

# Arthritis Matters

NUTRITION

RESEARCH

EXERCISE

HEALTH

Issue 67 | October 2020

R.R.P \$6.95

GET MOVING!

PLUS

All about rehabilitation

DISCOVER

the latest research on lupus

TRAVEL

the world with our virtual guide

RESTORE

your mind/body balance to  
manage arthritis

 **Arthritis**  
NEW SOUTH WALES

[www.arthritisnsw.org.au](http://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](http://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*, three times a year and attractive discounts on all classes and events.

For more information on becoming a Member, please visit:

[arthritisnsw.org.au/membership/about/](http://arthritisnsw.org.au/membership/about/)

Call: 02 9857 3300 Email: [info@arthritisnsw.org.au](mailto:info@arthritisnsw.org.au)

- ✓ Be heard
- ✓ Be informed
- ✓ Be supported
- ✓ Be rewarded



# Arthritis Matters

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For arthritis information  
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### Editorial

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**On the cover:** ANSW Health Educator Kat Keane designed the *Get Moving!* Exercise Series  
Photographer: Leanne Hinden

### Advertising

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**For enquiries or to advertise in *Arthritis Matters*:**  
02 9857 3300 or [info@arthritisnsw.org.au](mailto:info@arthritisnsw.org.au)

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## Commitment and collaboration



There is no denying 2020 has been a unique year!

Whilst many areas of our lives have changed, and questions asked about our society and identity in the past year, the speed of change is one of the things that has most astounded me. Particularly how quickly we have adapted to impacts of the COVID-19 pandemic.

The pace of change seems faster than ever.

Who would have thought that in the space of a few weeks we would have been locked down and stopped from meeting others?

And of course throughout 2020, the needs of our clients have changed significantly. And how we communicated with clients changed. And the way we worked with other organisations changed.

But both Arthritis NSW and our clients reacted to these changes. Whether it was moving exercise classes online, or moving to out-bound Infoline calls to check in on clients who might be isolated, we changed our work to reflect the new needs of our clients.

This speed of change provided an appropriate back drop for a review of what we do, who we support, and how. That has given rise to a new Strategic Plan about which you can read more on page 6. It builds on and refines what we do, sees us collaborate with others (other arthritis organisations to minimise duplication and waste, other health providers to help 'fill the gaps'), to ensure we better serve those with chronic arthritis. The plan also strengthens our business so we can continue to help people with arthritis for decades to come.

### Commitment

The one constant – the golden thread through this quickly changing environment, and our planning into the future – is our commitment to support people with arthritis. That will never change.

Reflecting on our commitment to collaborate, on page 5 you will read about a national partnership to enhance the Arthritis Infoline (1800 011 041) which is the first port of call for many people needing support, and the expansion of our kids' camps program, to extend this

life changing experience to more young people.

In addition, collaboration has helped develop Aboriginal and Torres Strait Islander education resources, a psoriatic arthritis website and to upskill health professionals in arthritis care.

Glen Puxty (the voice you usually hear on the other end of the Infoline!) also mentions a collaborative online strength program on page 16. He is thrilled that some of our warm water exercise classes have resumed, and we are striving to open more venues as soon as is safely possible. He also provides an update on our online strength classes for over 65s – The Joint Movement.

Also, our page 14 focus on chronic pain covers what you need to know about joint surgery.

So – we have plenty of services available even through big social changes. Don't ever hesitate to reach out if you need support. And I'd like to sign off with a big thank you to our members, donors, volunteers and supporters whose commitment and generosity helps ensure people with arthritis get the help they need.

A handwritten signature in black ink, appearing to read 'Alex Green'. The signature is fluid and stylized, with a long, sweeping line extending from the end.

**Alex Green**  
CEO  
Arthritis NSW

# Action Plan projects get the green light

The new financial year has signalled the go-ahead for six new projects that will improve the lives of people living with arthritis across Australia.



The projects have been funded by a \$4 million federal grant to Arthritis Australia announced by the Minister for Health, Greg Hunt, in late 2019. They cover the areas of consumer information, education and support, and health professional education.

Acting CEO of Arthritis Australia Franca Marine said the projects came out of the National Strategic Action Plan for Arthritis and would be delivered over the next four years through and with state and territory affiliates. 'My team is thrilled to be working so closely and collaboratively with Arthritis NSW,' she said.

Here are some of the projects that will be delivered under those grants.

## Enhance the national Arthritis Infoline support service

The national Arthritis Infoline support service connects callers to health professionals and trained volunteers in the states and territories who provide information about arthritis conditions and how they can be managed effectively.

The project aims to enhance the way we engage with callers and promote the Infoline more widely.

## Expand access to kids' camps

Kids' camps for children with juvenile arthritis are currently run in WA and NSW. However, due to limited resources, currently only around 190 children are able to attend each year. This project will give at least 100 additional children access to kids' camps by establishing a new camp in the ACT, expanding capacity in existing camps, and providing travel subsidies for children in other states and territories and from rural and remote areas to attend camps. Due to COVID-19, the delivery of kids' camps is on hold, but this will be reviewed by the end of 2020 and hopefully the camps can proceed in 2021.

## Develop education resources that address the needs of Aboriginal and Torres Strait Islander peoples

This project will engage with Aboriginal health consumers and health experts and researchers to re-design and re-orientate Arthritis

Australia's information resources on osteoarthritis, rheumatoid arthritis and lupus so that they are culturally appropriate, accessible and address the needs of Aboriginal Australians.

## Develop a website which will provide tailored information for people with psoriatic arthritis

This innovative website will provide information, tools and support for people living with psoriatic arthritis which responds to their needs, age and stage of life. The site, MyPsA, will be based on the ground-breaking MyRA website launched by Arthritis Australia in May for people with rheumatoid arthritis.

## Develop tailored consumer resources for people with arthritis in targeted populations

This project will develop new consumer information, tools and printable, online and video resources, to meet gaps and needs for certain groups of people with arthritis. The resources will focus on exercise, pain management and expanded information on fibromyalgia.

## Health professional education

This project will develop a central hub of evidence-based information, education, practice supports and training resources to upskill health professionals in the delivery of high-value arthritis care. The project will be delivered by a consortium of universities and peak arthritis health professional, consumer and research organisations.

The project will address: high value care for osteoarthritis; the management of inflammatory arthritis; the development of living guidelines for juvenile idiopathic arthritis; and a promotional campaign for the new modules on the importance of early diagnosis and intervention in inflammatory arthritis.

# Stakeholders define our new strategy

This crazy year, when COVID-19 stopped much of our ‘business as usual’ and I started my service as CEO, provided a great opportunity to assess what people with arthritis want, how we might best help, and how to ensure more people are supported into the future.

So, one of my first tasks as CEO was to undertake a stakeholder survey (thanks to the hundreds who responded!), which then informed a new organisational strategic plan. At the same time, we reviewed our recent history: What had the organisation done well? How might we improve? And how could we have most impact on those who most need it?

Some of the most revealing survey results, and the insights they prompted were:



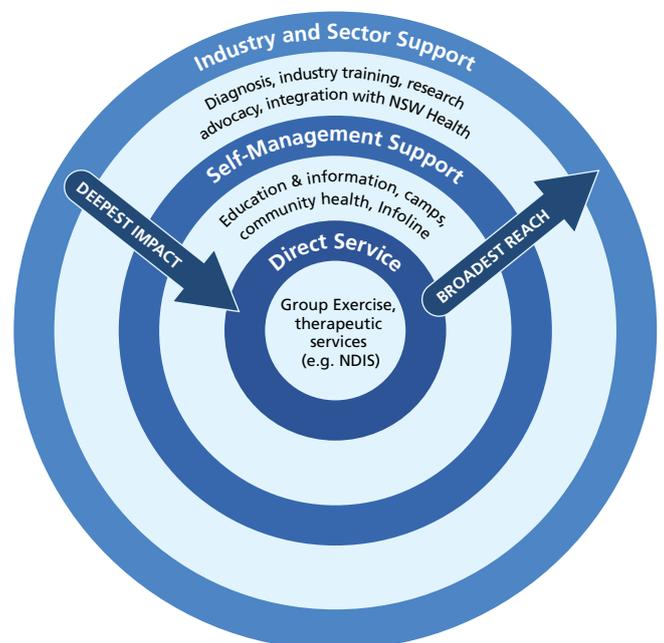
Survey result	Insight
53% of our clients have osteoarthritis, 23% rheumatoid arthritis, with other conditions under 10%.	We must continue to cater for different forms of arthritis.
GPs have been key to care for 86% of people.	We must support GP training and awareness.
The biggest impact on people’s arthritis is through: <ul style="list-style-type: none"> <li>• prescription meds</li> <li>• allied health / therapies</li> <li>• exercise (resistance training and esp. warm water).</li> </ul>	Medicinal information remains valuable. Increase the breadth of therapeutic services. Exercise therapy remains vital.
The biggest barriers to management are lack of services in areas and periodic disease flare ups.	Broader service coverage and digital/virtual delivery should feature in our planning, and we should provide more information on management of flare ups.
68% of people are unaware RA and JIA are covered under NDIS and 46% said they had not applied but believed they could.	Communicate the potential role of the NDIS to those who may be eligible, and deliver specialist services covered under the NDIS.
The top 3 answers to the question <i>What is most important to you</i> , were, in order: research, information, services.	Our mandate must span research, information provision and direct service delivery.

This model of service (right) was created to communicate how to best support clients.

And the resultant strategic plan (opposite page) was articulated on one page. It includes new organisational values that define how we intend to act, and highlights the different stakeholder groups to work with.

We believe that this plan will enable us better to deliver on our Mission to **help people living with arthritis**. If you have any questions about this plan or how we will help people living with arthritis, please don’t hesitate to contact me on [agreeen@arthritisnsw.org.au](mailto:agreeen@arthritisnsw.org.au).

## Model of Service



**Alex Green**  
 CEO  
 Arthritis NSW

**VISION:** Freedom from arthritis    **MISSION:** To help people living with arthritis

**VALUES:** • Collaborative • Sustainable • Innovative • Outcome focused

## STRATEGIC PLAN How we will focus our activity

<b>STAKEHOLDERS</b> Who we work with:	 People living with arthritis	 Arthritis Australia and related groups	 Healthcare ecosystem	 Community of those who care	 Those we work with
<b>HORIZON 1</b> Extend 2020-2022	<ul style="list-style-type: none"> <li>Continual feedback loops align our work with client needs</li> <li>Continuous outcome measurement and improvement framework measures which deepen impact</li> <li>Suite of services augmented to reflect client need including emerging digital delivery and telehealth</li> </ul>	<ul style="list-style-type: none"> <li>Collaboration on national projects with Arthritis Australia allows greater delivery and efficiencies</li> <li>A commitment to research funding drives research donations</li> <li>Collaborate to shared goals with related organisations</li> </ul>	<ul style="list-style-type: none"> <li>Strategically placed and clearly defined role for ANSW in healthcare system enables greater impact</li> <li>Networks established through NSW Health, PHNs, Divisions of GPs and RACGP for information distribution</li> <li>Integration of service into NDIS and My Aged Care to deliver scalable and sustainable service model</li> </ul>	<ul style="list-style-type: none"> <li>Champions, patrons and ambassadors advance the cause of people living with arthritis</li> <li>Future focused fundraising program is managed through stronger lead indicators of revenue</li> <li>Marketing to drive client referrals and demonstrate outcomes/impact to supporters and other stakeholders</li> </ul>	<ul style="list-style-type: none"> <li>NSW Health is an active partner in our work</li> <li>Staff-Board connection developed to support growth and retention</li> <li>Talent recruitment (Board, staff, external representatives) to deliver on this plan</li> </ul>
<b>HORIZON 2</b> Develop 2023-2025	<ul style="list-style-type: none"> <li>Embed digital technology including AI / VR into service offering to support clients and those who do not access physical services</li> <li>Use client insights to drive advocacy for funding and health service change</li> </ul>	<ul style="list-style-type: none"> <li>Structure shared service agreements with affiliates to achieve efficiencies</li> <li>Become an initiator of national Arthritis Australia activities to benefit clients nationally</li> </ul>	<ul style="list-style-type: none"> <li>Create arthritis accreditation scheme for allied health workers to promote expert care</li> <li>Establish and nurture GP referral pathways so ANSW can provide expert care to maximum clients</li> </ul>	<ul style="list-style-type: none"> <li>Develop products and partnerships with aligned companies for rehab and preventative programs to reach new clients</li> <li>Structure partnership model for pharmaceutical companies to support effective arthritis management</li> </ul>	<ul style="list-style-type: none"> <li>Incorporate Research &amp; Development into annual budget to contribute to cause and cure</li> <li>Deliver operating surplus to ensure sustainability and growth in order to help more people with arthritis</li> </ul>
<b>HORIZON 3</b> Create 2025+	<ul style="list-style-type: none"> <li>Promote excellence in care and 'one-stop-shop' hubs for management of arthritis</li> </ul>	<ul style="list-style-type: none"> <li>Achieve national influence, advocacy and economies of scale through stronger collaboration</li> </ul>	<ul style="list-style-type: none"> <li>Drive best practice of treatment and research by locating ANSW hubs at key NSW Health sites</li> </ul>	<ul style="list-style-type: none"> <li>Achieve recognition by, and partnership with, NSW Health for the quality and impact of our service</li> </ul>	<ul style="list-style-type: none"> <li>Provide efficient service by embedding contemporary work practices into operations</li> </ul>

# Get Moving! PLUS

Since its launch online in May, our *Get Moving!* Exercise Series has been keeping our members active while in the comfort of their own homes. Four months later, we are happy to bring you the next stage *Get Moving!* PLUS, which is rehabilitation and joint specific. ANSW Health Educator and *Get Moving!* designer Kat Keane explains below.

## Overview

The *Get Moving!* PLUS Exercise Series is an exercise library, much like the original *Get Moving!* Exercise Series, that contains exercises specific to joints and muscles that are often affected by arthritic and other musculoskeletal conditions. *Get Moving!* PLUS is a compilation of recorded videos aimed at specifically promoting joint mobility attributes.

You asked, we delivered! *Get Moving!* PLUS was created out of both demand from consumers wanting exercises for specific joints and the need for freely available, high quality joint specific mobility exercises. *Get Moving!* PLUS may be used to complement treatment you receive from a Physiotherapist, Myo therapist or Exercise Physiologist for pre or rehabilitation from a joint replacement surgery (or other similar) and/or musculoskeletal treatment due to pain and/or restricted movement in the context of arthritis.

## What is *Get Moving!* PLUS?

*Get Moving!* PLUS is not an exercise library for fitness purposes. Instead, it is an exercise library dedicated to promoting and improving the mobility and strength of joints and muscles that are affected by arthritis and other musculoskeletal conditions.

Many of the mobility exercises included are at low risk of injury and are easy to perform, though some are a little complex. For example, some require a resistance band, towel or other equipment, while other exercises are self-assisted (using your hands to create force or a block, or to promote a specific direction of movement). Some require a certain range of motion (ROM), balance and/or coordination level.

Unlike the first *Get Moving!* series, there are no fitness profiling levels, which means that anyone at any age can perform the exercises. These exercises are not to get you fit, but to get your joint 'fit' in a specific context (ie. pre and/or post rehabilitation, and severe arthritis and pain). Exercises are grouped by joint and mobility attribute with a range of regressed and progressed exercises that can be used for a variety of purposes. We highly recommend working with your healthcare professional for exercise recommendation and assistance.

## Key Focus 1: Mobility

Broadly speaking, the term mobility is an umbrella term used to describe the act of stretching, moving and strengthening a variety of tissues that surround the joint and the joint itself. Mobility is an indication of how well and efficiently we move. Flexibility, strength, movement, coordination, and body awareness are all attributes of mobility. Thus, mobility of a joint can be promoted a number of different ways, for example by 'traditional' stretches (active static and dynamic stretches or movements), passive stretches or mobilisations (where a musculoskeletal therapist does the movement for you), or balance and strengthening exercises.

Regularly performing and practicing mobility attributes is key to maintaining and promoting the health of joints, regardless of their condition. In particular, mobility exercises are significantly important for those with arthritic conditions (especially if they have loss of motion), those who may be waiting for a joint replacement (or anything similar), and for those who have undergone some kind of orthopaedic surgery to treat arthritis or other similar musculoskeletal conditions. Movement at this point is

critical; exercise engagement post-surgery can predict the outcome of quality and quantity of joint ROM.

## Key Focus 2: Rehabilitation

When you have knee or hip replacement surgery, your doctor will suggest you do physical 'rehab' afterward. Once discharged from hospital, you will likely see a physiotherapist on a regular basis to receive rehab treatment as well as do exercises on your own at home. Your home exercise program will include activities to help reduce swelling and increase the ROM and strength in the muscles around your new joint. This will help you move easier and get back to your normal activities quicker. The *Get Moving!* PLUS series includes some exercises that can be used in this capacity. We highly recommend you consult with your physiotherapist to help choose those exercises that are appropriate for your individual circumstance and stage of post-surgery rehab.

### Benefits of rehab:

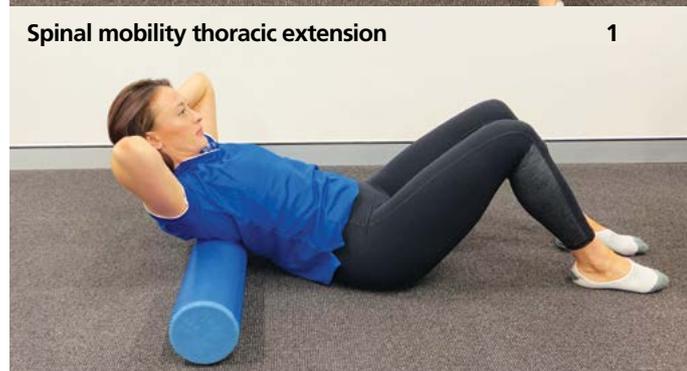
- restores normal movement in your joint
- builds up strength in the joint and surrounding muscles
- helps to ease pain and swelling
- lets you get back to your normal activities
- helps with circulation, particularly right after surgery, so you don't have problems with blood clots.

Once you get home, you should aim to exercise 20–30 minutes, two or three times every day – or as much as your doctor/healthcare professional suggests. Walking several times a day may also help. Start with only five minutes, and work your way up to 20–30 minutes, several times a day.

Whether you work with a therapist or on your own, stay as active as possible for your overall health.

### Pre-operative rehabilitation

Pre-operative rehabilitation is exercise-based intervention prescribed before undergoing surgery. It is also known as 'prehabilitation' or 'prehab'. Prehab may help you to recover more quickly, have a positive effect on pain pre and post-surgery, and improve postoperative function potentially resulting in faster return to work time. It is often used before hip and knee joint replacements and can be performed independently or under physiotherapy supervision. A pre-operative exercise program should consist of a strength/resistance training and cardiovascular



components. *Get Moving!* PLUS includes exercises that can be used in a prehab context, although, if you require more challenging exercises then check out the *Get Moving!* exercise library.

What's great about *Get Moving!* PLUS is that we considered various types of mobility exercises for commonly affected joints. We ensured to include exercises that require less equipment so you can replicate the exercises at home. Where we have used specialised equipment, we have tried to include options that may well work the same and that can be found around the house.

*Get Moving!* PLUS only includes a select amount and variety of mobility exercises. When it comes to exercise selection, we recommend choosing those you feel comfortable doing or what your healthcare professional has advised you do, and if there are other exercises you'd like to see included and demonstrated, then we encourage your feedback.

While *Get Moving!* PLUS provides mobility and rehabilitation type exercises for specific joints, it is not individualised to your specific condition and medical circumstance. Arthritis NSW recommends you consult and work with your GP or health care professional (Physiotherapist, Myotherapist or Exercise Physiologist) before starting any exercise program, especially if you have severe arthritis, or have recently undergone or are waiting for orthopaedic surgery.

With any type of exercise, if you feel unwell, lightheaded or have chest pain, cease exercising and seek medical advice as soon as possible.

For more information contact Health Educator Kat Keane at [kkeane@arthritisnsw.org.au](mailto:kkeane@arthritisnsw.org.au) or call 1800 011 041.

**Kat Keane**  
Health Educator  
Arthritis NSW



# KEEP SMILING AND MOVING

Jo Williams has enjoyed a full career as a teacher and raised three sons, all the while managing her osteoarthritis alongside other chronic conditions. She is now enjoying an active retirement with her husband Eric in the Blue Mountains.

I grew up in Baulkham Hills where my parents tended several acres of flowers, fruit and vegetables for the Sydney markets. My brother and I attended Castle Hill Primary and High Schools. They had a big impact on my life because they were very sporty schools. I swam competitively and did well at athletics, softball and netball.

## Sporty student

Conditions weren't great for maintaining good joint health but I was active. We wore Dunlop Volleys. There were no soft fall surfaces, mats to fall on or specialised cushioned shoes as there are today. High school was slightly improved with gym mats (about 1–2 inches of cushioning) and top dressing on the oval before athletics carnivals.

I finished high school in 1970 and went to Westmead Teachers College for three years where I tried more sporting activities. I began to have some back pain and occasional knee and ankle difficulties but I was too busy with life to get a doctor's opinion. This was before the time a good physio, chiro or masseuse were valued and I was still a poor student, so a couple of Aspros or Disprin, rubs and use of hot water bottles and cold compresses (a bag of frozen peas or iceblocks) were my basic remedies.

After college I was appointed to Coreen School for Specific Purposes at Blacktown where I worked with children of mild intellectual impairment and learnt about disadvantaged communities. I moved to Faulconbridge and enjoyed bush walking (very painful carrying an overnight pack), canoeing (my back was challenged), squash and surfing. I met and married Eric, a registered nurse from Glenbrook, in 1977 and we lived in Glenbrook, then purchased a house in Springwood. I worked at Springwood Public School (PS), then did a full-time Post Grad. Diploma in Special Education and was appointed to Crawford PS in 1980. I had three boys, Tim, Stuart and Gordon, who are now in their 30s. I suffered back pain badly with the first and last pregnancy, though we did drive the Strezleki Track in South Australia up to Innaminka in a High Ace van with me three months pregnant – poor suspension! I strained my back the next year while changing a nappy, sitting on the floor, legs wide apart and child in front of me, I twisted to the side to pick up a fresh nappy. DON'T EVER DO THAT! I twisted my right leg (foot stationary) getting into



Jo and her husband Eric

my car resulting in extreme knee pain. The orthopaedic surgeon suggested arthroscopic surgery to trim away a tear of the meniscus. However, without the operation, he said I'd come back in the future for a knee replacement anyway, because of the osteoarthritis there. I opted out of surgery then. This was my first diagnosis (around 40 years old). Returning in my early 60s, the surgeon recommended that I wait until I was in so much pain that I couldn't walk, as I was too young for a knee replacement.

## Physiotherapy

I returned to teaching casually and started to have unrelenting neck pain so a neurologist sent me for a pain relieving injection while scanning. I had a shock reaction, in that I couldn't move my body after the procedure and had to be lifted off and laid down to recover. That was a test site but I didn't return for the full injection. I'd been instructed to visit Penrith physiotherapist Allan Bourke as follow-up. I went to that appointment and still see Allan over 20 years later for physio support, at least once a month. I started wearing a foam neck support when in the car.

We purchased 90 acres at Upper Growee and built a rammed earth house with our three sons' assistance – the two youngest were carpentry apprentices. It took four years part-time. I injured my back sanding and painting with several bulging disks, took six weeks off work, and made many trips to Allan. Warm water therapy was wonderful. I often used a TENS machine. I transferred to a position at Mudgee PS, and Eric joined the Mudgee Mental Health Nursing Team.

I had a great job working across seven small and five bigger schools in the mid-western regional council area. Unfortunately, I didn't realise what impact all the driving would have on my body, especially my back, over nine years. Eric retired in 2011. I retired from Kandos PS in 2013 after again injuring my back opening a farm gate, twisting



Jo with two of her grandchildren Archie and Tilly



Jo (top left) uses walking poles to assist stability and increase arm exercise on a regular walk from Blackheath to Medlow Bath with friends L-R Mary, Rosemary, Patrick, Julia and Freda the dog.

and trapping my sciatic nerve. Surgery freed the nerve and gave me instant relief.

I joined the morning walking group, the special gym classes for isolated community members, and two aqua fit summer classes at the Kandos pool run by the community nurses. I suffer from hypothermia, no matter how high the water temperature, so I regularly wear a wetsuit, even in heated pools. I get double the exercise getting into and, even harder once wet, wriggling out of the suit. Tim, my eldest son, gave me neoprene booties to match! I did night classes of Tai Chi for Arthritis, run by a friend, in the Rylstone Hospital activities room – lovely slow movement aiding memory, balance, joint movement and peaceful contemplation with the music. For my back pain I used an inversion table that allowed me to hang almost upside down giving traction to my back.

## Blackheath

In late 2015 we moved to Blackheath and Eric and I joined several walking groups and exercise classes. I attempted to get back to cycling, as Eric is a keen cyclist, but after several falls off my electric bike and jarring my neck, I've given up! I used the local gym for a while. I knit with the local group called KnitWits. I joined the Arthritis NSW warm water classes at Katoomba Hospital for a short while but use Katoomba or Lithgow heated pools now with my own aqua fit equipment and program when needed.

Our sons live with their families away from the Blue Mountains. We have five grandchildren. Eric and I travel to Warriewood each week to mind two of them, Archie, 5, and Tilly, 3, for the day. They keep us young.

I rarely eat processed food, instead I have fresh fruits and vegetables, dried peas and beans, nuts and seeds and small servings of fish, chicken, red meats (no pork). No alcohol. I have Osteopenia\* now, so look for calcium rich foods and value exercise even more. COVID-19 has disrupted our lives at times – for weeks and months we had no exercise classes, group walking, minding or seeing family, and spent too much time sitting. Technology helps with Skyping family. Now we've started exercising in parks while social distancing, group walking, and babysitting. For five months I had none of my monthly massages which reduce muscle tension and joint pain. Since the pandemic started, I've taken my 90 year old mum to specialist appointments in her wheelchair – she's disabled by arthritis. I'm now doing the online program The Joint Movement with Arthritis NSW which has me using better techniques for adjusting/controlling movement by engaging core (tummy) muscles and resetting posture.

Triggers for my bouts of painful arthritis include: low pressure weather, repetitive use of hands, too much driving and being sedentary in poorly supporting seating or beds. I take daily doses of Panadol Osteo for joint pain and Gabapentin for nerve pain, a result of fusing of vertebra. Allan has used acupuncture on me especially early in major flare-ups. I have monthly manipulation of the facet joints in my neck which maintains scope and ease of movement.

## Recommendations

If you are newly diagnosed with arthritis, I recommend that you:

- report what you learn from your rheumatologist to your GP to enhance their understanding of the condition and share with others
- join Arthritis NSW as they provide up-to-date information on the conditions, recommended exercises and local groups
- contact local community health organisations and community centres which advise about relevant local groups that you can join
- find a good physio and/or masseuse, yoga and Tai Chi classes
- find gyms with Exercise Physiologists to set and supervise your program
- look for online YouTube instruction if you are isolated
- talk to others.

I use hot water bottles and wheat bags; stretchy knee, ankle, wrist guards; neck support and back brace when needed; hand weights and stretch bands; a thick gym mat; foot stability board for exercising ankles and foot muscles and joints (homemade); small balls (squishy and tennis) for hands and lying on or rolling under your feet; inversion table (home traction); TENS machine for nerve pain and tight sore muscles; towel rolls to lie on along your spine to counter the forward movement of shoulders during the day.

Just remember to keep smiling and moving.

\* Osteopenia is low bone density.

# Lupus under the microscope



There is no known cause for lupus, and there is yet no cure. However, the Garvan Institute is targeting this complex and painful autoimmune condition in their research program to find better and targeted treatments.

The normal role of your body's immune system is to fight off infections and diseases to keep you healthy. In an autoimmune disease such as lupus, your immune system starts attacking your own healthy tissues. For some people, lupus may just affect the skin and/or joints. In others, the lungs, kidneys, blood vessels, brain or other parts of the body may also be affected.

Australian data on lupus is scarce, however the *Medical Journal of Australia* gives figures suggesting a prevalence of the common type of lupus, Systemic Lupus Erythematosus, that ranges from 19 per 100 000 in people of European ancestry to 92 per 100 000 in Indigenous Australians.<sup>1</sup>

## Types

The most common type of lupus is Systemic Lupus Erythematosus (SLE), which affects many parts of the body. Other types include:

1. Cutaneous lupus, which causes a characteristic butterfly-shaped rash across the face, usually when exposed to sunlight.
2. Drug-induced lupus, which is caused by an over-reaction to certain medications. The symptoms are similar to SLE except that they are transient and disappear once the medicine is stopped.
3. Neonatal lupus is an acquired autoimmune disorder that is present at birth and caused by transfer of autoantibodies from pregnant mother to child. Symptoms include a rash, which is sensitive to sunlight, liver and blood problems resolve within 6–12 months of birth. The most serious complication of neonatal lupus, congenital heart block, results in permanent injury to the heart and requires a pacemaker.

## Cause

The exact cause of lupus is unknown, although it's likely a combination of genes, hormones and environmental factors. Because the symptoms of lupus are varied and unpredictable, diagnosis can be difficult and take time. A combination of prescribed medications and lifestyle changes mean many people with lupus can lead an almost normal life. However, it's a chronic inflammatory disease with the most serious health risks being cardiovascular disease, kidney disease and stroke. People with lupus have an increased risk for developing atherosclerosis (hardening of the arteries) myocarditis and endocarditis (inflammation of the heart) which can result in heart murmurs.

## The immune system

One way our immune system protects us is through the production of antibodies, which attack bacteria and viruses. However, people with lupus produce 'autoantibodies' that attack their own tissues. These autoantibodies cause inflammation, pain and damage to various parts of the body. Over time, this leads to long-term organ damage and even organ failure.

The Garvan Institute's lupus research is looking to identify and isolate the immune cells responsible for making these autoantibodies and determine how they're different from normal immune cells. This will help them to target the bad cells while preserving the rest of the immune system.

It's likely that certain genetic variations cause some people to be more susceptible to lupus. But understanding these variations can also point to more targeted treatment options. The Garvan's research uses cellular genomics to help accelerate the development of such treatments.

## Risks

The Garvan has found that there appears to be a genetic predisposition to lupus, so if your parents had an autoimmune disease, you're more likely to develop a disease like lupus. However, genes alone do not determine who gets lupus. It is likely that several factors, many of which have not yet been identified, cause disease.

Women aged between 15 and 45 are also more likely to be affected. Other risk factors and triggers include:

- exposure to sunlight, which is common cause of flare-ups
- medications – antibiotics, blood pressure and anti-seizure drugs
- infections like a cold or viral illness
- ethnicity – lupus is more common in Indigenous Australians, Africans, Hispanics, Asians and Native Americans.

## Symptoms

Symptoms vary greatly between individuals and can fluctuate between flares and times of minimal or no symptoms (remission). They include:

- sun-sensitive rashes on the face and body
- painful inflammation of one or more joints, which may cause the disease to be mistaken for rheumatoid arthritis
- impaired kidney function due to severe inflammation and blood vessel blockages
- mouth ulcers
- chest pain due to pleurisy (inflammation of the lining of the lungs)
- blood clotting problems
- hair loss
- unexplained headaches, fits or mood swings
- extreme fatigue
- recurrent miscarriages.

## Treatment

Considering the variety of lupus symptoms, it's very important to confirm a correct diagnosis. This is done by reviewing medical history and performing a complete physical examination, including blood tests for anti-DNA antibodies which are a hallmark of systemic lupus erythematosus, taking skin and kidney biopsies to ascertain the extent of the disease, and checking for abnormalities in blood cells.

This also means ruling out a range of diseases which have similar symptoms.

Current treatment focuses on improving quality of life by minimising flare-ups and the expression of symptoms. This includes lifestyle modifications, sun protection and diet.

Further disease management includes medication such as anti-inflammatories, steroids and immunosuppressant drugs.

## Garvan research

Our lupus research hopes to identify and isolate the immune cells responsible for making self-attacking auto-antibodies. We want to know how they're different from normal immune cells.

Establishing these differences will show how they develop, and what causes them to switch to attack the body. This will lead to new treatments, for example by revealing cellular vulnerabilities that respond to targeted drug therapies. The ultimate aim is to eliminate the bad (self-attacking) cells while preserving the rest of the immune system.

The Garvan's research uses cellular genomics to study these individual cells, and understand how and why they've 'gone rogue'. The mutations or variations in the DNA of these cells may point to the common root cause of all autoimmune disease.

The research team is also focusing on lupus nephritis: a common and devastating symptom of lupus where autoantibodies attack the kidneys.

## Key areas of investigation

Immunology researcher and Executive Director of the Garvan Institute of Medical Research Professor Chris Goodnow believes there may be a common cause underlying all autoimmune diseases. These are the 'rogue' immune cells causing tissue and organs damage as the body attacks itself.

'Most of the current treatments for lupus are directed at the immune system itself, suppressing the whole immune system with steroids and other drugs, because we can't identify and eradicate the cells that have gone rogue,' Professor Goodnow said.

The current research project will identify bad mutations in immune cells (which result in rogue cells) and use sophisticated cellular genomic technology to determine exactly what each cell is doing.

'We can then pinpoint chinks in the armour of the rogue cells, and make them susceptible to new drugs and immunotherapy. We'll have a better understanding of which drugs are best suited to a particular person's genetic profile,' he said.

Work to identify rogue cells from patients with lupus and Sjogren's Syndrome is underway. These findings can now be applied to 36 other common and debilitating autoimmune diseases. To find out more about the Garvan Institute's lupus research visit: [garvan.org.au/research/diseases/lupus/our-research](http://garvan.org.au/research/diseases/lupus/our-research).

More information is available from our Lupus Information Sheet: [arthritisnsw.org.au](http://arthritisnsw.org.au)

1 [mja.com.au/journal/2017/206/5/australian-lupus-registry-and-biobank-timely-initiative](http://mja.com.au/journal/2017/206/5/australian-lupus-registry-and-biobank-timely-initiative)



# Be wise about joint replacement surgery

Joint replacement involves replacing a damaged joint with an artificial joint, and the decision about whether to have joint replacement surgery is a big one. Following research and funding in the UK, an online decision tool has been developed to help anyone in the world who is considering this type of surgery.

In the year ending December 2015 more than 102,000 hip and knee procedures were performed in Australia<sup>1</sup>. Joint replacements were once only offered to older people with severe arthritis of the hip or knee. Now they are increasingly performed on younger people if there is a need. This is largely due to advances in materials being used to build artificial joints, making them longer-lasting.

For people with arthritis, having a joint replacement can be life-changing, but while it's beneficial for some, it's not always the best option.

Some people will experience long-term pain and complications after having hip and knee replacements, so it's important that people have a good understanding about all the choices that are available to them.

## JointCalc

Versus Arthritis is a British organisation formed in 2018 following a merger between Arthritis Care and Arthritis Research UK. Versus Arthritis funded research with the National Joint Registry, conducted at the University of Sheffield and University of Bristol, which led the way to develop an online decision tool called 'JointCalc', which is designed to help people understand the potential risks and benefits of knee or hip replacement surgery and is tailored to their own individual circumstances.

**Why was the research carried out?** While people considering joint replacement surgery are often engaged in the decision-making process, they are usually dependent on the advice of their clinicians on the risks and benefits of surgery itself and of the type of joint replacement used.

In most instances, the surgeon will make a decision using the available evidence from past experience of the procedures in the general population, but individual characteristics such as age, sex, underlying diagnosis, surgical technique, and type of joint replacement significantly affects the outcome of surgery and risk of complications.

This research aimed to develop an online decision aid that would empower patients to be active partners in the decision-making process and improve individual outcomes.

**What role did patients play?** Patients and their carers played a critical role in the development process, from the drawing board through to 'approval' of the final version of the tool.

In the research team's latest paper, published online in July 2020<sup>2</sup>, they describe the health information system that was used to make the online tool possible.

They used information from the UK National Joint Registry dataset of around 2.5 million hip and knee operations to develop and validate a personalised, web-based decision aid to help patients, considering joint replacement, make evidence-based choices about their treatment.

**How does the online tool work?** JointCalc is freely-available to use for anyone in the world with access to the internet who is considering joint replacement surgery. It can be used by people in their own home or by GPs during patient medical appointments.

Using personal characteristics (such as age, weight, height, and type of surgery), and data from the National Joint Registry and NHS Digital, the tool gives patients a personalised estimation of pain and function after the operation, risk of dying after the operation, and the risk of needing revision surgery.

Patients can then have more informed conversations with their doctor about their treatment options and make a decision that is right for them.

**How successful has the tool been so far?** In the past nine months since the JointCalc website was launched, over 15,000 people have visited the site from 110 countries worldwide, with more than 5,000 getting personalised results.

Professor Mark Wilkinson, who has been leading the development of JointCalc at the University of Sheffield said:

‘We’re delighted to see that patients’ responses frequently indicated that the website helped them reach an informed decision about their surgery.

‘We’ve also received feedback that the tool is informative, helpful and easy to use and responses show that users find JointCalc user-friendly and relevant to their problem.

‘The successful application of this tool is not only improving patient outcomes, but it’s increasing the cost-efficiency of joint replacement surgery and post-operative surveillance for the health service.’

### Looking to the future

Waiting times for joint replacement surgery are likely to be longer than ever as our health systems deal with the COVID19 pandemic, so it will be very helpful for patients to have a better understanding of the risks and benefits to them before requesting a referral from their GP to secondary care.

It can only help if people are better informed before seeing a surgeon, and that those who decide to seek secondary care, then choose to go through with the surgery knowing some of the risks and benefits.

To try the online tool JointCalc visit: [jointcalc.shef.ac.uk](http://jointcalc.shef.ac.uk)

1. Joint replacement: A practical guide to understanding joint replacement surgery. Arthritis Australia 2013, reviewed 2016.
2. [versusarthritis.org/news/2020/july/making-informed-decisions-about-joint-replacement-surgery/](https://www.versusarthritis.org/news/2020/july/making-informed-decisions-about-joint-replacement-surgery/)



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# NEW MOVES

Arthritis NSW's Gentle Exercise programs have seen some new and exciting changes lately, as well as the re-opening some of our warm water classes.

## The Joint Movement

I'll begin with the biggest change for Gentle Exercise in The Joint Movement Program (TJM). We are co-hosting our online program with our good friends Arthritis Queensland via the versatile computer program Zoom. To make it more accessible, we have removed any paywalls for the immediate future and anyone over the age of 65 who has a working internet connection can join for free! We have seen some amazing success coming from the unlikely exercise areas of private lounge rooms and we are grateful for the tireless work of our instructors who have helped improvise and develop the program these past few months. If you are interested in joining the class or learning more, please contact either myself at

Arthritis NSW or Jess at Arthritis Queensland:  
07 3857 4200 or email [jessica.neri@arthritis.org.au](mailto:jessica.neri@arthritis.org.au).

## Warm water restart

We have also restarted Warm Water classes in limited locations and we cannot thank the venues and their instructors enough for kindly opening up again. We have always shown great respect to our friends helping us run the classes, now more so than ever with the need to socially distance and remain flexible to different requirements that ensure the safety of our participants, the instructors and the venue co-ordinators themselves. It is a testament to this fact that we are able to open in a limited capacity. We understand it can be stressful for all parties, especially with the ongoing COVID-19 threat persisting, but it is truly fantastic that we are able to provide classes where we can, even in their current reduced state.

While we are gradually reopening classes, I am always on the lookout for new venues in new regions of NSW. I hope to offer more in the near future so watch this space for a new class near you! There are still vacancies at Lady Davidson Private Hospital in North Turramurra and at Wollongong Physical Therapy so hurry now to book a place before they are all snapped up! If you are interested to learn more about Warm Water classes or you are aware of a venue that may be interested in working with Arthritis NSW, contact me on 02 9857 3300 or email: [gpuxyt@arthritisnsw.org.au](mailto:gpuxyt@arthritisnsw.org.au).

Finally, if you are in a location that is still waiting for a Warm Water class or you are unable to attend The Joint Movement Program you can still view our *Get Moving!* Exercise Series on our website. These fantastic videos have been viewed by members of Arthritis NSW to professionals throughout the physiotherapy and exercise physiology industry. The videos are suitable for any fitness level and focus on gentle exercise to get people moving again! Our Health Educator Kat Keane has produced more exercise videos that are rehabilitation and joint specific and you can read more about *Get Moving!* PLUS on page 8.

**Glen Puxty**  
Program Administration Officer  
Arthritis NSW

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# A practical approach to stretching, flexibility and meditation

Once you start a journey of improving flexibility and body awareness to manage arthritis, you'll find that there's much more to explore. There are many valid approaches, and this article draws on perspectives from the Mayo Clinic, author and teacher Kit Laughlin, and Danny Rutten, my friend and physiotherapist from Entire Physiotherapy in Queanbeyan.

Danny Rutten is a physiotherapist with an interest in sports, and a mechanical engineer, who likes to think about stretching as muscle lengthening in order to relax and improve function. He says that you can manage arthritis in two efficient ways: a) to strengthen muscles providing support for joints, and b) to lengthen, relax and therefore reduce the pressure on joints.

Strengthening is covered in our great new program *Get Moving!* while the new series *Get Moving! PLUS* introduces mobility – incorporating flexibility, co-ordination and balance. To maximise benefit from these programs, it's good to acknowledge the similarities in relation to progression, where you start at the basic level and slowly increase in repetitions, add weights or perhaps increase complexity. With stretching or lengthening you can hold longer, add resistance, combine movements or use angle changes and gentle extensions to increase the effect. All of these things require an increased level of body awareness to ensure safety and to maximise benefits – herein lies the importance of relaxation. This article introduces relaxation into the exercise context, talks about technique from in a more clinical perspective then moves toward the diverse realm of mindfulness and meditation.

## Relax to understand

To quote a simple statement from Kit Laughlin: *Learning to relax connects me directly to what is happening in my body now.* This is especially important in working out **what** needs to be lengthened, strengthened or mobilised, **how much**, and for **how long**. If you start an exercise program with one side or body part that is tighter or less stable – and stretch everything evenly – you won't address the problem as efficiently as a targeted approach. Physiotherapist Danny supports Kit's contract-relax approach to stretch, lengthen and strengthen. A targeted

program can address imbalances and enhance awareness, so that your body relaxes and moves more freely to restore stability.

We'll talk more about relaxation and meditation concepts later, but let's first summarise some great tips from the Mayo Clinic\*. Information below is extracted from *Focus on flexibility*<sup>1</sup>, written earlier this year.

## Stretching: focus on flexibility

Studies about the benefits of stretching have had mixed results. However, research has shown that stretching can help improve blood flow, flexibility and the range of motion of your joints. This in turn can decrease your risk of injuries and enable your muscles to work most effectively. In practical terms, stretching improves flexibility – which may in turn help you to relax and be more comfortable in sitting, standing, moving and sleeping.

The Mayo Clinic has advised that before you plunge into stretching, make sure you do it safely and effectively. While you can stretch anytime, anywhere, proper technique is key. Stretching incorrectly can do more harm than good (in a similar way to any form of exercise) – the Clinic suggests that you use the following tips to keep stretching safe:

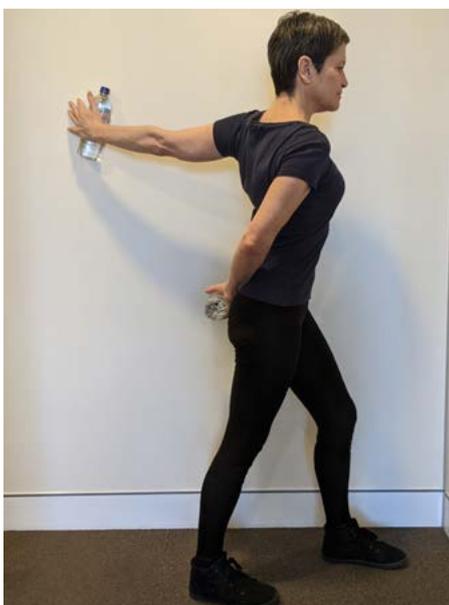
1. **Don't consider stretching a warm-up.** Try performing a dynamic warm-up which involves performing movements similar to those in your physical activity, eg. if you're gardening or doing housework, move your arms in a similar range to warm up.
2. **Strive for symmetry.** Everyone's genetics for flexibility are a bit different. Rather than striving to go further into stretch, focus on having equal flexibility side to side. Being unequal may be a risk factor for injury.
3. **Focus on major muscle groups.** Concentrate your stretches on major muscle groups such as your calves, thighs, hips, lower back, neck and shoulders. Make sure that you stretch both sides.
4. **Don't bounce.** Stretch in a smooth movement, without bouncing. Bouncing as you stretch can injure your muscle and actually contribute to muscle tightness.
5. **Hold your stretch.** Breathe normally and hold each stretch only for as long as comfortable and build up over time.
6. **Don't aim for pain.** Expect to feel tension while you're stretching, not pain. If it hurts, you've pushed too far. Back off to the point of no pain, then hold the stretch.
7. **Keep up with your stretching.** Stretching can be time-consuming. But you can achieve the most benefits by stretching regularly, at least two to three times a week.
8. **Bring movement into your stretching.** Gentle movements, tai chi or yoga, can help you be more flexible in specific movements and also help reduce falls.

## Why relaxation is important

Kit Laughlin explained in a recent interview with Arthritis NSW (and has explored in his writing) that when you look at our thinking closely enough, it's about what's happened in the past, or what might happen in the future. He says: 'Usually, the habitual mind has a preference for one or the other. The body, on the other hand, exists only in this same continuous present: the body's sensations are momentary – they come and go continuously. If we pay attention, we can experience this clearly. Learning how to relax and meditate teaches you how to do nothing and be comfortable in that nothingness.'



*This combines a calf stretch and lats stretch (latissimus dorsi). Body alignment gets the best results – feet facing straight ahead. If the neck or shoulders are tight, lower your arm position, or place hands over a bench.*



*This combines a shorter position calf stretch (or Achilles stretch if you bend the back leg), with pectoral stretch and shoulder opening position. Once again, alignment is important, and adding a slow rolling of the bottle further back facilitates nerve gliding or 'flossing'. Another bottle is behind the back to facilitate lowering of the upper traps, and mobility for the shoulder.*

Therefore, if you use relaxation time to sit comfortably in a good posture, breathing is enhanced. The focused attention of your mind improves your ability to listen and respond to your body. Kit explained: 'Over time, your meditation practice, combined with letting go of remaining tension, can slow and eventually stop thoughts completely. One is simply aware of what's happening now.'

This is a similar concept to what is often referred to as mindfulness, with a focused approach in clinical psychology. We can also explore that further in future articles in *Arthritis Matters*. For now, whatever form we are thinking of, Kit Laughlin encourages us to think about a 'one-to-one relationship between levels of physical tension in the body and the intensity of mental activity. Reduce the physical tension and the mental activity always reduces too.'

### Where meditation fits in

Meditation is considered a type of mind-body complementary medicine. The following is extracted from a Mayo Clinic overview piece *Meditation*<sup>2</sup> that helps to put it in perspective.

Meditation can produce a deep state of relaxation and a tranquil mind. It can give you a sense of calm, peace and balance that can benefit both your emotional well-being and overall health. Increasing self-awareness and tolerance are among the many emotional benefits of meditation.

Meditation might also be useful if you have a medical condition, especially one that may be worsened by stress. While a growing body of scientific research supports the health benefits of meditation, some researchers believe it's not yet possible to draw conclusions about the possible benefits of meditation.

With that in mind, some research suggests that meditation may help people manage symptoms of conditions such as chronic pain, sleep problems, anxiety and tension headaches. Talk to your health care provider about the pros and cons of using meditation – it's an addition to, rather than a replacement for, medical treatment.

### Types of meditation

Meditation is an umbrella term for the many ways to a relaxed state of being. There are many types of relaxation techniques that have meditation components and all share the same goal of achieving inner peace.

1. **Guided meditation:** Sometimes called guided imagery. With this method of meditation you form mental images of places or situations you find relaxing.

2. **Mindfulness meditation.** This type of meditation is based on being mindful, or having an increased awareness and acceptance of living in the present moment.
3. **Qi gong.** It is a part of traditional Chinese medicine and combines meditation, relaxation, physical movement and breathing to restore and maintain balance.
4. **Tai chi.** It is a form of gentle Chinese martial arts in which you perform a self-paced series of movements in a slow, graceful manner while practicing deep breathing.
5. **Yoga.** You perform a series of postures and controlled breathing exercises to promote a more flexible body and a calm mind.

In another article on Pilates, the Mayo Clinic reports that regular practice can achieve the benefits of core strength and stability, posture, balance and flexibility<sup>3</sup>. We will explore that in future articles. But no matter what form you are practising, the Mayo Clinic suggests that you start with activities you actually like to do, that fit into your daily routine – that's the best way to guarantee you'll stick with a more flexible way of life.

Remember, there's no right way or wrong way to meditate. What matters is that meditation helps you reduce your stress and feel better overall. This view is complemented by physiotherapist Danny Rutten in his approach to lengthen muscles, relax and retrain the brain. The central nervous system has control over the musculoskeletal system, therefore the brain is an important part of our movement. It makes sense that if we focus on being in the present, relax into quality stretching and movement, results will follow for mind and body.

### Janine Robertson

Health Services Quality Manager  
Arthritis NSW

\* The Mayo Clinic is one of the largest not-for-profit, academic health systems in the US, with 65,000 employees. It cares for patients with serious, complex illnesses, operates in five states and cares for more than one million people a year, from all 50 states and nearly 140 countries.

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- 1 [mayoclinic.org/healthy-lifestyle/fitness/in-depth/stretching/art-20047931](https://www.mayoclinic.org/healthy-lifestyle/fitness/in-depth/stretching/art-20047931)
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# Staying ahead of arthritis



## Mary

Mary was originally diagnosed with osteoarthritis in 1999, but her condition has developed into inflammatory osteoarthritis.

'Initially, I had a bad back and found out that I had three bulging damaged discs in my lower back. I

saw a back surgeon, a rheumatologist and a physiotherapist. I started doing exercises with the physiotherapist and gradually got movement back and the pain reduced. I joined a gym and was doing three Body Balance classes a week (a combination of yoga, Pilates and Tai Chi). I also swam laps a few times a week, which helped. Then I started aqua aerobics.

'In 2004 after a trip to New Zealand when I was in constant pain, I was referred to an orthopaedic surgeon and in 2005 I had my right hip replaced. It was replaced again as I had one of the recalled hip replacement products and my body was rejecting it. In 2009 I had my left knee replaced, 2013 my right knee and in 2017 my left hip so I now have a perfect set!

'In between, I had over 100 cortisone injections to try to hold off surgeries.

'In 2012 and 2015 I had both feet operated on to reduce the length of the bones and to straighten my toes as they had curled up with arthritis. I manage my arthritis by seeing my rheumatologist regularly. I see my physiotherapist monthly, and my osteopath when needed. I continue with my weekly warm water classes with Arthritis NSW (missed for months this year due to COVID-19). I am the co-ordinator of the Ryde Arthritis Support Group. We meet every month, but since COVID-19 we have been meeting via Zoom.

'My husband and I intend to resume holidaying once there is a vaccine for COVID-19. This year we have already cancelled eight holidays! And during these difficult times, I've been walking with a couple of friends for the social and health benefits.

'In late 2018 I was diagnosed with breast cancer. Nothing prepares you for that. I had my treatment last year and am continuing to be monitored.

'Stay safe everyone and try to stay strong. I'm looking forward to coming out the other side of all this.'



## Mamata

Mamata's arthritis started with her knees around 2013. Once arthritis was diagnosed, the surgeon advised her to carry on with exercise and hydrotherapy. He didn't want to perform knee replacements so early in her life. She managed to do so until 2015.

'I'm basically an active person and love travelling. Every year around June–July, my husband and I would go to Europe. We went for a European river cruise in June 2015. During the cruise we had very hectic schedules with lots of walking on cobbled, uneven and steep roads in little European towns. This triggered severe pain and swelling in my knees. I knew I couldn't wait any longer for the surgery.

'Therefore, in June 2016 I had bilateral knee surgery at Royal North Shore Hospital. After 6–8 weeks, I started driving and leading more or less a normal life. But I continued hydrotherapy and a certain gym regime for pain management. I go for walks 3–4 days a week, go to Zumba class and dance. I travelled again. During June–July 2019, we went to UK to watch few World Cup Cricket matches and then took a Douro River Cruise to Portugal and Spain.

'Usually during Christmas, we spend 4–5 weeks in India, though it seems we will spend Christmas 2020 in Sydney with my grandchildren.

'I also have arthritis on my thumb joints and shoulder joints, but it's not too severe. I manage them well with warm water exercise. I have been a member of Arthritis NSW for nearly four years.

'Life during lockdown initially was very restrictive as I hardly ever sat at home before. I used to pick up my grandkids from school two days a week, take them to their various extracurricular activities and give them dinner. Since COVID-19, those activities stopped once they started back to school as practising social distancing is difficult with kids. So now I only see them once a week and give them distant hugs. I also miss meeting my friends at a cafe or restaurant. Video chatting is the norm now. But I have no complaints as long as we all follow the rules and stay safe and healthy.'



### Brian

Brian is 55 and was diagnosed with rheumatoid arthritis in 2019 after a snow skiing holiday in New Zealand.

'I work as a swimming pool plumber in Sydney, although I've worked in many places around Australia including Alice Springs and Parabardoo

in WA. I've been married for 31 years and have a wonderful daughter. I have always been active: working, water skiing, camping and playing social cricket.

'In August 2019 we enjoyed a family snow ski holiday in Queenstown NZ, but on return I was feeling a bit tired with a sore left shoulder. Within a few days I had been admitted to Emergency and following lots of tests was transferred to Royal North Shore Hospital for shoulder surgery.

'In September I was again admitted to Emergency with right foot pain but then referred to a podiatrist. In October I was back in Emergency with shoulder, arm and hip pain. I was seen by a rheumatologist and started on my first medications. After three months of chaos, I was diagnosed with rheumatoid arthritis.

'The pain continued over Christmas and in January I was back in Emergency, and again in February where I was transferred to the Sydney Adventist Hospital in March for four weeks while they tried to control the pain, the severity I cannot even explain. I have now endured many nights in hospital, tests, procedures and medications over the past 12 months.

'I was unable to work for several months, and luckily have an understanding employer. I have reduced my working days to cope with the pain and fatigue. During COVID-19 my new normal has been hospital, work and resting on the weekends. I have always had the support of my extended family which is really important to me.

'I joined the Arthritis NSW Facebook page to connect with others and gain more information, and enrolled into the Lane Cove Warm Water Exercise class in August. I hope that I can find a combination of treatment that enables me to live comfortably.

'In the future I would love to travel another 'big lap' around Australia as it has been 30 years since my last full lap.'



### Jan

Apart from a few visits to a physio over the years for niggling back pain, up until September last year Jan had no serious problems with arthritis.

'One day I suddenly had pain so excruciating that I had great difficulty even walking. Over time, after countless fruitless visits to

all types of practitioners, my main problem was not being able to get out of bed because of the extreme pain. The only way I managed was with the help of my husband. Pain killers and injections didn't help the pain. Eventually my GP sent me to a neurologist who diagnosed me with degenerative osteoarthritis of the spine. He recommended an operation on my back to release a nerve and after that, thankfully, for the first time in many months I could get out of bed unaided.

'Unfortunately, while I was recuperating, and doing some very slow walking for exercise on our old treadmill, it suddenly malfunctioned and went full speed. The safety cord and me pressing the stop button didn't work. I fell face first on it, broke my nose and had a subsequent black eye plus I took some skin off my arms and legs. Luckily my back wasn't affected. That was my big worry. Everything else healed. The treadmill is now scrap metal.

'The only pain left after the operation was in my lower back when walking a distance.

'The warm water exercises have been a lifesaver. Each week I can do more physically than I could do the week before. I've brought along my husband and a friend, who both have knee and shoulder problems.

'The specialist told me that I may have further trouble in another area of my spine in the future so I see the exercises, plus walking whenever I can, as a hopeful deterrent.

'Since the pandemic I have learnt a few domestic skills. I started knitting cotton face cloths, later given to a little granddaughter. I then knitted a woollen scarf, which I gave to another granddaughter. They are both too young to see the mistakes. I also made strawberry jam, inspired by a Maggie Beer recipe. I now have to stop eating it as I'm piling on COVID-19 kilos which I don't need!

'We initially had some online groceries delivered but now, suitably masked, we do our own grocery shopping. Our large family have ensured that we haven't been lonely as they've visited regularly, while doing their best to socially distance.'

# LIVING VIRTUALLY

While we are no longer house-bound, many of us are still spending a lot of time at home and could do with something to keep us stimulated.



Our Social Media Co-ordinator Leanne Hinden has compiled a list of free online resources – Zoom/Skype, travel, performing arts, galleries, animals, libraries and more. Enjoy and share them with your friends and family.

Remember to also move – go for a walk, do some gardening and get some lovely sunshine on your face!

## Connect with loved ones

**Zoom:** video tutorials on how to use it: [support.zoom.us/hc/en-us/articles/206618765-Zoom-Video-Tutorials](https://support.zoom.us/hc/en-us/articles/206618765-Zoom-Video-Tutorials)

**Skype:** getting started: [support.skype.com/en/skype/all/start](https://support.skype.com/en/skype/all/start)

## Performing arts

**Filmed on stage:** the theatre community is giving viewers from around the world the opportunity to stream select theatre productions for free! Visit: [filmedonstage.com/news/76-free-musicals-and-plays-you-can-now-stream-during-the-coronavirus-outbreak-updating-daily](https://filmedonstage.com/news/76-free-musicals-and-plays-you-can-now-stream-during-the-coronavirus-outbreak-updating-daily)

**Sydney Opera House:** Sydney's great dame of concert halls recently released a huge digital offering, with concerts, talks and behind the scenes content. Visit: [sydneyoperahouse.com/digital/season.html](https://sydneyoperahouse.com/digital/season.html)

**Australian Ballet** brings free cinema-quality full-length performances to your home. Visit: [australianballet.com.au/the-ballets/digital-season](https://australianballet.com.au/the-ballets/digital-season)

**Sydney Symphony Orchestra:** a huge catalogue of live concert videos to explore: Visit: [watch.sydneysymphony.com](https://watch.sydneysymphony.com)

**Melbourne Comedy Festival:** Needs some laughs? This festival is available on ABC iView. Visit: [iview.abc.net.au/show/melbourne-comedy-festival](https://iview.abc.net.au/show/melbourne-comedy-festival)

**Cirque du Soleil:** A 60 minute special featuring Alegria, KOOZA and KÀ!: Visit: [bit.ly/2YxKbFY](https://bit.ly/2YxKbFY)

**ABC Classic Sunday Opera:** Visit: [abc.net.au/classic/programs/sunday-opera](https://abc.net.au/classic/programs/sunday-opera)

**Andrew Lloyd Webber Musicals:** The Show Must Go on releases musicals weekly for free. Visit: [youtube.com/theshowsmustgoon](https://youtube.com/theshowsmustgoon)

## Galleries and museums

**The Louvre** offers virtual tours for a few big exhibits, including the Egyptian Antiquities – a huge exhibition spanning multiple floors and featuring ancient items from the Pharaonic period. Visit: [bit.ly/3j9sRPP](https://bit.ly/3j9sRPP)

**The British Museum** has a great interface to explore – enter via an enormous timeline, and click on coloured dots representing areas of the world, and items of that era and area. Visit: [britishmuseum.withgoogle.com](https://britishmuseum.withgoogle.com)

**National Gallery of Victoria's** (NGV) impressive art collection on a virtual curator-led tour. Visit: [ngv.vic.gov.au/channel/](https://ngv.vic.gov.au/channel/)

**Museum of Old and New Art :** Enter and say G'day to Tim and his elaborate tattoos between 10am and 4.30pm through the Tasmanian museum's live stream. Visit: [mona.net.au/](https://mona.net.au/)

## Travel

**Australia's Aquatic Experiences:** 360 degree coastal and aquatic videos: Visit: [bit.ly/3hskC0q](https://bit.ly/3hskC0q)

**Palace of Versailles:** Wander through the Palace and gardens with the purpose built VR tour. Visit: [en.chateauversailles.fr/news/life-estate/versaillesvr-palace-yours#a-unique-visit](https://en.chateauversailles.fr/news/life-estate/versaillesvr-palace-yours#a-unique-visit)

**Austria:** Experience Austria virtually. Visit: [austria.info/en/virtual-austria](https://austria.info/en/virtual-austria)

**Explore.org:** Live cams from around the world. Visit: [explore.org/livecams](https://explore.org/livecams)

## Animals

**Sea Life Sydney:** Virtual aquarium. Visit: [sydneyaquarium.com.au/explore/virtualaquarium/](https://sydneyaquarium.com.au/explore/virtualaquarium/)

**Taronga Zoo TV:** Watch your favourite animals live. Visit: [taronga.org.au/taronga-tv](https://taronga.org.au/taronga-tv)

**Monterey Bay Aquarium:** California's famous aquarium is live-streaming several of their well-known exhibits over the lockdown, and one of the cutest by far is the sea otter cam. Visit: [montereybayaquarium.org/animals/live-cams/sea-otter-cam](https://montereybayaquarium.org/animals/live-cams/sea-otter-cam)

**Lone Pine Koala Sanctuary:** tune in for heart-warming live streams of cute and cuddly koalas alongside other Australian native animals. Visit: [koala.net/webcams](https://koala.net/webcams)

## Libraries

Many local public libraries offer access to eBook loans and other online services. Visit your local library website to see what's available.

**City of Sydney Library:** free for all NSW residents: Visit: [library.cityofsydney.nsw.gov.au/Montage/Default.aspx](https://library.cityofsydney.nsw.gov.au/Montage/Default.aspx)

**State Library of NSW:** Free to join. Visit: [sl.nsw.gov.au](https://sl.nsw.gov.au)

**Gutenberg Project:** Project Gutenberg is a library of over 60,000 free eBooks, mainly classics where the copyright has expired. Books can be downloaded or read online. Visit: [gutenberg.org](https://gutenberg.org)

# THANK YOU!

We have many generous donors and appreciate that they think of us when they are looking to make a difference in people's lives. We recently caught up with two of them: Greg Kean and John Churchill, who coincidentally are keen owners of vintage cars.

## Association of British Car Clubs

It's no surprise that Greg Kean owns a 1938 Morris. He's the President of the Association of British Car Clubs which has been donating the proceeds of the annual All British Day at the Kings School in North Parramatta to Arthritis NSW childrens' camps for at least 20 years.

'The All British Day became a part of Kings annual fundraising art show because many of the school parents owned British cars and belonged to British car clubs,' Greg said. 'I became involved in the club in 2006. If they had held the day in 2020, it would have been their 40th year.'

'The All British Day has been able to donate the car entry fees because the school never charged for the venue. I believe someone initially suggested a children's charity should receive the money and the first nominated was Camp Footloose.'

On a typical All British Day, 1500 British cars will start arriving at 6.30 am. The oldest at the show is a 1912 model and the newest one will have just come off the showroom floor. Announcements are made throughout the day that the event supports Arthritis NSW. 'The art show evolved into a Spring Fair and we estimate that 30,000 people attended in 2019. The cars attract a lot of attention,' Greg said.

## John Churchill

All British Day has been supported for the past 20 years by regular Arthritis NSW donor John Churchill and his son who both own 1939 Austin 8s.

John donates to ANSW in memory of his wife Noreen who died five years ago, and lived with arthritis for 20 years.

'Noreen didn't complain so I didn't know of all of the pain. Her fingers were buckled and she used to have pain in her elbows,' John said. 'She had both knees replaced due to arthritis and used to say that she could get around a bit better after that.'

John and Noreen had two children, five grandchildren and four great grandchildren, raising their family in a two-storey house in Warilla he built in 1959. John still lives there and his grandson lives next door.

His links to Arthritis NSW go back to 1999 when Noreen started going to the warm water classes at the Port Kembla Hospital after her knee replacement. 'In 2006 they needed a co-ordinator and I had to join Arthritis NSW to be able to do the job. Then I was asked to be treasurer of the Warilla/Shellharbour Branch 2010 and still am.'



Greg Kean presents the club's donation to an ANSW representative at the All British Day in 2015. In return, Greg received a framed collage of photos of Camp Footloose kids and their families.



John Churchill with his prized 1922 Dodge

John developed osteoarthritis in his spine 30 years ago. 'I only take Panamax and if my knees get really bad I rub horse liniment into them, which helps a lot.'

John also owns a 1922 Dodge which he's driven to Dalby and Perth and even on set for the remake of *The Great Gatsby*. 'Scouts spotted the Dodge at a display day at Eastern Creek in 2012 and asked if I was interested in driving it in the movie. I said yes and four weeks later I was being fitted for wardrobe. I spent 11 days filming inside the old power station in Balmain. It was a great experience.'

**If you would like to make a donation to Arthritis NSW visit: [arthritisnsw.org.au](http://arthritisnsw.org.au)**

# GO NUTS!

According to [arthritis.org](http://arthritis.org), we should eat just over a handful of nuts and seeds daily<sup>1</sup>. Why? They are jam-packed with inflammation-fighting monounsaturated fat. And though they're relatively high in fat and calories, their protein, fibre and monounsaturated fats are satiating. Just keep in mind that more is not always better. The best sources are pistachios, almonds, pine nuts and walnuts.

## Roast vegetables with pine nut crumble

### Ingredients

- 3 Desiree potatoes, peeled
- 1 kumara (orange sweet potato), peeled
- 600g Kent pumpkin, peeled, deseeded
- 2 tablespoons olive oil
- 4 slices white bread, roughly chopped
- 1/4 cup pine nuts, toasted
- 1/3 cup grated parmesan cheese
- 1/4 cup flat-leaf parsley leaves, chopped
- 1 garlic clove, crushed
- 40g butter, melted, cooled



### Instructions

1. Preheat oven to 200°C. Cut potatoes, kumara and pumpkin into 5cm pieces. Place all vegetables into a roasting dish in a single layer. Drizzle with oil. Season with salt and pepper. Toss to coat. Roast for 45 minutes or until golden and just tender.
2. Place bread and pine nuts into a food processor. Process until crumbs form. Transfer to a bowl. Add parmesan, parsley, garlic and butter. Season with salt and pepper. Mix well. Remove vegetables from oven. Sprinkle crumble over vegetables. Roast for a further 10 minutes or until crumble is golden. Serve.

Source: [food.com/recipe/roast-vegetables-with-pine-nut-crumble-269770](http://food.com/recipe/roast-vegetables-with-pine-nut-crumble-269770)



## Walnut butter

Walnuts are more abundant in antioxidants than most nuts, fighting free radicals and oxidative damage to the body. They also reduce harmful LDL cholesterol and contain anti-inflammatory polyphenols.

### Instructions

1. Spread raw walnuts in a single layer on a baking sheet. Toast the walnuts in the oven at 165°C (fan assisted) for 10 minutes. Then leave them to cool to room temperature.
2. Pour the walnuts into your food processor or blender of choice and blend till smooth. To avoid overheating the machine (and nuts), do this in intervals of around 2–3 minutes. Then pause
3. to scrape down the sides of the blender/processor. To get a deliciously smooth homemade walnut butter, blend for approximately 15 minutes. Once the homemade walnut butter is ready, transfer it to an airtight glass container and keep this in the fridge for 1–2 months. It can also be frozen, for longer.

Source: [alphafoodie.com/simple-homemade-walnut-butter](http://alphafoodie.com/simple-homemade-walnut-butter)

1. [arthritis.org/health-wellness/healthy-living/nutrition/anti-inflammatory/the-ultimate-arthritis-diet](http://arthritis.org/health-wellness/healthy-living/nutrition/anti-inflammatory/the-ultimate-arthritis-diet)

## Pistachio pomegranate granola

Pistachios are a great source of healthy fats, fibre, protein, antioxidants and various nutrients, including vitamin B6 and potassium. Servings: 16

### Ingredients

- 3 1/2 cups thick rolled oats
- 1/4 cup pepitas
- 3/4 cup puffed rice
- 1 cup pistachios raw
- 1 1/2 teaspoons cinnamon
- 1/2 teaspoon sea salt
- 1/2 cup coconut oil
- 1/2 cup pure maple syrup
- 1 tablespoon honey
- 2 tablespoons brown sugar
- 2 teaspoons vanilla
- 1 egg white
- 1 1/4 cup pomegranate raisins

### Instructions

1. In a pot over medium heat mix together coconut oil, maple syrup, honey and brown sugar.
2. Remove from the heat and stir in vanilla extract.
3. In a large bowl mix together oats, pepitas, puffed rice, pistachios, cinnamon and salt.
4. Pour the hot oil syrup mixture over the oats.
5. Using a whisk, whip the egg white until it's frothy.
6. Fold the egg white into the oat mixture.
7. Line a large baking tray with foil and pour out the oats on to the baking sheet, spreading them out with a spatular.
8. Bake at 165°C for 30–40 minutes or until golden. Do not stir during baking or cooling.
9. Let cool completely and then break up into clusters and add the pomegranate raisins.

### Note

The egg white and not stirring the granola is what creates those yummy nuggets of goodness so make sure you follow the recipe exactly.

Source: [ohsweetbasil.com/pistachio-pomegranate-recipe](https://ohsweetbasil.com/pistachio-pomegranate-granola-recipe)



## Tomato and almond dip

This tomato dip is best served with grilled bread. It's vegetarian, vegan, plant-based, and dairy-free.

### Ingredients

For the tomato dip:

- 3/4 cup roasted almonds
- 400ml can crushed fire roasted tomatoes, or a can of crushed tomatoes

- 1 garlic clove
- 1/2 teaspoon salt
- 1/4 cup olive oil

For the grilled bread:

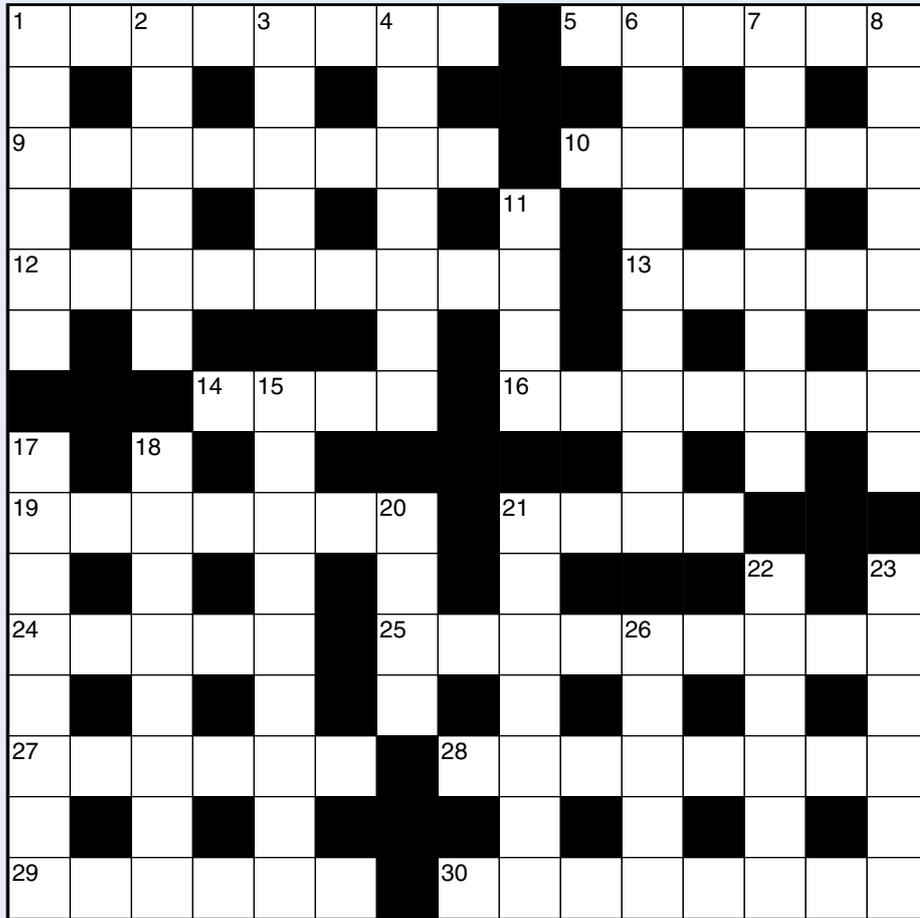
- 1 baguette or artisan loaf
- Olive oil

### Instructions

1. In the bowl of a food processor, combine the roasted almonds, fire roasted tomatoes, garlic, and salt. Process until the nuts are finely ground.
2. Scrape down the bowl. With the processor running, add the olive oil in a steady stream until a thick texture forms. (Store any leftovers refrigerated for 1 week.)
3. For the grilled bread: Slice the baguette into slices. Brush olive oil onto each side of the bread. In a grill pan or on a grill, toast each bread slice over medium high heat until browned, a few minutes per side.

Source: [acouplecooks.com/roasted-tomato-almond-dip-with-grilled-bread](https://acouplecooks.com/roasted-tomato-almond-dip-with-grilled-bread)

# Crossword



© Lovatts Puzzles

## DOWN

1. Very generous
2. Rich cream cake
3. Gibberish, ... jumbo
4. Convent
6. Dusk to dawn
7. Century's final decade
8. Limbo
11. Major symptom of most types of arthritis
15. Utilises excessively
17. This action in which the body is supported by the knees may be impacted by osteoarthritis and rheumatoid arthritis
18. Basket
20. Loosely woven sheet used as either a permanent or temporary support for organs and tissues during surgery, surgical ...
21. Mentally anguish (over)
22. Lend a hand
23. Respiratory condition associated with a higher risk for rheumatoid arthritis
26. Niggled

## ACROSS

1. 5 Across may feel unstable or loose when arthritis is caused by damage to this fibrous connective tissue
5. Arthritis is the inflammation of these structures in the human body
9. Lack of sun exposure can mean you are not getting enough of this substance which your body requires to absorb calcium (7,1)
- 10 & 24. Inflammation of tendons caused by overuse of the muscles of the forearm (6,5)
12. TV melodrama (4,5)
13. Paris cathedral, ... Dame
14. Human frame
16. Valuable chunks
19. To a sickening degree, ad ...
21. Car (industry)
24. See 10 across
25. Abnormal curvature of the spine that occurs most often before puberty
27. Trainee doctor
28. Sensitive
29. Lubrication
30. Revenge campaign

## 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
Corowa	Heather	02 6033 4393	Challenge Enterprises, 93 Guy St, Cnr of Redlands Rd, Corowa	1st Wednesday 1-30
Cowra	Christine	0427 423 596	Upstairs, Calare Building, 103 Kendal St, Cowra	1st Tuesday 2pm
Dubbo	Heather	02 6887 2359	Macquarie Club, 313 Macquarie Street, Dubbo	2nd Thursday 10am
Holroyd/ Merrylands	Michelle	02 9631 7363	Nelson Grove RV, 2 Newport Street, Pemulwuy	4th Monday 10am
Kincumber	Jeanette	0418 226 891	Brentwood Village Auditorium, Scaysbrook Dr, Kincumber	4th Friday 10am
Macarthur	Charmaine	0423 500 066	Campbelltown Library, Hurley St, Campbelltown	1st Wednesday 10am
Maitland District	Veronica	02 4966 4649	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 1pm
Nowra	Gary	02 4423 3633	Paceway Cafe, 3 Stewart Place, 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	CWA Rm, Cnr Tindale St & Castlereagh St, Penrith	2nd Wednesday 930am
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 1030am

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](mailto:friends@arthritisnsw.org.au).



# Arthritis

NEW SOUTH WALES

[arthritisnsw.org.au](http://arthritisnsw.org.au)

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North Ryde NSW 1670

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