the past two years. It has been my miracle cure and has allowed me to get some of my quality of life back and reduced the pain and stiffness. In addition to medication, I see an exercise physiologist twice a week, an osteopath fortnightly and attend warm water classes twice a week. This is all part of the keep moving theory and it helps immensely.'



Sheila

Sheila was diagnosed with osteoarthritis in her 30s, with gout in her 60s, followed by ankylosing spondylitis (AS) in her 70s.

'I was first aware I had a problem by the pain in my joints, mainly in my wrist and fingers. X-rays showed what was wrong. I found it hard

to grip things and my husband spent some time picking and cleaning things up that I had dropped. The gout was a different symptom altogether. My right elbow became red, swollen and sore, and blood tests showed the problem. I just thought the AS was severe back ache and my doctor referred me to a rheumatologist and after enough scans to make me glow in the dark he made the diagnosis.

'I have had my left and right hips replaced three months apart, a right reverse shoulder replacement, and my left foot bones repaired and plated. I am now waiting to see my ankle and foot surgeon about how he will deal with my left ankle. I have been very lucky to have had only two GPs since I have lived in Australia and to me they are the best. I have never been told 'you just have arthritis' and they have been a wonderful help with trying to control my symptoms.

'The arthritis made a huge difference to my life. When OA hit me I had an eight-year-old daughter, a four-year-old daughter and a 10-month-old son. I was luckier than most because my husband was a three shifts worker, and my parents lived with us. My two daughters were fantastic with their baby brother and helped so much. When I had flare ups, everyone pitched in.

'I have all the latest treatments to help me. I have two hourly sessions of hydro therapy at Shellharbour Private Hospital per week. I have found that shellfish flares up my gout so I avoid that but I try to maintain a healthy diet. I keep as active as I can while also dealing with AS.

'I live in a Warrigal Village which my husband and I moved into 10 years ago. My husband died three and a half years ago and, as I will be 81 in February, living here has been a blessing. My family are always there to help me when needed.'

POLYMYALGIA RHEUMATICA

Polymyalgia rheumatica means 'pain in many muscles'. It is a condition that causes inflammation of the joints and tissues around the joints. This causes muscles to feel painful and stiff, especially in the shoulder, neck and hip areas. Polymyalgia rheumatica is different to fibromyalgia, a condition that does not cause inflammation.

Symptoms

Symptoms usually come on quickly, over several days or weeks and sometimes even overnight. The main symptoms are:

- muscle pain and stiffness in the upper arms, neck, buttocks and thighs on both sides of the body
- pain and stiffness worse in the morning, and after not moving, such as after a long car ride or sitting too long in one position
- difficulty sleeping and doing daily activities, eg. lifting your arms to put on a jacket, bending over to pull on shoes or getting up from a low chair, due to pain and stiffness.

Cause and diagnosis

The exact cause of polymyalgia rheumatica is not known. Genetics and/or environmental factors, such as an infection, may play roles in causing this type of arthritis. This has yet to be proven in research.

There is no single test that can diagnose polymyalgia rheumatica. Your doctor will diagnose polymyalgia rheumatica from your symptoms, a physical examination and blood tests that measure levels of inflammation. These tests measure the erythrocyte sedimentation rate (ESR) or C-reactive protein (CRP) blood level. However some people with polymyalgia rheumatica can have normal blood tests. It may take several visits before your doctor can tell if you have polymyalgia rheumatica as the symptoms can be like other types of arthritis.



Treatment

Treatment for polymyalgia rheumatica usually involves medicines called corticosteroids. Your doctor will usually start you on a dose that relieves your symptoms, and then slowly reduce the dose to the lowest possible amount that keeps you symptom free. Corticosteroids can cause side effects so it is important to be reviewed regularly by your doctor while taking these medicines. For information about corticosteroids see the Australian Rheumatology Association's Patient Medicine Information.¹

The good news is that the symptoms of polymyalgia rheumatica usually improve with treatment. In fact, most people find their symptoms improve dramatically within a few days of starting treatment. It usually takes between several months to three years for polymyalgia rheumatica to settle completely. Most people will need to continue treatment during this time to keep the symptoms under control. Polymyalgia rheumatica can return, particularly when you stop treatment, however this is rare if you have been free of symptoms for some time. Polymyalgia rheumatica does not cause permanent damage to the joints.

What I can do

As well as seeing a doctor, you can play an active role in your treatment. Live a healthy life by staying physically active, eating a healthy diet, giving up smoking, and reducing stress.

Acknowledge your feelings and seek support. Having polymyalgia rheumatica can turn your everyday life upside down. As such it is natural to feel scared, frustrated, and sometimes angry. Be aware of these feelings and get help if they start affecting your daily life.

Giant cell arteritis

About one in five people with polymyalgia rheumatica may also develop a serious condition called giant cell arteritis or temporal arteritis, where the blood vessels, usually on the side of the head, become inflamed. It is diagnosed by biopsy. If it is not treated, giant cell arteritis can cause permanent damage, such as blindness. If you have headaches, blurred or double vision, pain in the jaw muscles when chewing or the side of your head is sore to touch or swollen, you should see your doctor straight away.

1. rheumatology.org.au/patients/medication-information/prednisolone

More information from reliable sources

arthritisnsw.org.au
arthritisresearchuk.org
rheumatology.org.au
rheumatology.org
arthritis.org

This information has been reprinted from Arthritis Information Sheet: Polymyalgia rheumatica, Arthritis Australia 2007, reviewed 2017.

THANK YOU!

Where would we be without our generous donors? Below we have shared the personal stories of two of our regular donors: Erica Pitman and Newcombe Kritsimas Partners.



Erica Pitman

Erica is a counsellor who has worked with not-for-profits for many years and understands the importance of donations to Arthritis NSW. As previous Executive Officer of the Central West Women's Health Centre in Bathurst, Erica presented Living Well with Chronic Illness at Arthritis NSW's inaugural Rural Health Program seminar in 2018.

'I donate regularly to Arthritis NSW because anything I can do to help improve the lives of those with arthritis now and in the future is worthwhile,' she said.

Fifteen years ago, aged 39, Erica's world turned upside down when she was diagnosed with rheumatoid arthritis. 'At that time, I was using a walking stick to get out of bed, to go to the bathroom, thanks to the mass of inflammation in my knee and ankles. I truly thought I would be in a wheelchair within a few years.

'I had seven years on a combination of drugs, followed by three years in total remission. The past four years I have been back on two drugs. It is not obvious that I have a condition – I walk normally most of the time, however I'm unable to kneel, squat or run. Fatigue also catches up with me at the end of the day,' she said.



Andrew

John

Erica manages her arthritis using a variety of methods. 'I use a combination of medications and alternative therapies and follow the advice of my rheumatologist,' she said. 'I maintain a healthy diet, exercise and consider the impact on my health of every decision I make. I've also trained myself to take 10-minute power naps the moment I know that I have nothing left.'

Newcombe Kritsimas Partners

Andrew Newcombe and John Kritsimas' business makes regular donations to Arthritis NSW because their children each have been diagnosed with juvenile arthritis (JIA).

Andrew's eldest daughter was diagnosed about 12 years ago and is under the care of paediatric rheumatologist Dr Jeffery Chaitow. 'The diagnosis came with heartache but also relief that we knew what was causing her issues,' Andrew said.

Dr Chaitow encouraged Andrew to send his daughter to Camp Footloose, ANSW's kids' only camp for 9–18 year olds. 'At Camp Footloose she received support and encouragement to deal with her condition and met new friends who were experiencing the same issues. She is now a 20-year-old woman and pushes herself to be the

best she can be – a trait she learned at Camp Footloose.'

By coincidence, Dr Chaitow was the paediatrician of John's newborn son who, at a young age, was diagnosed as having JIA as well. Andrew encouraged John to attend Camp Twinkletoes, ANSW's camp for families of children aged up to 8-years-old with JIA. The Kritsimas family attended in 2018 and found it very valuable.

'We request that our donations go to the children's camps. We hope that through our donations and the kindness of other donors that this essential service continues for many years,' said Andrew.

'We also write to our clients at Christmas and tell them that in lieu of Christmas cards, we are donating to Arthritis NSW. Many of our long-term clients have followed the progress of our children and are deeply encouraged by this. We hope that by sharing our stories that we can make more people aware of a largely unknown and unspoken condition that impacts many children.'

If you would like to make a donation to Arthritis NSW visit: arthritisnsw.org.au.

Challenge your arthritis with mocktails

Where's the cocktail shaker? It's time to toast the last of summer with a delicious mocktail. Each recipe below contains wonderful flavours and ingredients to ease the discomfort of arthritis. Cheers!

Nettle tea mojitos

A mocktail with a super herb-like nettle makes this drink functional and delicious!

Ingredients

- 1 lime
- Half cup hot water
- 2 nettle tea bags
- Half tsp raw honey
- 1 cup crushed ice
- Half cup sparkling water or cold water
- Half cup fresh mint leaves (plus more for garnish)

Instructions

1. Brew tea with the half cup hot water and 2 tea bags in a cup according to directions on the package (about 5 min).
2. To your cocktail glasses, split the tea in half, pouring in each glass. Add 1/4 tsp of raw honey to each glass and stir to dissolve in the hot water.
3. Squeeze half a lime in each glass and stir.
4. Tear mint leaves by hand a bit to release some of the oils and divide evenly among glasses, muddle with a spoon in the bottom of the glass.

5. Add crushed ice, followed by the sparkling or cold water to fill to the top.
6. Garnish with whole mint leaves and serve!

Stinging nettle acts as an:

- antioxidant
- antimicrobial
- anti-ulcer
- astringent and analgesic.

Source: foodbymars.com/nettle-tea-mojitos



Papaya cocktail

Made with fresh fruits like papaya, peaches, and pears, you'll be refreshed while helping out your digestive system. Make sure to use ripe papaya and peaches, otherwise you may need to add a teaspoon of raw honey to sweeten it up. This smoothie snack not only helps prevent bloating and digestive stress, it's also a highly anti-inflammatory smoothie thanks to the papaya and ginger.

Ingredients

- 1/2 cup filtered water or coconut water
- 3/4 cup papaya
- 3/4 cup sliced peaches
- 1/2 cup pear usually 1/2 pear
- 1 teaspoon fresh ginger
- 2 mint leaves
- 1 cup ice

Instructions

1. Place all ingredients into the blender in the order listed and secure lid.
2. Blend for 30 seconds or until desired consistency is reached. Serve immediately.

Papaya contains several protein-digesting enzymes that may help lower inflammation and improve healing from burns. Some research has found that these enzymes may also help reduce the severity of inflammation-related symptoms for people living with asthma, osteoarthritis, and rheumatoid arthritis. One papaya provides more than twice the daily dose of Vitamin C.

Source: blenderbabes.com/lifestyle-diet/heart-healthy/flat-tummy-anti-inflammatory-smoothie-cocktail/

Ginger lemon mocktail

This drink is bubbly and refreshing!

Ingredients

- ice cubes made from pure water
- 2 to 4 tablespoons ginger concentrate, see recipe below
- 3 tablespoons lemon juice from one lemon
- 1 to 3 teaspoons raw apple cider vinegar
- raw honey or liquid stevia extract, to taste
- sparkling mineral water *

Instructions

1. Fill a pint-size Mason jar with ice.
2. Add the ginger concentrate
3. Squeeze in the juice of the lemon.
4. Add apple cider vinegar.

5. Pour in the sparkling water, but don't fill your glass completely. Leave some room to add more ginger, lemon, vinegar, and/or raw honey or stevia to your taste preferences.
6. When it's just right, give it a good stir, and you're done!

Ginger concentrate

Keep in the fridge for up to one week.

1. Run a 3 to 4 inch piece of washed ginger root through a juicer or blender.
2. Pour the bright yellow juice into a pint-size Mason jar.
3. Fill with water. This is the 'concentrate'.

Benefits of ginger:

- helps heal and protect the gut
- relieves nausea, bloating, and upset stomach
- boosts the immune system and is an excellent remedy for colds or the flu
- potent detoxifier
- clears the sinuses
- relieves pain caused by migraines, inflammation, menstrual cramps, and arthritis
- is a warming food and can help with low body temperature and/or slow metabolism.

Benefits of lemon:

- is a great source of Vitamin C
- aids in digestion
- is a great detoxifier
- can help with constipation
- flushes the liver and kidneys
- boosts energy and mental clarity.

Benefits of raw apple cider vinegar:

- aids in digestion, relieves heartburn and constipation, and increases stomach acid
- is super detoxifying
- can help with weight loss
- is alkalizing
- reduces sugar cravings.

Source: traditionalcookingschool.com/food-preparation/recipes/ginger-lemon-mocktail



Berry Blaster mocktail

This super healthy mocktail recipe will leave you refreshed and revitalized.

ingredients

- 7 fresh raspberries
- 3 fresh blackberries
- 50 ml pomegranate Juice
- 25 ml apple juice
- 12 ml lemon juice
- 1 tsp of honey (runny is better)
- ice

Instructions

1. Fill half the cocktail shaker with ice. Add all ingredients and shake well for 45/60 seconds
2. Strain into an old-fashioned glass filled up with ice

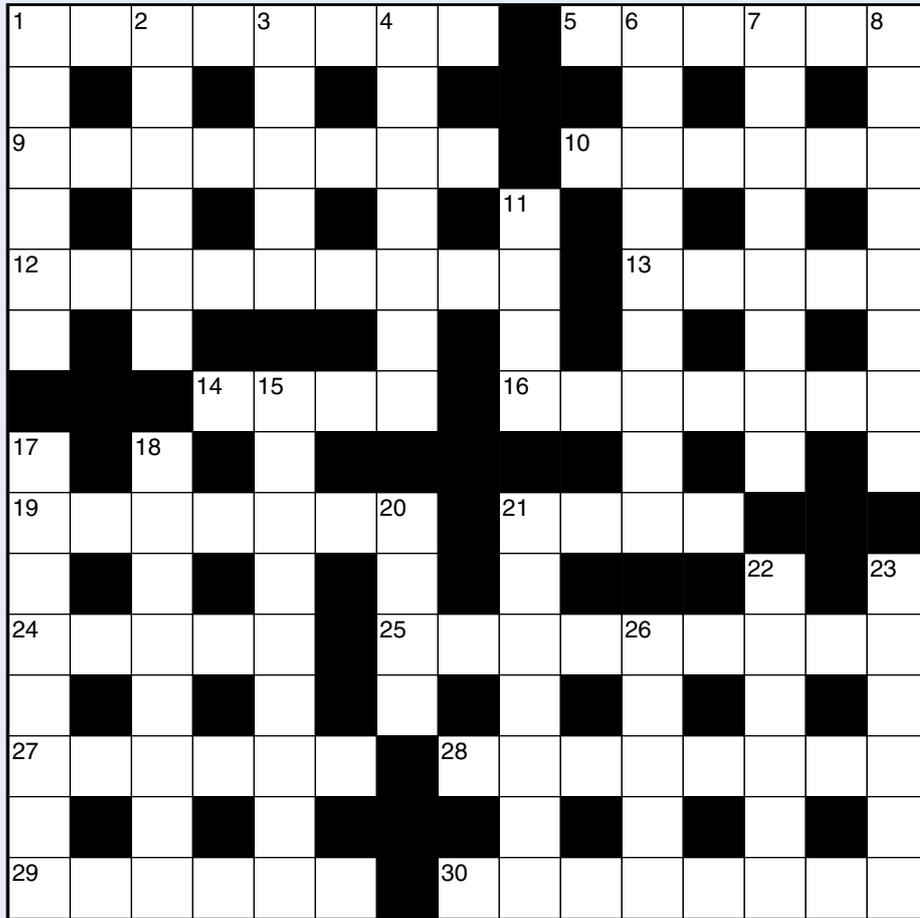
Blackberries contain vitamins A, B, C and E and a wide range of nutrients like magnesium, calcium. The deep purple colour comes from antioxidant – anthocyanins.

Raspberries are high in fibre, vitamins, minerals and antioxidants. They help protect the body against diabetes, cancer, obesity, arthritis and other conditions.

Honey has been linked to improved heart health, blood and antioxidant status.

Source: italianfoodfast.com/berry-blaster

Crossword



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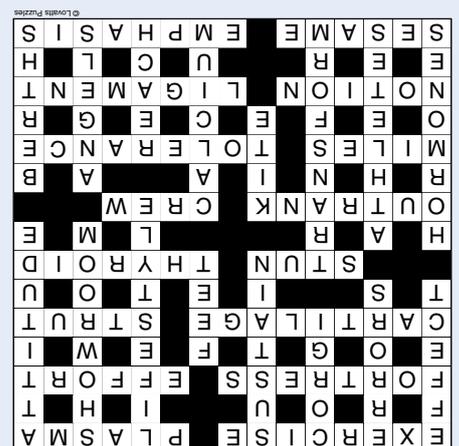
DOWN

1. Consequence
2. Miscalculations
3. Royal dog
4. Maintain
6. Osteoarthritis can develop due to a person's medical history as well as general ... factors
7. Area for displaying goods
8. Point of view
11. Paws or hooves
15. Radically alter
17. Changes in these chemicals in the body, particularly oestrogen, can lower bone density
18. Olympic sprinters
20. Flying frame
21. Vitamin D plays an essential role in the absorption of this element for healthy bones and teeth
22. Divine messengers
23. Docks at wharf
26. Arrive at (destination)

ACROSS

1. Regular sessions of this kind of activity can develop and maintain bone health
5. Clear or yellowish blood component that contains red and white blood cells
9. Castle
10. Attempt
12. Painful joints occur when this flexible substance between bones begins to break down
13. Walk ostentatiously
14. Electric shock weapon, ... gun
16. The malfunctioning of this important gland can be a risk factor for developing osteoporosis
19. Take precedence over
21. Aircraft staff
24. Non-metric distance units
25. Patience
27. Thought
28. Inflammation that causes arthritis can also impact this fibrous connective tissue, leading to stiffness and pain
29. Magic saying, open ...!
30. Special importance

Crossword solution



Find help, guidance and support through our local networks

Who to Contact			Meeting Place	Meeting Schedule
Bathurst	Nelma	0431 829 709	Bathurst RSL, 114 Rankin St, Bathurst	2nd Thursday 10am
Cowra	Christine	0427 423 596	Upstairs, Calare Building, 103 Kendal St, Cowra	1st Tuesday 2pm
Dubbo	Heather	02 6887 2359	Western Star Hotel, Erskine Street Dubbo	2nd Thursday 11am
Holroyd/ Merrylands	Michelle	02 9631 7363	Club Merrylands Bowling, Newman Street, Merrylands	4th Wednesday 10am
Kincumber	Jeanette	0418 226 891	Brentwood Village Auditorium, Scaysbrook Dr, Kincumber	4th Friday 10am
Long Jetty	Robyn	0451 062 914	Coffee Club - The Diggers Club 315 The Entrance Road, The Entrance	1st Thursday 10.15am
Macarthur	Charmaine	0423 500 066	Campbelltown Library, Hurley St, Campbelltown	1st Wednesday 10am
Maitland District	Joe (temp)	02 4966 4208	East Maitland Bowling Club, New England Hwy, East Maitland	1st Thursday 10am
Newcastle	Judy	02 4088 3146	Mayfield Ex-Services Club, 58 Hanbury St, Mayfield	3rd Monday 11am
Nowra	Gary	02 4423 3633	Zest Café, Shop 2, Holt Centre, 29 Kinghorne Street, Nowra	1st Thursday 10am
Parkes	Sandra	02 6863 4904	Pink Orchid Café, 16-18 Busman St (odd months); AOG Church Hall, 7 Rees Ave (even months), Parkes	Last Tuesday of the month 10am – meet bi-monthly
Penrith	Jan	02 4722 5940	Penrith RSL, 8 Tindale Street Penrith	2nd Wednesday 9.30am
Ryde	Mary	0402 257 568	Ryde-Eastwood Leagues Club, Ryedale Rd, West Ryde	4th Thursday 1pm
Wagga Wagga	Lorraine	02 6926 3203	Rules Club, Cnr Fernleigh & Glenfield Roads, Glenfield Park	1st Thursday 1pm
Warilla/ Shellharbour	Sheila	02 4296 1340	Warilla Bowling Club, Jason Ave, Barrack Heights	3rd Thursday 1.30pm
Woy Woy	Heather	0423 017 450	Ettalong Bowling Club, 103 Springwood Street, Ettalong	3rd Tuesday 10.30am

For further meeting details, please contact the person listed or refer to our website.

If you would like to form a support group, call us for a convenor's pack on 02 9857 3300 or email: friends@arthritisnsw.org.au.



Arthritis

NEW SOUTH WALES

arthritisnsw.org.au

Arthritis NSW
Locked Bag 2216
North Ryde NSW 1670

Authority to fundraise CFN12845
ABN 64 528 634 894

Arthritis Infoline: **1800 011 041**
Phone: **02 9857 3300**
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