

Arthritis Matters

NUTRITION

RESEARCH

EXERCISE

HEALTH

Issue 63

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DAILY EXERCISE

Make your health your first priority

CRICKETER ALEX BLACKWELL:
Our new STRONG Ambassador

CAMP TWINKLETOES 2019:
Support and fun for everyone!

PAIN DIARY:
Track your pain to help keep it
under control

Arthritis
& Osteoporosis
NEW SOUTH WALES

www.arthritisnsw.org.au

ABOUT US

Arthritis & Osteoporosis NSW is a member-based health charity founded in 1967 to help improve the quality of life of people affected by arthritis, osteoporosis 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 www.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 and Strength & Balance program. We deliver annual camps for children affected by juvenile arthritis: Camp Twinkletoes for children under 8 years old and their families, and Camp Footloose for children and young people aged 9 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 monthly eNewsletter at eepurl.com/9rFd5



BENEFITS OF MEMBERSHIP

Understanding | Support | Community

We would love to have you as a **financial Member** of the organisation. 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:

www.arthritisnsw.org.au/membership/about/

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

- ✓ Be Heard
- ✓ Be Informed
- ✓ Be Supported
- ✓ Be Rewarded



Arthritis Matters

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For arthritis information
Arthritis Infoline

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Arthritis Matters

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ADVERTISING

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

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Expanding services and adding value



Hello everyone, and welcome to the latest issue of *Arthritis Matters*.

The first half of 2019 was very busy for Arthritis NSW (ANSW). Many of our activities culminated in May which is National Arthritis Awareness Month. We held Camp Twinkletoes on May 4–5 and re-visited Bathurst on May 15 to deliver a second community health seminar and determine the impact of our first seminar 12 months ago. We also aired several advertisements on Radio 2CH throughout the month to raise awareness of our planned giving program.

We have partnered with MSK Australia and I am pleased to announce that this has resulted in access to free webinars for all Arthritis NSW members. Details on how to register will be communicated soon.

More children's camps

ANSW has been delivering Camp Twinkletoes as an annual event for many years for the parents of young children with juvenile arthritis (JIA). In many cases the children have been recently diagnosed and the families are struggling to understand their child's condition. However, many families return each year to re-connect and share their stories and solutions. This year, we ran the camp for nine families at Naamaroo, next to Lane Cove National Park. We followed our tried and true format of entertaining the children and their siblings while their parents received information on

juvenile arthritis from specialists in paediatric rheumatology and clinical psychology. I've attended three Camp Twinkletoes and I'm always moved by the parents' appreciation for the education they are given, and the children's delight in meeting new friends who have arthritis.

I am happy to report that ANSW will run four children's camps in 2019/2020. Camp Twinkletoes and Camp Footloose will each go ahead at a Sydney venue, and will also be delivered in a regional or rural centre to give families outside Sydney a chance to attend. This development is part of our objective to extend our reach into the rural community and I'm looking forward to providing more details in the next issue of *Arthritis Matters*.

Bathurst revisited

On May 15, the ANSW Health Services Team returned to Bathurst to measure the impact that last year's education session made on the participants who took the suggestions on board. Turn to page 12 for our report. The Rural Health Initiative is now a program that is committed to delivering community education sessions in four regional or rural centres per year.

Our future with you

In April, we invited our members and donors past and present to participate in an email survey to determine our future direction to benefit you and maximise our position in the community. We were inspired by a very encouraging response rate to the survey which has given us a clearer view of our audience and stakeholders and what you need. Thanks to these results, we will soon be developing new strategies to help meet those needs.

Musculoskeletal Australia

As mentioned earlier, ANSW has formed a partnership with Musculoskeletal Australia, previously Arthritis Victoria. Both organisations have formulated a memorandum of understanding and there will be more information on the benefits this relationship will bring to our members in the near future.

Arthritis Matters is your magazine and I want it to be relevant to you. If you would like to see a particular arthritis topic or event featured in these pages, please contact us at: info@arthritisnsw.org.au.

A handwritten signature in black ink that reads "Sandra".

Sandra Vincent
Chief Executive Officer



Our STRONG Ambassador Alex Blackwell

Arthritis NSW is proud to announce that former Australian cricket captain Alex Blackwell is our Ambassador for our STRONG programs.

Alex (*pictured above right*) led Australia to World Cup and Ashes victories and is the first woman elected director to Cricket NSW. She put aside her career as a medical doctor to pursue cricket, and then went on to work as a genetic counsellor in the world of prenatal and preconception genetic testing. She is an ambassador for SportNSW and Wheelchair Sports NSW. She is currently balancing her new roles in coaching, sports administration and cricket broadcasting with Fox Sports and Macquarie Sports Radio.

Natural fit

Alex understands firsthand the importance of physical activity for personal wellbeing and social connection, making her a natural fit as ambassador for the program.

'Having been a professional cricketer for many years I understand the impact that movement and physical activity through sports has had on my life,' Alex said. 'Being active makes

me feel better and this helps me to be a productive person in all aspects of my life. While I haven't experienced arthritis myself, I can try to put myself in the shoes of someone who has, and when I do this I think about how it might be a significant challenge to engage in sport. When I learned that your STRONG programs were tailored for people with arthritis, I understood how powerful this program was and wanted to help spread the word so more people can reap the benefits.'

Culture of innovation

Alex's connection with Arthritis NSW was made through our board director Allan Ryan. 'Allan told me what Arthritis NSW does and it became apparent to me that this organisation shows strong leadership via its contemporary governance practices and has an impressive culture of innovation which drives value for its members. For these reasons I was interested to learn more and get involved.'

'One of my dearest friends lives with ankylosing spondylitis which has had a profound impact on her life; as she was once an elite athlete. Her new reality makes intense physical activity

no longer beneficial to her. We've discussed the STRONG program and she believes it is exactly what she has been looking for, gentle exercise programs tailored to people experiencing conditions like hers that provide social benefits as well as physical outcomes.'

Alex plans to learn more about STRONG and then spread the word in her own circles and to larger audiences.

'I intend to deliver talks to prospective sponsors of Arthritis NSW using my own story regarding the benefits of group physical activity, strength and balance to inspire them to support the organisation so the program can expand and reach more people,' Alex said. 'It would give me great pleasure to participate in a class at some stage too and interact with the members! I would like to see firsthand how this fantastic program, that I am choosing to support, is making a difference in people's lives.'

Alex Blackwell
STRONG Ambassador



Re-train your posture

Earlier this year, Physiotherapist Lana Johnson spoke to audiences during Seniors' Week on the importance of maintaining good posture to support our joints and ease the burden of osteoarthritis. Below she shares her experience and insights with us.

We all know much of the burden of osteoarthritis comes from the excessive load put through the big weight bearing joints of the body. But did you know that there is a simple and highly effective way to reduce this load on arthritic joints, and distribute the load evenly throughout your body, so it transmits forces in the way it was designed to?

Posture

Much of what begins the process of osteoarthritis stems from poor posture, which equates to excessive loads being transmuted through a variety of weight bearing joints. Knees, hips, the lumbar spine and the neck often take the brunt of poor posture and as a result have a higher percentage of osteoarthritis than other less weight bearing joints of the body. The great thing about this causative factor is that the body and brain are very plastic, meaning you can begin to undo these poor postural habits today and it doesn't cost very much to begin.

Posture is a skill

I'm sure you have all, at some stage or another, listened to the naggings of a loved one telling you to stand up straight or stop slouching. And while you may have pushed back with resentment, deep down you knew they were right! You reply that it's difficult: 'I can't hold it for very long, it's not comfortable'. And right you are, but you could have said the same things when you started to learn to walk or drive or any other life skill you have needed to acquire. After all, posture is a skill and the great thing about that is that it can be learnt, you just need a good teacher.

So, I encourage you to seek some professional, postural help. My suggestion would be a physiotherapist who has an interest in Pilates. These professionals literally live and breathe posture, biomechanics and are interested in how the body transfers loads optimally throughout the body. I wish I could demonstrate to you the difference in how your body can feel with just a few small adjustments.



Putting your pelvis directly over the top of your hips, or ensuring your head is sitting right on-top of your spine can make such a difference. Sometimes just a 2mm change can have a drastic impact to the way your whole body moves and feels. The secret is in getting the *right* 2mm change and for this you need a special pair of eyes and hands, a coach to observe your body and give insight into where you can improve, because there is so much that can be changed, learned and improved upon when it comes to posture.

Techniques

Below are a few basic techniques that you can try while sitting in the comfort of your own home. As a caveat, this is by no means a perfect situation as the importance of the phrase 'everybody is different' cannot be overstated here. What works for one person may not work for another and it is better, when it comes to posture, to have an expert set of eyes and hands looking at your individual body. Regardless, these tips have a fairly high success rate.

Weight distribution in standing

Take a second to pay attention to the weight distribution of your body in standing. Take a few steps on the spot and come to rest in a stance that feels normal for you. Now, notice – where is the weight? Is it distributed evenly through your left and right legs? Is it even through the fronts and backs of your feet, does each heel, left and right feel the same, do all 10 toes feel even? The chances are you notice significant differences here between your two legs. This is a good indication that you are not distributing loads evenly throughout your body.

The fix? Now try to distribute the load evenly, sometimes you need to take your shoes off, really feel your feet on the floor and see what you can do about shifting your posture so that the loads are evenly distributed between both feet. Take note of what you needed to do to achieve this. Was it as simple as consciously standing on both legs evenly.

Weight distribution in sitting

Sitting in a comfortable, flat surfaced chair (not your lounge chair) put your hands underneath your bottom and feel for your sit bones. Sit bones are the two bony prominences at the bottom of your pelvis, the bones that are made to take the load of your spine in sitting. Now, feel where the weight is distributed throughout your pelvis. Is it even through both sit bones, or does one side feel as though it is taking more load?

Now, try standing up, still with your hands on your sit bones and as you sit down pull your sit bones wide, so they take the load evenly. Once you have sat with even sit bones, take your hands out from underneath your bottom and pay attention to how your body feels now. Does it feel different now that your weight is bearing down evenly through both sides of your pelvis?

Breathing

How often have you noticed that your shoulders are up around your ears, you're holding tension in your neck and you're not taking deep breaths? If you're like most of us, too often. Next time you catch yourself feeling tense, try stopping, taking a breath and gently letting go of your shoulders so they can return to their rightful place on the back of your ribcage.

Breath awareness is a great postural skill. By turning your awareness to your breath, for as little as five slow breaths, you can make a huge difference to where you're holding tension in your body. This gives the brain a chance to reorganise your motor patterns and find you a more even, comfortable and accurate placement of your body. Which in turn helps to redistribute the loads evenly throughout your body.

I hope this article helps to highlight how important it is to be aware of your posture in your daily life. You only get one body. Now is the time to pay attention to it – look after it and if it hasn't been well cared for in the past, take heart in knowing it's very forgiving and will respond well to small changes that you can begin today, from the comfort of your own home.

For more information, contact info@bpstensegrity.com

Lana Johnson

Physiotherapist
BPS Tensegrity

Keep a pain diary



Most of the callers who come through the Arthritis NSW Infoline are triggered by pain. Sometimes the pain simply becomes too difficult to cope with, and affects other areas of your life. It can be even harder to take when pain or dysfunction stops you from doing the things that you like to do.

One thing that we have found useful for our callers is to suggest they keep a diary. The diary records your activities, everything from housework to exercise, medications, and mood or how well you sleep. Some people call this their 'pain diary', and the National Prescribing Service (NPS) helped us produce a booklet that works to help manage pain. Arthritis NSW has copies of this booklet available for members.*

So what is a pain diary? It is simply a record of things that will help you to describe to your healthcare team how your pain has been. It also records medicines, other therapies and your visits to healthcare professionals.

Tracking your pain

If you ask yourself 'why should I keep a pain diary?' the answer would be that it can help you and your healthcare team understand what makes your pain worse and what helps to relieve it. It also helps you to track your response to your pain management plan (including changes in your medicines or other therapies). It is particularly useful when you have ongoing pain, changes in your activity levels or changes in your medicines.

The information that you record will help you and your healthcare team prepare and guide your pain management approach or plan. If pain levels are under control you may not need to use the diary as often. The more information you record in your pain diary, the more helpful it will be for you and those around you.

So how do you complete the NPS Medicinewise diary? First of all, record all the information that is relevant to your pain in the diary – you may not need to fill out all columns each time. There is a rating scale that helps to describe your situation – zero (0)

means no pain and a ten (10) means worst possible pain. Select the number that best describes your pain.

If you want to keep your own form of a pain diary, the important categories are:

Date and time: The more often you record this information, the more accurate your guide will be.

Describe your pain: Is it dull, sharp, stabbing or constant? Is it moving or in the same place?

Rate your pain: Use a scale from 0–10, or you might want to create your own description

Asking yourself questions such as the ones below will also be useful in your management of symptoms:

- **What made my pain worse?** This might include particular movements or tasks (eg. carrying loads or moving things around, cleaning or gardening for too long in one position)



Medicines Line

Information provided by Medicines Line includes:

- how a medicine works
- how to take medicines
- side effects
- interactions with other medicines
- medicines during pregnancy and breastfeeding
- medicines for children
- storage of medicines
- how to obtain consumer medicine information (CMI) for your prescription medicines
- referrals to reliable services and support organisations, eg. support organisations for people with your health condition
- promotion of the quality use of medicines and provision of information that is independent, evidence-based, appropriate and safe
- encouraging responsible use of medicines by increasing public awareness about medicines.

- **What helped me get through the day?** This can be anything from having a cup of tea, lying down for a while, or practising some breathing exercises.
- **How long did it last?** Sometimes pain goes away more quickly, and it's good if you can work out why by tracking your activities, medication and other self-management strategies
- **How was my activity levels and mood?** Mood can be affected by medicine and non-medicine approaches such as a visit, social event or other activity that might have a negative or positive result – it could distract you from pain or might cause fatigue and irritability. Learning the right combination of activity, rest and social engagement can make a big difference to pain levels.

There are other things that you may want to record, such as whether pain affected your daily life, including sleep, work, mood, social life etc. It is also important to note down if there are problems with medicines, such as reactions or side effects.

All this information will make it easier for you to know what to do when pain strikes, and guide your healthcare team to help you in the best possible way.

For more information on medicines, contact the **National Prescribing Service Medicines Line** on **1300 633 424**. They have an excellent information service that is usually answered by nurses, operating 9am to 5pm on Mondays through to Fridays. The NPS can guide you on when and how to use medicines to improve health and wellbeing. In addition to providing information, the service encourages you to discuss the information with your own doctor or pharmacist, who are best placed to help interpret the medicines information.

For other sources of information to help manage your pain, try the contacts below:

Arthritis NSW
arthritisnsw.org.au/
 Dealing with Pain fact sheet

Pain Australia
painaustralia.org.au/

Exercise is Medicine

(Arthritis Fact Sheets):
exerciseismedicine.com.au/

Janine Robertson

Health Services Project Officer
 Arthritis NSW

*Arthritis NSW will post the NPS Medicinewise diary to members on receipt of postage costs.

Kids shine at Camp Twinkletoes 2019



The Arthritis NSW Health Services team delivered Camp Twinkletoes 2019 to nine families on May 4–5, at Naamaroo, a group venue in bushland setting next to Lane Cove National Park.

Specialists in paediatric rheumatology and psychology presented education sessions to the parents while their children, a total of 17 including siblings, were entertained by a team of volunteers with games, arts and craft, a native wildlife petting zoo, meditation and yoga.

The presentations gave parents a comprehensive overview of the medical, behavioural and psychological aspects of juvenile arthritis (JIA). Paediatric rheumatologist Dr Davinder Singh-Grewal went over the different types of JIA and how each is managed medically.

Rhiannon, mother to Christian, 8, said it was great to get an overview of his condition, the effects it can have long term and the general outlook. 'Christian was only diagnosed in February this year so it is all very new to us, we are just starting from the basics,' Rhiannon said. 'You just get told things in hospital so it's good to listen to other people and get an insight on what to expect afterwards.'

'Hopefully we can help Christian cope with everything he has gone through and with whatever will happen from here.'

Empowerment

Paediatric rheumatology nurse Anne Senna covered the behaviour of children living with JIA and how their parents can empower their children to talk about their condition, and help them in school and hospital settings.

Alicia, mum to Sabrina, 5, said she found Anne's talk extraordinarily helpful. 'This is the first time we've had any illness in any of our children and Anne's talk prepared us to navigate the unknown,' Alicia said. 'We were able to relate to what she was saying about our day-to-day activities, managing Sabrina, going to school, visiting the hospital, and it was very useful.'

Murray, dad to Madeline, 2, said that Anne's session gave him and his wife Bianca issues to think about when



Freedom from arthritis for young people 

Madeline was older. 'But the most valuable thing we learned from that session was to tell her day care centre about her arthritis,' Murray said. 'We hadn't told them because she can run and climb, and we feel her condition isn't impacting her. But, thanks to the session, we've decided to tell her day care because if they are aware of her condition and they see her doing something different to other children, they can tell us.'

Mindfulness

Psychologist Meg Farnsworth talked to the parents about the psychology of pain and anxiety and how it can be alleviated with mindfulness.

Lisa, mum to Amelia, 6, said that she found Meg's presentation valuable



because Amelia was seeing a psychologist. 'I was told recently by a paediatrician that the pain was in her head, because she is in remission and doesn't have active flare-ups at the moment,' Lisa said. 'So, it was good to hear Meg talk about how anxiety links back to pain, and how all these worries can lead to pain. You start to doubt yourself after a while, but Meg's information suggests that maybe Amelia's not playing on her condition, which some people say she is doing.'

In the final session, our camp volunteers Annaliese Roach and Caitlyn Peacock and their mothers Alex Roach and Michelle Peacock, took part in a Q&A session with the

parents about growing up with JIA and parenting a child with the condition. Annaliese and Caitlin both attended Camp Twinkletoes as young children and have returned to Camp Footloose every year.

Lauren, mum to Brydee, 2, felt reassured by this session as she worries about Brydee in the future. 'Listening to Caitlin and Annaliese, they weren't too fazed by their condition,' Lauren said. 'They also said their arthritis never stopped them from doing what they wanted to do and they don't remember a lot, which was good to hear because I would hate for Brydee to remember being in pain.'

During the breaks throughout the day, the parents shared stories of how they were managing their child's condition, their other children, medication, school and family life. 'It was really informative to hear the other parents talking about the different ways they help their kids cope,' said Lisa. 'We were talking on the break about how our kids were diagnosed and hearing the different stories. I've never met anyone who has a kid with arthritis before.'

Rhiannon agreed: 'It's been good to learn from the parents that even though the kids are all different and have different conditions, in many ways they go through the same things.'

Lindy Sivyver
Marketing & Campaigns Coordinator
Arthritis NSW

BATHURST KEEN TO STAY STRONG



More than 80 people attended the Arthritis NSW community education seminar held at the Bathurst RSL on 15 May.

Many who attended Arthritis NSW's seminar last July were happy to return to report on the positive impacts to their lives after adopting the health strategies, and provide valuable feedback.

This year's seminar *Staying Strong with Arthritis*, presented exercise, mindfulness and wellbeing strategies. Co-presenters St Vincent's Outreach Centre gave a talk on exercise, screening and lifestyle strategies to prevent arthritis.

Health Services Manager Andrew Cairns said that the program deliberately returned to Bathurst to measure the success of last year's seminar. 'We invited everyone who attended last year to complete a survey on whether they adopted any of the health strategies we promoted in the 2018 session and whether it made a positive impact to their lives,' Andrew said.

'It was great to learn that so many people took our strategies on board and that they were empowered by the event to start taking control of the management of their condition through exercise. It was especially

pleasing to have it reported back that a majority were noticing benefits in things like reduced pain, stress reduction and even sustained weight loss,' he said.

Member Mary Johnson, of Bathurst, said that the 2018 seminar had reaffirmed for her that she was already doing the right thing with her diet and exercise.

'I have osteoarthritis in my left elbow and right knee and I exercise regularly and eat lots of fruit and vegetables,' Mary said. 'Thanks to the warm water exercise I was already doing, I'd regained use of my left arm and had a more positive frame of mind.'

Member Stephen Godfrey of Lithgow attended the ANSW seminar in Parkes last year and described it as informative and relevant. 'I have osteoarthritis in my knee and Andrew spoke about the benefits of exercise and weight control,' Stephen said. 'So I made a determined effort to lose weight to ease the strain on my knees by walking more and doing water exercise. I lost eight kilos in 10 months.'

'It made a huge difference to my life. I'd been taking a low grade prescription anti-inflammatory and my doctor told me recently that I could stop taking it. The other benefit is that after a day's work in the yard, I'm still mobile, whereas previously I would often need to rest my knee and apply an ice-pack the following day.'

Co-ordinator of the Bathurst Arthritis Support Group Nelma Brooks is living proof of the benefits of staying active with arthritis. To read her story turn to page 14.

Lindy Sivyer

Marketing & Campaigns Coordinator
Arthritis NSW

Top left: Andrew Cairns delivers the ANSW presentation, Staying Strong with Arthritis, to the audience on 15 May.

Top right: Members of the Bathurst Support Group attended the seminar: L-R: Nelma Brooks, Julie Liddell, Mary Johnson (seated), Michelle Morgan, Kristine Smith, Rebecca Rose (seated) with her arm around her mother Michelle (kneeling).

Enthusiasm drives exercise

Arthritis NSW is excited to announce updates to several of our exercise classes.

First of all, our Strength & Balance program in St Leonards has moved to the North Sydney Community Centre, courtesy of our friends from North Sydney Council. Our veteran instructor, Exercise Physiologist Mel, now leads classes on Tuesdays and Thursdays at 2pm in the Bay Room.

We would also like to welcome our new instructor to Arthritis NSW, Exercise Physiologist Dae Uk, who leads both the warm water classes at Ryde Royal Rehabilitation and at Epping YMCA to great acclaim. Dae Uk teaches warm water classes at Ryde Royal Rehab on Tuesdays at 4pm and 5pm and the Strength & Balance program at Epping YMCA at 10am. There is also potential for a class at 11am. There are still some places available so if you would like to learn more about these classes, contact Glen

Puxty at Arthritis NSW. Alternatively, if you live in a location that doesn't have classes and you know of a site that is perfect for either water or land-based activities, contact Glen and he will happily look at the possibilities of setting up classes in your town.

Member Patricia Hume, 85, has been attending the warm water classes on Tuesday afternoons at Ryde Royal Rehab for two years. With osteoporosis in her spine and ongoing pain from a knee replacement, she has found it much easier to exercise in warm water than on dry land. 'It is soothing and helps me to stay mobile. I'm still in a lot of pain but I feel a great freedom of movement,' she said.

Patricia's doctors are very supportive of her attending the classes to help her cope with her conditions. 'It's also helpful to share my concerns with others doing the exercises who have a similar variety of conditions. Class instructor Dae Uk Han is an exercise



physiologist who began delivering our exercise programs this year. He says he enjoys teaching and supervising the warm water exercise class because of the enthusiasm that all participants bring every week.

'The people who come to class live with a chronic condition that has the potential to affect every aspect of their lives, which is highly admirable,' Dae Uk said. 'Given that everyone knows the benefits of warm water exercise, through their eagerness and the organisation's advocacy, the class is so successful. It is a pleasure to teach and supervise an exercise group that is always seeking improvement, through education and lifestyle changes such as exercise, and showing enthusiasm despite adversities'.

Glen Puxty
Program Administration Officer
Arthritis NSW



Exercise Physiologist Dae Uk takes his warm water class through some stretches.

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Whether you are cruising,
flying or driving.

This portable scooter folds up
in just 20 seconds.

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SCA33002

She *never* gives up!

Bathurst resident Nelma Brooks has lived with osteoarthritis for 36 years. In that time she has raised three children, managed a pet shop, run various local volunteer groups and programs and minds her toddler granddaughter – all made possible through daily exercise.

Granddaughter Selina helps Nelma in her garden.



Nelma leads a busy life in Bathurst. Her usual mornings start at the gym, followed by a swim. Once a week she does Tai Chi with a group of 12 others. She walks everywhere. For the past five years she has been the co-ordinator of the Arthritis NSW

Bathurst Support Group. For the past 15 years she has run the local Court Support Scheme which provides help and advice to people who have to attend court. She looks after her three-year-old granddaughter, as she has done her eight other

grandchildren, and spends time tending the flowering shrubs and vegetables in her garden, which grow in beds that her son-in-law built a metre off the ground. In her spare time she knits, sews and crochets with a group Knit Happens. First they produced items for the school fete, now they knit distraction sleeves for dementia patients and children with special needs. They knitted poppies for each child at the local school to wear for the ANZAC parade.

Wellbeing a priority

Nelma's life reflects the happy, productive schedule of an able-bodied 72-year-old who values family and community but, most importantly, makes her personal health and wellbeing her first priority. Years ago, when she found the pain of arthritis encroaching on her life, Nelma realised that exercise was the answer and taught herself what to do from a library book.

Her arthritis story began when she was 36 and started to get pain in her knee. She was living in Kurrajong Hills on sloping land and first blamed it on having to walk the hills. 'My doctor told me I had my mother's knees because she had had a knee replacement. He told me to take Panadol, so he wasn't much help,' remembered Nelma.

'I soldiered on until we moved to a 100 acre property, 20km outside Bathurst. Once there, I still had to feed the animals and raise my young family so I bought some Theroskin braces to support my knee joints and away I went.'



Nelma does resistance training at her local gym



Nelma with her pool buddies L-R: Pam English, Nelma, Shirley Bryant (back), Millie Malicanin.

Raising a family

When Nelma was 45, her marriage ended and she took on the management of a pet shop in town. One day in 1999, she bent over to pick up a 20kg bag of gravel to put in a fish tank and passed out from the pain. Scans revealed that a disc in her lumbar spine had started to degenerate. She closed the pet shop.

'I was 52 at this point and living in town so I could walk everywhere, which was my only form of exercise. Even if it hurts, you can still walk for 10 minutes to the shop,' Nelma said. 'Then, about 16 years ago, I decided to try walking and exercising in the water. I took a book on aquarobics out of the local library, worked out what to do and started going to the pool in my local gym, which is heated to 29 degrees.'

Gym training

Nelma also joined an endurance training program for seniors which was run by a professor at the Charles Sturt University. After two years on the program, she was at a loss when the professor moved to Queensland, however he encouraged her to join the gym.

The trainers at the gym advised her on what to do. 'Now I go seven days a week. I spend 30 minutes on the treadmill and then use the weight

machines for my arms and shoulders. Sometimes I cycle. Then I go to the pool and run laps and walk laps, anything to strengthen the muscles in my legs and lower back,' she said. 'I train in the gym alone, but the pool is social and there's lots of talking.

'I take a Tai Chi class once a week at the local senior citizens centre which is 10 minutes walk away. They also do seated Tai Chi and some of the Bathurst Support Group go to that. The instructor has arthritis too, so she knows what to do with us.'

Quality of life

Nelma's exercise program has been built over time. There was gradual progression where she started walking everywhere, then she started exercising in the pool 15 years ago, then she added the gym sessions three years ago. She is very happy with the quality of life she has achieved since she made exercise part of her daily routine. 'Five years ago I was on a high dose of Tramadol which is an opiate for pain and also took Panadeine Forte intermittently. Now I don't take anything for pain or blood pressure, because of the exercise. I only take drugs for my cholesterol.

'There's nothing now that I can't do: wash the windows, climb a ladder, walk everywhere. I look after my grandchildren, I'm independent. I'll

only ask my children to help me do something as a last resort.'

Her family has been very pleased with her progress. As well as building her garden beds, her son-in-law built the house, making sure everything had easy access. It is also wheelchair-friendly if she ever needs it.

Inspiration

'I try to be aware that I have arthritis and that I'm getting older,' said Nelma. 'I nag people to exercise. My arthritis support group has been inspired by my activity levels and some have started to do the seated Tai Chi. One of my daughters has rheumatoid arthritis and is a farmer. She knows that the more she walks, the healthier she'll be because she's seen how exercise has worked for me.'

Lindy Sivyver

Marketing & Campaigns Coordinator
Arthritis NSW

Are you at risk of osteoporosis?

In Australia, more than one million people have osteoporosis. Your risk of developing osteoporosis can be influenced by your gender, family medical history and nutrition.



Men and women may have certain risk factors that can make them more likely to develop osteoporosis. You should discuss these with your doctor. Anyone over 50 years of age with risk factors may require a bone density test. A bone density test is a simple scan that measures the density of your bones, usually at the hip and spine. You lie flat on a padded table and the arm of the machine passes over your body. The scan takes about 10–15 minutes. The results will tell you and your GP if you need to act to keep your bones strong, slow bone loss and reduce the risk of breaks.

Gender

Women are at a greater risk of developing osteoporosis because of the rapid decline in oestrogen levels during menopause, which causes bones to lose calcium and other minerals at a much faster rate. As a result, bone density loss of about two per cent a year occurs for several years after menopause.

Men also lose bone density as they age, however testosterone levels in men decline more gradually so their bone mass remains adequate for longer.

Family history

Bone health can be inherited so consider your family history of osteoporosis. If your parents or siblings have been diagnosed with osteoporosis, broken a bone from a minor fall or rapidly lost height, this can indicate low bone density.

Calcium levels

Low level intake of both calcium and vitamin D can increase your risk of osteoporosis. Adults require 1,000 mg per day of calcium (preferably through their diet) which increases to 1,300 mg per day for women over 50 and men over 70. Your body needs Vitamin D to absorb calcium and a lack of sun exposure can mean you are not getting enough.

Medical history

Certain conditions and medications can impact on your bone health. They include:

- Corticosteroids – used for asthma, rheumatoid arthritis and other inflammatory conditions
- Low hormone levels: in women – early menopause; in men – low testosterone
- Thyroid conditions – overactive thyroid or parathyroid

- Conditions leading to malabsorption, eg. coeliac disease, inflammatory bowel disease
- Some chronic diseases, eg. rheumatoid arthritis, chronic liver or kidney disease
- Some medicines for breast cancer, prostate cancer, epilepsy and some antidepressants.

Lifestyle

Lifestyle factors can also influence the risks of developing osteoporosis. They are:

- low levels of physical activity
- smoking
- excessive alcohol intake
- weight – a thin body build or excessive weight (studies suggest that hormones associated with obesity may impact bones).

Know your bones

Osteoporosis Australia and the Garvan Institute have developed an online bone health survey that can help you to better understand your risk factors. Visit: knowyourbones.org.au.

Source: *Osteoporosis Australia: osteoporosis.org.au/risk-factors.*

Portion sizes made easy

Controlling your weight is an important part of any health program that aims to manage and improve arthritis. Extra body weight increases the stress on many joints, particularly the knees, hips and lower back. There is also a clear link between being overweight and an increased risk of developing osteoarthritis. If you lose weight, you will decrease the stress on your joints, reduce pain and move around more easily.

Studies have shown that the more food and drink a person has on their plate or in their cup, the more they'll devour. According to Dr Alice Gibson, accredited practising dietitian and a research associate at the University of Sydney's Boden Institute, portion control is one of the most significant challenges for Australians.

'Most Australians don't know what a portion or serve looks like,' she said. 'There's also the common belief that portion control doesn't matter if you're eating healthy food, which simply isn't true.'

That's where our hands come in.

Researchers at Harvard Medical School agree. They say our hands are the perfect instruments for sizing up meals and snacks as you can simply gauge how much of a particular food to eat by measuring it against a certain part of your hand.

While Dr Gibson admits it's not an exact science due to everyone's hands being different sizes, she says the idea has benefits beyond that.

'Regardless of accuracy, the fact someone is paying attention to how much food they're putting on their plate is a really good thing.'

How to measure a serve with your hand

- Peanut butter: 1 thumb (1 tbs)
- Butter: 1 fingertip (1 tsp)
- Cheese: 2 fingers (40g)
- Milk: 1 whole fist (1 cup)
- Cooked porridge: 1 handful (1/2 a cup)
- Cooked veg: 1 front fist (1/2 cup)
- Cooked pasta: 1 fist (1/2 cup)
- Cooked meat: 1 palm (80g–100g)
- Almonds: 1 handful (20 nuts)
- Raw salad: 2 handfuls (1 cup)

Source: bodyandsoul.com.au/nutrition/nutrition-tips/how-to-measure-portion-size-using-your-hand/news-story, June 2017.

VISUAL HAND GUIDE TO PORTION SIZES

@THEFLEXIBLEDIETINGLIFESTYLE

The front of your closed fist is about 1/2 cup

A clenched fist is the size of a 1 cup serving

Your fingertip is about 1 teaspoon

Your thumb is about 2 tablespoons
* Measure one tablespoon from your knuckle to the tip of your thumb

Your palm is 80-100g, which is a standard serving of meat



Children's camps doubled

Arthritis NSW has doubled the number of children's camps to be delivered in FY2019/20 to include two camps held in regional NSW.

Our children's camps give children and young people living with juvenile idiopathic arthritis (JIA) an opportunity to participate in fun and educational activities, in a safe and

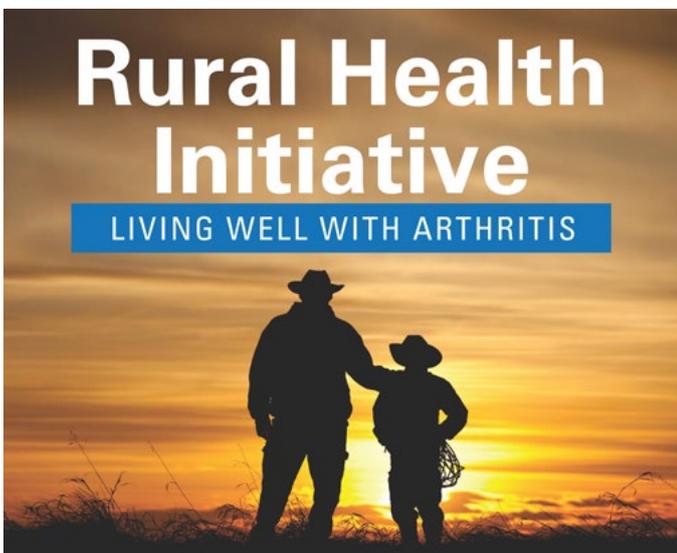
supportive environment. To read about Camp Twinkletoes 2019, for families with JIA children aged up to nine years, turn to page 10.

Camp Footloose is for young people aged nine to 18 living with JIA. 'We evaluated the social impact of Camp Footloose on the lives of the children who attended in 2018 and the results showed that there had been positive changes in the physical, psychological and social elements of JIA on the children after the camp,' said Health Services Manager Andrew Cairns. When asked about the prospect of doing more work for children with JIA, he said: 'Many children with JIA live in regional and rural areas and we want to give them the chance to attend a camp and experience the benefits without having to travel to the Sydney region.'

Therefore, additional camps are being proposed. Camp Footloose will be held in late September 2019 and again in April 2020 a regional or rural setting to address that community's needs. Camp Twinkletoes will be held in November 2019 at regional or rural venue and in May 2020 in the Sydney area.

To help fund the expanded children's camps program, Arthritis NSW has opened the Kids Get Arthritis Too Appeal for 2019. If you would like to support these wonderful camps you will find a donation form in this issue of *Arthritis Matters*.

Rural health is here to stay



Thank you to those generous donors who gave to the Arthritis NSW Rural Health Appeal at Christmas 2018, which raised almost \$19,000 to fund our rural health events in 2019.

Due to the success of last year's Rural Health Initiative, it is now one of our permanent programs. The Rural Health Program will commence in FY2019/2020 with four events per year. Two events will be held in 2019 and two further events are planned for early 2020.

Arthritis NSW is looking forward to developing these events to maximise our audience reach in rural and regional NSW. Once we have finalised the locations and dates, the details will be available on our website: arthritisnsw.org.au, our social media platforms and in our eNewsletter.

New Bequest Program

Arthritis NSW has created a Bequest Program to launch on July 1.

Business Development Manager Joanne Boik said the program would invite selected regular donors to join

and commit to a future legacy.

'We are putting together a bequest program by invitation that honours the legacy of the man who founded Arthritis NSW in 1967, Mr Bruce Williams,' Joanne said. 'The invitation pack will include a registration card and request to the donor to notify

Arthritis NSW of their intention to include the organisation in their Will.'

Those who accept the offer to join the program will receive invitations to special events where they will meet the Arthritis NSW Board of Directors, President and CEO.

Forging links with retirement villages

With demand for our health education increasing daily, Arthritis NSW is continuing to build alliances with retirement villages in the Sydney area and will soon be making headway into villages on the north and south coasts.

Since March, our Health Service Manager Andrew Cairns and Business Development Manager Joanne Boik have visited three retirement villages: Huon Park Village, The Landings at North Turramurra and Nelson Grove – Pemulwuy.

At Nelson Grove, Andrew delivered our *Managing Arthritis* presentation to staff and residents which include members of our Holroyd Support Group. Thanks to this link, the village is considering offering its facilities to the group for their meetings. Ultimately, Arthritis NSW hopes to use the village facilities to benefit residents by running our Strength & Balance classes there, and guide residents living with arthritis to self-manage their condition. As more support group members transition to

retirement villages, we can bring the self-management lifestyle to them.

Joanne provided the audience with information on Arthritis NSW and the services and programs we provide. As Nelson Grove is a new Lend Lease property, we are hoping, through this connection, to extend our visits to other Lend Lease villages.

Support groups grow their membership



Two members of the Macarthur Support Group at their community garden in the grounds of the Campbelltown Library. The group grows vegetables and flowering shrubs on raised beds and have the choice of distributing them among their members or selling their produce to raise money.

Many of Arthritis NSW's support groups are actively recruiting new members personally as they share their common interests and experiences with each other. This year to date, Business Development Manager Joanne Boik has visited 12 groups to share our latest program developments and stay in touch with these valuable people who provide our connections with local

communities. The groups visited were: Holroyd, Bathurst, Woy Woy, Newcastle, Macarthur, Hawkesbury, Long Jetty, Warilla, Cowra, Parkes, Penrith and Maitland. Thank you to these groups for your warm welcome and hospitality.

The Macarthur Support Group meeting featured a trainer from the Guide Dogs NSW, a local person who spoke on the benefits of having

a therapy dog for people who are living with arthritis. The Macarthur group has 21 members who hold their meetings in the Campbelltown Library, which has also given them the use of their grounds to establish a community market garden.

Joanne Boik
Business Development Manager
Arthritis NSW

COMMUNITY GROUPS

Our community group presentation program has gained traction with Andrew Cairns and Joanne Boik speaking to more than

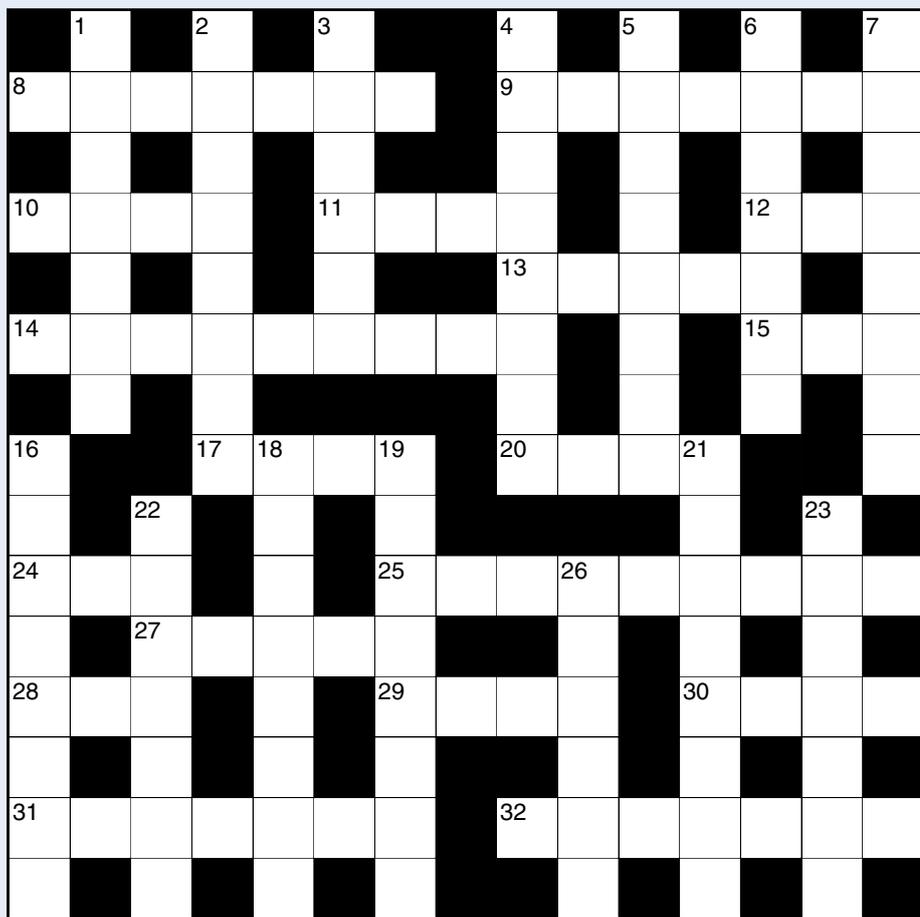
500 people attending seven events this year to date. They were: Seniors Week at the Hills Shire Council, Sutherland Shire Council local residents, The Friendship Space at Warringah Library, The Assyrian Women's Group at Fairfield, the

Turramurra Nursing Home residents and carers, the Probus Club at Minto and the Avoca Lions Club.

Call us on 02 9857 3300 if you are a member of a group who would be interested in a presentation.

Crossword

In this issue, the answers to some of the crossword clues relate to the article on page 16 *Are you at risk of osteoporosis?* For more information on osteoporosis, visit our webpage: arthritisnsw.org.au/osteoporosis



© Lovatts Puzzles

DOWN

1. Remedy for all ills
2. Scampered
3. Biceps or triceps
4. Rheumatoid arthritis is just one of several chronic ... that can impact on your bones' wellbeing
5. Hip and leg pain caused by nerve damage
6. Harmonious
7. Lack of strength, as bones may have in older individuals
16. It occurs at around 2% per year for several years following menopause (4, 4)
18. Inability to sleep
19. Comprehensive
21. Forward movement
22. Excessive intake of this can be a contributing factor to poor bone health

23. A bone ... scan may result in a diagnosis of osteoporosis
26. Pulsates

ACROSS

8. The loss of this mineral from bones is a primary reason why osteoporosis symptoms develop
9. Incorporate
10. Scalp growth
11. Protective custody
12. Writing fluid
13. Room within roof
14. Inhabitants
15. Grow older
- 17.. To optimise your bone health, keep your ... full of nourishing food and with plenty of 8 across
20. Break sharply

24. Surgeon's instruction, ... by mouth
25. Women are more likely to develop osteoporosis due to the rapid decline of ... levels after menopause
27. Group of singers
28. Sign of the zodiac
29. Remaining
30. 31 across and 32 across can both be considered as ... factors for osteoporosis development
31. This habit has been shown to directly harm your bone health
32. Studies suggest that the hormones associated with this may affect the state of your bones



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 www.arthritisnsw.org.au/support-us/planned-giving-bequests/

STIR THE POT

It's the season to enjoy delicious warming soups and here are four anti-inflammatory soup recipes packed with vegetables for you to try this winter.

Cream of broccoli soup Serves 4

Ingredients

- 1 tablespoon extra-virgin olive oil
- 1 small onion, chopped
- 1 celery rib, chopped
- 1 teaspoon salt
- ½ teaspoon garlic powder
- ½ teaspoon onion powder
- ¼ teaspoon ground white pepper
- 1/8 teaspoon celery seeds
- Eight cups (700g) broccoli florets, divided
- Four cups (425g) cauliflower florets
- 3 cups chicken broth
- 1 cup milk of choice

Instructions

1. Heat the olive oil in a large stock pot set over medium heat. Add the onion, celery, salt and pepper and cook until slightly softened and fragrant, about 3 minutes.
2. Add the garlic powder, onion powder, celery seeds, about seven cups of the broccoli florets, all of the cauliflower florets and chicken broth; cover loosely and cook until the cauliflower and broccoli florets are fork tender, about 8–10 minutes.
3. Ladle about half the soup into a high-speed blender; process until smooth and creamy and transfer to a clean container. Repeat with the rest of the soup.
4. Return soup to the stock pot; chop the remaining cup of broccoli florets finely and add to the soup, with the cup of milk. Stir, bring back to a simmer over medium heat, then serve promptly.

Source: Thehealthyfoodie.com

Lebanese lentil soup Serves 4

Ingredients

- 1 tablespoon olive oil
- 1 medium onion diced
- 2 medium carrots peeled and diced
- 3 stalks celery diced
- 4 cloves garlic minced
- 2 teaspoons cumin
- 2 teaspoons cinnamon
- 1 cup brown lentils uncooked
- 4 cups chicken broth low sodium
- 4 cups water
- 1 lemon juiced
- Salt and pepper to taste
- 8 cups spinach

Instructions

1. Heat oil in a large soup pot over medium-high heat. Add the onions, carrots and celery and cook until tender, about 6–7 minutes, stirring frequently. Season with salt and pepper.
2. Stir in the garlic, cumin and cinnamon. Heat until fragrant, about 30–60 seconds. Add lentils to the pan and heat 1–2 minutes to slightly toast. Pour in the chicken broth, water and lemon juice then bring pot to a boil. Reduce heat to low and simmer until lentils are tender, about 30–45 minutes.
3. Right before serving, stir in the spinach and cook until bright green and wilted, about two minutes. Season with additional salt, pepper and lemon juice to taste before serving warm.

Source: thelemonbowl.com

Black bean soup Serves 4

Ingredients

- 1 tablespoon canola oil
- 1 small onion, chopped
- 1 tablespoon chili powder
- 1 teaspoon ground cumin
- 2 450ml cans black beans, rinsed
- 3 cups water
- ½ cup prepared salsa
- ¼ teaspoon salt
- 1 tablespoon lime juice
- 4 tablespoons reduced-fat sour cream (optional)
- 2 tablespoons chopped fresh coriander (optional)

Instructions

1. Heat oil in a large saucepan over medium heat. Add onion and cook, stirring, until beginning to soften, 2–3 minutes. Add chili powder and cumin and cook, stirring, 1 minute more. Add beans, water, salsa and salt. Bring to a boil; reduce heat and simmer for 10 minutes. Remove from the heat and stir in lime juice.
2. Transfer half the soup to a blender and puree (use caution when pureeing hot liquids). Stir the puree back into the saucepan. Serve garnished with sour cream and coriander, if desired.

Source: Eatingwell.com

Roasted butternut pumpkin apple soup Serves 4

Ingredients

- 4 tablespoons extra-virgin olive oil, divided
- 1 butternut pumpkin, peeled and cut into ½-inch pieces (about 6 cups)
- 2 red, sweet apples, cored and cut into ½-inch pieces (about 4 cups)
- 1 small onion, chopped
- 1 celery rib, chopped
- 3 cups low-sodium chicken or vegetable stock
- 1 cup water
- ¼ teaspoon ginger
- ¼ teaspoon nutmeg
- ¼ teaspoon cinnamon
- Salt and pepper to taste

Instructions

1. Preheat oven to 400 degrees.
2. Place the diced butternut pumpkin on one sheet pan and the diced apple on a second sheet pan.
3. Season pumpkin with 1½ tablespoons olive oil and a sprinkle of salt and pepper. Stir to get everything coated. Season apple with 1 tablespoon olive oil and stir to coat.
4. Roast pumpkin and apple for 25–30 minutes, until tender and browned.
5. Meanwhile, heat remaining 1½ tablespoons olive oil in a large stock pot over medium heat.
6. Saute onion and celery for 6–8 minutes, until tender. Season with a pinch of salt and pepper.
7. Add chicken or vegetable stock and water and bring to a simmer.
8. Once the pumpkin and apple are roasted, add to the pot. Add ginger, nutmeg and cinnamon.
9. Blend the soup until smooth.
10. Season to taste with additional salt and pepper.
11. Serve with topping of roasted pumpkin seeds or finely diced raw apple.

This soup thickens as it sits, so if you want a thinner soup, stir in some more chicken or vegetable stock or water to get it to your desired consistency. This helps when reheating any leftovers, too.

Source: Familyfoodonthetable.com

Settling into the JIA journey

Four families who attended Camp Twinkletoes in May share their stories on how juvenile arthritis became part of their lives.



Amelia

Amelia, 6, was diagnosed with juvenile idiopathic polyarticular arthritis when she was 17 months old. The condition progressed from her knees to her wrists, ankles and fingers.

'I first knew something was wrong when Amelia was 16 months old

and couldn't straighten her legs in the morning,' said her mother Lisa. 'She couldn't walk properly, cried all day and all night and couldn't play with her friends or at the park anymore. She always had temperatures between 38–39 degrees, sometimes higher. But most of all, it was the constant pain my poor baby was going through.

'I took Amelia to five different doctors and was told it was a viral infection or it was behavioural and would pass. One GP sent us to a paediatrician at John Hunter Hospital. We didn't get any answers, but as we were leaving the hospital, Amelia had a seizure. She was admitted for three days with blood tests, neurological testing and much more. On the third day Dr Jeffrey Chaitow saw us and told me that Amelia had juvenile arthritis. Her seizure was a febrile seizure from the undiagnosed inflammation throughout the body.

'Since then, Amelia has been trialled on five medications. She went into remission after a few months on methotrexate, naproxen and prednisone. However, the side effects were too much for her. Another medication worked very well for two years and she was in remission. Unfortunately, Amelia began to develop chronic iritis and her medication changed again.

'Amelia missed a lot of daycare. The constant fevers meant she was sent home a lot. At school, she isn't as fast or as able to climb on equipment as her friends – this limits her playtime which upsets her. Sports day is hard when she is having a flare up or if she has had a big week. Amelia has anxiety from the pain her new needle causes. She loves dancing although she complains of pain after most lessons, and swims two days a week which helps her arthritis.'



Harry

Harry, 4, was diagnosed with polyarticular juvenile arthritis just after his third birthday in March 2018. Arthritis has affected joints in his fingers, wrists, knees and ankles.

Harry's mother Lisa said she noticed something was wrong while on a family holiday at the

beach. 'We noticed Harry was limping, and he had swollen fingers, knees and ankles. He couldn't hold hands because he couldn't bend his fingers and he began to complain that his legs were too sore to walk in the morning. Also, he just wasn't himself, he lost confidence, he didn't want to play on playground equipment, he wouldn't go on waterslides or in the ocean.

'Our GP sent us straight to a paediatrician who arranged for blood tests which revealed that Harry had arthritis. The GP then sent us to Westmead Children's Hospital and they were wonderful. Once the rheumatology team examined Harry they were certain it was polyarticular juvenile arthritis. We also saw an occupational therapist who gave us stretches and ideas for playing with certain toys to help Harry to exercise his fingers and wrists.

'Once a diagnosis was made, Harry was put on prednisone, naproxen and added methotrexate a few months later. He also had steroid injections for his wrists, knees and ankles. He has coped well with these injections and always wakes up very happy after the procedures. It was a struggle to get him to take medications in the beginning but very quickly it became part of the routine.

'Harry lives a very active life, he goes to preschool, he swims, he takes part in a multi-sport program, he loves going to different parks and playgrounds and enjoys riding his bike and scooter with his older brother Matthew. Arthritis only affects Harry's confidence when he's having a flare up but he rarely complains of pain.

'On family outings we think about how much walking is required and make time for regular breaks. We also time our meals to coincide with medication times and always make sure Harry eats enough as the medication can cause an upset stomach.



Brydee

Brydee, 2, was diagnosed in October 2017 with polyarticular arthritis, when she had just turned one. Her ankles, knees, wrists, elbows and fingers have been affected. Brydee's mother Lauren shares her story.

'When Brydee was about nine months old she started to try and walk. Shortly after that we noticed that she couldn't bear any weight on her right leg and her knee was swollen. Her legs started to become stiff in the mornings and she seemed really unsteady when trying to stand up and cruise around. She started crying through the night as she was in pain and would become very upset when we tried to change her nappy or try to dress her.

'It took three months to get a diagnosis. We took her to different hospitals where doctors told us that she had just banged her knee and she would be fine, but it only got worse. I even asked one doctor if it was juvenile arthritis and he told me to stop googling her symptoms and that it definitely wasn't arthritis. We took her to a physiotherapist and orthopaedic surgeon who had no idea what was wrong. We took her to John Hunter Hospital where they told us she had reactive arthritis and that it would be gone in two weeks. Two weeks later, a local paediatrician told us more results had come back from Newcastle and that it was not reactive, and was in fact juvenile arthritis. A week later we travelled to Sydney to see Dr Davinder and Anne Senna who confirmed her diagnosis.

'We believe that because Brydee has had so many medical appointments, some have been quite upsetting for her, she seems to be more clingy in unfamiliar settings than other children.

'Brydee does ballet lessons, swimming and loves kicking and catching balls. Because of her condition we make sure that whenever we are travelling somewhere, we have lots of stops so that her knees don't get too stiff.'



Christian

Eight-year-old Christian was diagnosed with systematic idiopathic juvenile arthritis (SIJA) in February this year. His mother Rhiannon said she noticed in early 2018 that Christian had neck pain. 'No one could work out what was causing the pain so it was put down to his cerebral palsy,

however in November Christian's neck pain returned along with a lump on his forearm.

'Christian was diagnosed with osteomyelitis in his neck and shoulder. After surgery he spent most of Christmas in hospital on antibiotics and was sent home with antibiotics infused via a pump. Three weeks later he was back in hospital with a lump in his shoulder, where he also developed a rash along with a 40-degree temperature, and pneumonia.

'Two weeks into his hospital visit he was helicoptered to Randwick Children's Hospital, put into ICU, intubated and kept heavily sedated as he was in septic shock. After many tests we were finally told that he had developed Macrophage Activation Syndrome, a rare and life-threatening medical condition that often occurs with SIJA. He was sent home a month after arriving at Randwick.

'He has up and down days. He missed the first half of first term at school. He really struggled being away from everyone while in hospital and having to learn how to walk, eat and drink all over again after being in ICU. He was very glad to be back at school with all his friends. He is taking things day by day, getting back into routine and normality.

'Christian being in hospital was the hardest time for the family. Our family looked after our two other children, aged 5 and 6, while we were both at hospital, then we split time between us. 'Christian is very close to his siblings and it was really hard on them while he was being diagnosed. We try to keep them involved in the process to help them understand and feel included because it's been hard for them to understand why Christian has been getting so much extra attention.'



Families can help ease the

The onset of arthritis brings physical limitations and impacts your ability to work and socialise. Invariably, one partner will take on more physical and financial responsibilities to manage the family. These lifestyle changes can cause stress and frustration, but a unified family strategy of understanding and patience will keep everyone working together.

Arthritis affects 1 in 5 Australians, rising to 1 in 3 over the age of 65. The pain of arthritis can vary in intensity. According to Arthritis NSW Health Services Manager Andrew Cairns, pain is a message that travels from a specific trigger, for example, your osteoarthritic knee, to the brain. 'The brain, simply put, acts like a volume dial that can turn the severity of the pain up or down, based on a complex assortment of factors like beliefs, attitudes and memories etc. For example, stress, anxiety and boredom can turn the pain volume up, while focused activity such as a favoured hobby or exercise can turn it down,' Andrew said.

'Importantly, physical activity such as walking doesn't harm the damaged joint and is the best way of turning the pain volume down. Warm water exercise is also great for soothing and supporting your body and offers resistance to your movements so it helps you build strength as well.

'You can also make changes to your diet to improve your arthritis. Your intake of foods high in trans and saturated fats, such as pies, biscuits and fried food, will influence your weight and the stress load on your knee joints for example. However, research has found that foods high in



pain of arthritis

monounsaturated fats, such as olive oil, canola oil, sunflower oil, avocados and many nuts and seeds may reduce disease activity in rheumatoid arthritis.'

Family support

Your family is an important part of your support network as they can encourage your priorities to eat a balanced diet high in healthy fats, and to exercise. They can also act to boost their understanding of arthritis and its impacts on you. Below are some suggestions from [verywellhealth.com](https://www.verywellhealth.com). Ask your loved ones to read them and think about adopting one or more of them.

Be willing to learn: Read a book or online article to understand the challenges faced by a person with arthritis, such as pain, fatigue, stiffness, swelling and treatments.

Don't assume you know: Arthritis is unpredictable and you can't assume you know how the person is feeling. Just because they are not visibly in pain, it doesn't mean they are not suffering silently.

Be a good listener: If a person with arthritis views a family member as a confidante, they will share their emotions about their condition. Listen to them and they will tell you what they need.

Be adaptable: Arthritis demands adaptability from everyone in the family. If you were to graph their good days and bad days, it wouldn't be a straight line. Be willing to ride those bumps too.

Go to doctor appointments: Ask if you can accompany them to their doctor's appointments. This shows your support and lets you raise questions and hear the responses directly from the doctor.

Join a support group: Participate in an arthritis support group. The interaction will offer you broader understanding, as not all people have the same symptoms, treatments, or cope the same way.

Offer unconditional love: Offer the same unconditional love you would if they didn't have arthritis. They may have new limitations and different needs, but relationships must remain constant.

Create understanding: If they have ever told you 'you don't understand what arthritis is like', have a frank conversation about where they feel you miss the mark. Work to create understanding.

Don't be overprotective: Though people with arthritis have limitations imposed by the disease, they still can do a lot. Don't shrink their world by being overprotective.

Communicate how their arthritis affects you: Discuss the impact their disease has on you. There is a very real impact on you if you are close and it should not be disregarded. They need to listen to you as much as you need to listen to them.

Source: [verywellhealth.com/arthritis-tips-for-family-and-friends-190425](https://www.verywellhealth.com/arthritis-tips-for-family-and-friends-190425)

One hour walking a week could prevent disability



According to a study published in the *American Journal of Preventive Medicine*, just one hour a week of brisk walking can stave off disability in older adults with osteoarthritis.

A report of the study, published in sci-news.com stated that an estimated 14 million older adults in the United States had symptomatic knee osteoarthritis, which is the most common form of osteoarthritis. About two in five people with osteoarthritis develop disability limitations.

The lead author of the study, Northwestern University's Professor Dorothy Dunlop, said that the study aimed to see what kind of activity would help people remain free of disability.

Professor Dunlop and colleagues analysed four years of data from more than 1,500 adults in the National Osteoarthritis Initiative from Baltimore, Pittsburgh, Columbus and Pawtucket, Rhode Island.

The adults all had pain, aching or stiffness in lower extremity joints from osteoarthritis but were free of disability when they began the study. Their physical activity was monitored using accelerometers.

The team found an hour of weekly moderate-to-vigorous physical activity allowed older adults to maintain their ability to perform daily tasks such as getting dressed or crossing a street before a traffic light walk signal changed.

Reduced disability risk

The weekly hour of exercise reduced their risk of mobility disability, such as walking too slowly to safely cross a street or at a rate of less than one meter per second, by 85 per cent. It also reduced their risk of daily living disability (difficulty performing morning routine tasks such as walking across a room, bathing and dressing) by almost 45 per cent.

Four years after the start of the study, 24 per cent of adults who did not get the weekly hour of brisk physical activity were walking too slowly to safely cross the street, and 23 per cent reported problems performing their morning routine.

'This is less than 10 minutes a day for people to maintain their independence. It's very do-able,' Professor Dunlop said. 'This minimum threshold may motivate inactive older adults to begin their path toward a physically active lifestyle with the wide range of health benefits promoted by physical activity.'

US Federal guidelines recommend that older adults with arthritis participate in low-impact activity.

For health benefits such as reducing the risk for heart disease, these guidelines recommend older adults participate in at least 2.5 hours a week of moderate-intensity activity.

'But that level of activity can be daunting for inactive older adults with lower extremity pain,' Professor Dunlop said. 'We hope this new public health finding will motivate an intermediate physical activity goal. One hour a week is a stepping stone for people who are currently inactive. People can start to work toward that.'

Dorothy D. Dunlop et al. One Hour a Week: Moving to Prevent Disability in Adults With Lower Extremity Joint Symptoms. *American Journal of Preventive Medicine*, published online March 20, 2019; doi: 10.1016/j.amepre.2018.12.017

Source: sci-news.com/medicine/brisk-walking-osteoarthritis



Professor Davinder Singh-Grewal talks to parents at Camp Twinkletoes 2019.

Working with our champions

Arthritis NSW works with a number of senior health professionals who champion our programs. Thanks to these relationships, more people living with arthritis can access information and services that help them find freedom from arthritis.

One of our champions is Professor Davinder Singh-Grewal, a paediatric rheumatologist of 22 years' experience.

'Professor Singh-Grewal is one of a small number of paediatric rheumatologists in NSW who work to diagnose and treat an estimated 3000 children with juvenile arthritis (JIA) throughout the state,' said Arthritis NSW Health Services Manager Andrew Cairns. 'He is a regular speaker at our children's camps and has referred many of his JIA patients to Camp Twinkletoes and Camp Footloose.'

Inspired by families

Professor Singh-Grewal said that he chose his field because he worked with paediatric rheumatologist of 30 years Dr Jeffrey Chaitow when he was a young doctor in training. 'I was inspired by the range of the conditions

Jeffrey treated and the fantastic children and families that he worked with,' Professor Singh-Grewal said.

'I refer my patients to the Arthritis NSW camps because they provide an opportunity for young people with arthritis to come together and enjoy each other's company in an environment where they feel safe and supported. I think the experience helps them build the skills of self-reliance and confidence which helps them in their everyday lives. Camp Twinkletoes also involves parents and helps them build support networks.'

Media spokesperson

Professor Singh-Grewal acted as our media spokesperson with ABC TV last year to highlight the social benefits of attending Camp Footloose. 'I had a lot of feedback from not only patients and their families but also the general public who saw the story on the ABC. So I think the opportunity to showcase the camps helped build awareness of JIA within the general public. Hopefully, this will lead to improved resources for children with JIA and their families,' he said.

Medical voice

Professor Singh-Grewal is also a Director on the Arthritis NSW Board. 'My role is to be a medical voice on the Board and I work to direct research to ensure that Arthritis NSW's services, including the children's camps, are delivered in line with best practice internationally and so will provide the most benefit for our members,' he said. 'This is a process of continuing improvement and we are always looking for feedback from Arthritis NSW members to help improve service.'

Professor Singh-Grewal is appointed at the Children's Hospital at Westmead, Sydney Children's Hospital at Randwick and John Hunter Children's Hospital in Newcastle. He is a Clinical Associate Professor at both the University of Sydney and University of New South Wales. He has completed a PhD in the field of Juvenile Arthritis and also a Masters in Medical Science.

Lindy Sivyer

Marketing & Campaigns Coordinator
Arthritis NSW



August 2019

Kidsflix: Toy Story 4 tbc
August 10, Ballina Fair Cinema

Kidsflix: Angry Birds Movie 2 tbc
August 18, Hoyts Moore Park

September 2019

Camp Footloose
(date and venue to be confirmed)

November 2019

Camp Twinkletoes regional
(date and venue to be confirmed)

Kidsflix: Playmobil tbc
November 2, Odeon Orange
November 9, Hoyts Penrith
November 23, Hoyts Charlestown

December 2019

Kidsflix: Frozen 2 tbc
December 7, Hoyts Chatswood

Warm water exercise

Classes operate during the NSW Public School term. The following class times are subject to availability. To register your interest, visit our website at arthritisnsw.org.au/warm-water-exercise to complete and submit the form or call us on 02 9857 3300.

Canterbury Hospital, Campsie
Monday 12.00pm (women only)
Wednesday 1.30pm

Mowll Village, Anglican Retirement Village, Castle Hill
Monday 1.30pm
Tuesday 1.30pm and 2.30pm
Thursday 1.30pm and 2.30pm

Karonga School, Epping
Saturday 8.00am

Lane Cove Physiotherapy, Lane Cove
Tuesdays 1.30pm
Wednesdays 12.30pm
Thursdays 5.00pm

St Lukes Hospital, Potts Point
Wednesday 12.30pm
Saturday 9.00am
Saturday 10.00am

Royal Rehab, Ryde/Putney
Tuesdays 4.00pm and 5pm
Saturdays 10.00am

Physical Therapy, Wollongong
Mondays 10.00am
Wednesdays 6.00pm
Fridays 10.00am

Strength & Balance

Epping YMCA, Epping
Mon and Wed 10.00am
Mon and Wed 11.00am

North Sydney Community Centre, North Sydney
Tues and Thurs 2.00pm

Volunteer

Arthritis NSW is grateful for the support of our wonderful volunteers who help us deliver our services and keep our office running smoothly. We are always keen to hear from people interested in volunteering with us, particularly in the following areas:

- fundraising activities
- keeping our database up to date
- phoning members, support groups and branches to update our records
- helping at Camp Twinkletoes and Camp Footloose
- helping with Kidsflix registration and check in.

Please call us on **02 9857 3300** if you are interested in helping us in any of these areas.

Crossword solution



Find help, guidance and support through our local networks

Location	Who to Contact			Meeting Place	Meeting schedule
Bathurst	SG	Nelma	0431 829 709	Bathurst RSL, 114 Rankin St, Bathurst	2nd Thursday 10am
Corowa	SG	Heather	02 6033 4393	Challenge Enterprises, 93 Guy St, Cnr of Redlands Rd, Corowa	1st Wednesday 130pm
Cowra	SG	Christine	0427 423 596	Upstairs, Calare Building, 103 Kendal St, Cowra	1st Tuesday 2pm
Dubbo	SG	Heather	02 6887 2359	Macquarie Club, 313 Macquarie Street, Dubbo	2nd Thursday 10am
Hawkesbury	BR	Julienne	02 4574 1928	Windsor Library, 300 George St Windsor	3rd Tuesday 10am
Holroyd/Merrylands	BR	Michelle	02 9631 7363	Merrylands RSL 14 Military Rd in the coffee shop	4th Wednesday 10am
Kincumber	SG	Jeanette	0418 226 891	Brentwood Village Auditorium, Scaysbrook Dr, Kincumber	4th Friday 10am
Long Jetty	SG	Liz	02 4332 5245	Nareen Gardens Retirement Village, 19 Bias Avenue, Bateau Bay	1st Thursday 10am
Macarthur	SG	Beth	0407 265 419	Campbelltown Library, Hurley St, Campbelltown	1st Wednesday 10am
Maitland District	BR	Veronica	02 4966 4649	East Maitland Bowling Club, New England Hwy, East Maitland	1st Thursday 10am
Newcastle	SG	Judy	02 4088 3146	Mayfield Ex-Services Club, 58 Hanbury St, Mayfield	3rd Monday 1pm
Nowra	SG	Gary	02 4423 3633	Café Continental, 3 Stewart Place, Nowra	1st Thursday 10am
Parkes	SG	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	BR	Jan	02 4722 5940	CWA Rm, Cnr Tindale St & Castlereagh St, Penrith	2nd Wednesday 930am
Ryde	SG	Doris	02 9817 7470	Ryde-Eastwood Leagues Club, Ryedale Rd, West Ryde	4th Thursday 1pm
Wagga Wagga	SG	Lorraine	02 6926 3203	Rules Club, Cnr Fernleigh & Glenfield Roads, Glenfield Park	1st Thursday 1pm
Warilla/Shellharbour	BR	Sheila	02 4296 1340	Warilla Bowling Club, Jason Ave, Barrack Heights	3rd Thursday 1pm
Woy Woy	SG	Heather	0423 017 450	Ettalong Bowling Club, 103 Springwood Street, Ettalong	3rd Tuesday 1030am

BR – Branch **SG** – Support Group

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



Arthritis & Osteoporosis

NEW SOUTH WALES

www.arthritisnsw.org.au

Arthritis & Osteoporosis NSW
Locked Bag 2216
North Ryde NSW 2113

Authority to fundraise CFN12845
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Arthritis Infoline: **1800 011 041**
Phone: **02 9857 3300**
Fax: **02 9857 3399**

Sign up for our monthly eNewsletter: eepurl.com/9rFd5
Facebook: facebook.com/ArthritisNSW