arthritis matters

ISSUE 47 | OCTOBER 2021





The Eyes Have It!

In this issue of *Arthritis Matters*, we are looking at things to do with looking. Arthritis can affect our eyes causing unpleasant symptoms in and/or damage to these incredible organs.

Here are a few facts to ponder, if painful eyes were an issue:

- The giant squid has the largest eyes in the animal kingdom at 25.4cm (that is a lot of redness)
- Dragonflies have more than 28 000 lens per eye (which could mean a lot of blurriness?)
- Ostriches would have a lot to squawk about, their eyes are the biggest of any land animal, (bigger than their brains, so maybe they won't notice!)
- Geckos have no eye lids, instead of blinking, they lick their eyeballs (yum).
- Proportionally, tarsiers (little primates) have the largest (all the better to see you with) and,
- most spiders have eight eyes (all the more 'yous' to see ... sorry!)

Our eyes are amazing. They:

- Contribute up to 85% of our knowledge of the world;
- Have approximately 2 million moving parts;
- Transmit 10 million 'bits' of information per second to the brain:
- Can distinguish 10 million colours

 including five hundred shades of grey:
- blink 10 thousand times each day, approximately;
- have on average 120 lashes, over a lifetime measuring nearly 30m if laid end to end.

There are many good reasons why we should look after our eyes.

For more information on how arthritis can affect the eyes, see pages 4 and 5.

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Please let us know if you prefer to receive your copy by email.



19A Main Road, Moonah TAS 7009

Tel: 03 6228 4824

Email: info@arthritistas.org.au

www.arthritistas.org.au

ARTHRITIS INFOLINE: 1800 011 041

Welcome to our New Rheumatologists

Our organisation seizes every opportunity to lobby for increased access to specialist rheumatology services for all Tasmanians and will continue to do so, especially given the lack of access to public rheumatology services in the north and north-west regions. Whilst we were dismayed to learn of the departure of two of our Specialists in these COVID-19 times, we were buoyed to learn that two new Rheumatologists have taken up practice in Hobart earlier this year. We warmly welcome Drs Emma Mitchell and Mat Reynolds.



EMMA MITCHELL, a graduate of the University of Tasmania, trained in Rheumatology in Hobart and Melbourne.

Prior to returning to Hobart earlier this year, Emma worked as a consultant in Rheumatology and general medicine in country NSW.

She is excited to be back in

Tasmania, working as a staff specialist in Rheumatology at the Royal Hobart Hospital and privately at Hobart Cardiology and Medical Specialists. Emma is interested in all aspects of Rheumatology, and in her spare time, enjoys trail running.



MAT REYNOLDS Having grown up in country Victoria, Mat Reynolds recently returned to Australia from NZ and currently works as a staff specialist in Rheumatology at the RHH, as well as privately in Suite 5, Hobart Private Hospital.

He has a particular interest in inflammatory diseases of the spine and is currently training in bedside

ultrasound to incorporate this into his rheumatological practice.

When not working, Mat can be found at the gym and having been on a significant weight-loss journey himself, is keen to engage patients in exercise as part of their treatment programme.



Vale Rob McQuilkin

ROBIN 'ROB' MCQUILKIN was a much loved and respected volunteer at Arthritis & Osteoporosis Tasmania. After retiring as Biochemist in Charge at Hobart Pathology, Rob looked for volunteering opportunities and

became a valuable addition to our InfoLine team. Covering the Wednesday morning shift for 13 years, Rob could always be counted upon for a robust discussion and analysis of recent research findings or topical events.

He retired from volunteering in December 2016 and was awarded Honorary Life Membership in 2017 for his dedicated service. Rob passed away peacefully in May 2021.

DONATIONS

As a small non-profit association donations are a crucial part of our overall funding, and we sincerely thank the following individuals and organisations for their support:

DONATION IN MEMORY Late Irene Marston Late Geoffrey Parker **BEQUEST**

Late Brian McVeigh

A fond farewell to our long-term InfoLine Volunteer Jennie

JENNIE HUTT has recently retired after almost ten years of service to Arthritis & Osteoporosis Tasmania.

A dedicated volunteer, Jennie's broad range of skills and interests have been a huge asset to our little organisation.

A quiet achiever, possessing amazing attention to detail, Jennie kept our office organised and managed our inventory and stock control, in addition to her InfoLine duties. We very much appreciated her willingness to fill roster vacancies and to help with any task that was needed.

Supporting Tasmanians to better understand their condition and live well with their arthritis was Jennie's prime motivator. Callers to our office and the InfoLine were always met by her friendly, efficient, and understanding assistance.

Thank you, Jennie, for committing a decade of your life to voluntarily assisting our organisation in supporting Tasmanians living with arthritis. You are and will continue to be, greatly missed.



Annual Donor Appeal Raises \$17,500!

A huge thank you to all those people who supported our midyear donor appeal. Funds raised will remain in Tasmania and enable us to continue to provide free community information and support to Tasmanians living with arthritis, osteoporosis or related conditions.

It's still not too late to donate if you haven't already, and we now have our own QR code which if you hover over with your phone camera will take you to our secure donation page on the GiveNow donor portal.

Advocacy Update

A major issue on our advocacy agenda continues to be greater access to affordable public rheumatology and pain management services, particularly for those people with arthritis living outside the Greater Hobart Region. Our concerns have been raised with the new Minister for Health, the Hon Jeremy Rockliff MHA.

Access to hydrotherapy pools is also of concern, particularly as the Glenorchy KGV hydrotherapy pool has been closed for almost 18 months, whilst repairs are carried out by the owner, the Glenorchy City Council. Sadly, OneCare Ltd has recently advised us that it will be permanently closing the hydrotherapy pool at its Barossa Park Wellness Centre in Glenorchy due to the high operating costs.

CEO's message

Our Strategic Priorities for 2021-2024

The Board recently signed off on a three-year Strategic Plan 2021-2024. The development of the Plan was greatly informed by the feedback from Members and key stakeholders, through surveys conducted last year.

Arthritis & Osteoporosis Tasmania's vision continues to be that all Tasmanians with arthritis, osteoporosis, or related musculoskeletal conditions, have access to the best possible information, support and services available. Supporting the achievement of this vision are four strategic priority areas - Working Together, Advocacy & Influence, Information & Support, and Effective Organisation.

Central to the new Strategic Plan is the provision of information and support services for the 1 in 4 Tasmanians living with arthritis and related musculoskeletal conditions. Having access to current, evidence-based information on conditions and treatment strategies is vital for people to make informed decisions with the support of their healthcare team. AOT will be reviewing and improving its website, developing information resources to fill identified gaps, and identifying novel ways to increase community knowledge and awareness of the prevalence and impact of arthritis.

As a small not for profit organisation, with 2.9 FTE employees, working together is a vital component of the Plan. We not only depend on our dedicated team of volunteers but work collaboratively with a range of organisations and key stakeholders to plan and deliver services and extend our reach to all Tasmanians with arthritis.

Advocacy will feature strongly over the next three years, with AOT calling for increased access to affordable public rheumatology services for those residing in rural and remote areas, specifically in the northeast, northwest and central regions of Tasmania.

AOT will continue to work with Government to achieve the development of a Tasmanian Musculoskeletal Model of Care, which will improve referral pathways and access to care, and result in

efficiencies such as shorter waiting times for outpatient clinics.

All this would not be possible without an effective organisation and financial sustainability is fundamental to AOT's continued existence. AOT will be looking to grow its fee for service online training services for health professionals working with people with arthritis. This will not only provide increased revenue to sustain the organisation and

the provision of free community services, but also enhance arthritis knowledge and understanding among those health care providers delivering services to Tasmanians with arthritis and related conditions.

A copy of AOT's Strategic Plan can be downloaded from our website at https://arthritistas.org.au/wp-content/uploads/2021/07/AOT-SP-2021-24-FINAL-v1.0.pdf or phone 1800 011 041 and ask for a copy to be posted to you.

Feature article



Eyes and Arthritis

Eyes are complex organs that can be affected by advancing age, injury, disorders specific to them, unwanted medication side-effects, and also diseases of other systems in the body. Types of inflammatory arthritis are auto-immune conditions that can adversely affect the joints, and sometimes the eyes.

Why the eyes? This is because your eyes contain tissues/membranes made of collagen, a connective tissue, can be 'attacked' by some types of arthritis. These conditions include (but are not limited to) Psoriatic Arthritis, Rheumatoid, Reactive Arthritis, Polymyalgia Rheumatica, Lupus, Ankylosing Spondylitis and Juvenile Idiopathic Arthritis.

Eye-related symptoms in these conditions can include: pain, blurred vision, redness and swelling of the white part of the eye, tearing, irritation, extreme sensitivity to bright light (photophobia) and/or some cases 'floaters,' which are tiny spots or threads of collagen that drift through the field of vision.

Eye-related issues associated with (but not limited to) types of arthritis include:

Dry eye disease or keratitis sicca: occurs when tear production is not

adequate for the effective lubrication of the eyes - may lead to infection or scarring of the cornea, the clear layer of the eye in front of the iris and the pupil.

Scleritis: Refers to inflammation of the sclera, the white of the eye (which forms 80% of the eyeball). It is an indication that inflammation is out of control, not only in the eye but in the body as a whole.

Uveitis: Inflammation of the uvea, the vascular layer of the eye between the retina (the light sensing layer of the eye) and the sclera - note: in Juvenile Idiopathic Arthritis, uveitis may be silent (without symptoms). For more information on uveitis, see page 5.

Cataracts: These form when inflammation in the eyeball causes protein in the lens of the eye to clump together, causing vision to become cloudy or blurry and/or colours to fade, and makes night vision difficult.

Glaucoma: a group of eye conditions that can result in damage to the optic nerves and loss of vision. One symptom is seeing a rainbow-coloured halo around lights. May be caused by a build-up of pressure in the eye or by medications including corticosteroid treatment.

Peripheral ulcerative keratitis: a condition that involves inflammation and ulceration of the cornea (the clear layer of the eye in front of the iris and the pupil).

Retinal vascular occlusion: occurs when blood vessels leading to the retina become blocked (similar to what happens to arteries during a heart attack). It may present as sudden vision loss, like a veil closing over the eye or as a blind spot in the field of vision.

If you develop sore or red eyes, consult an optometrist or your GP, and if you have inflammatory arthritis and develop any eye issues do the same as a referral to an ophthalmologist and/or rheumatologist may be indicated.

If you are on medications for your arthritis including Plaquenil (Hydroxychloroquine – an anti-malarial drug) or Prednisone (a corticosteroid) be sure your optometrist knows.

Also, if as a result of arthritis you find it difficult to use eye drops, for the management of eye dryness in arthritis or Sjögren's Syndrome, speak to your pharmacist or an Occupational Therapist about alternative eye drop dispensers (that allow you to aim the hydrating product at your eyes rather than accurately aiming a dropper).

On Page 5, a local Ophthalmologist answers some of our questions about uveitis – its diagnosis, how it presents and its management.

Our Member Story, on page 9, relates to Sjögren's Syndrome, another condition that affects the eyes. Some fifty percent of people with this condition also live with a type of inflammatory arthritis. Our Member, Jennie shares some of her trials and her top tips for living with this challenging condition.



Our questions about Uveitis

- answered by Ophthalmologist
Dr Dean Cugley

WHAT IS IT?

Uveitis is a relatively uncommon condition, which relates to inflammation that occurs within the eye. It typically arises as a result of infection (especially in the setting of immune altering medications for other conditions), or from non-infectious auto-immune related inflammation. Less commonly it is due to medications or other conditions. Associated conditions include ankylosing spondylitis, psoriatic arthritis, lupus and rarely, rheumatoid arthritis. It is a serious cause of vision limitation in working-age people.

HOW IS IT DIAGNOSED?

Uveitis can be diagnosed by an Optometrist but most cases will involve an Ophthalmologist (a medical eye specialist). Diagnosis is arrived at through careful history and conducting an eye examination primarily with a slit lamp biomicroscope, as evidence of inflammation can be directly seen by the human eye with magnification. Inflammatory cells and protein within the eye can be seen. A thorough eye exam with dilating eye drops is needed to arrive at this diagnosis and determine its full extent.

WHAT SIGNS & SYMPTOMS NEED TO BE LOOKED OUT FOR?

The symptoms of uveitis can vary, depending on which part of the eye is primarily involved. By far the most common is anterior uveitis in which inflammation affects the front part of the eye and can present as a painful red eye, which is made worse in bright conditions. It may initially be treated as conjunctivitis, which doesn't respond to treatment. Less commonly, it can present with floaters and blurred vision, or other symptoms.

WHAT COMPLICATIONS CAN OCCUR AND WHAT DOES TREATMENT INVOLVE?

No specific preventative measures exist. Prompt diagnosis, identification of cause, screening for associated conditions /complications and focused treatment of the condition shortens the disease duration.

Complications, such as raised pressure in the eye, cataracts and retinal swelling (macular oedema), which can affect the vision, should also minimized with treatment. Treatment duration is usually 6 weeks or more, and include anti-inflammatory treatments (drops, tablets or injections) or

antibiotics if infection is suspected or proven. If the condition is persistent, immune-modifying treatments (i.e. methotrexate, mycophenolate, azathioprine, adalimumab etc.) may be needed to limit the side effects of anti-inflammatory (corticosteroid) treatments.

The condition may be long-term (aka chronic), recurrent and/or have flare ups. So, if there has been a previous episode of uveitis then any future red eye should be checked for this diagnosis and not attributed to other common causes, such as conjunctivitis.

TIPS & TAKE HOME MESSAGES:

- Any painful red eye, or red eye not improving with treatment requires assessment from an optometrist/ ophthalmologist
- Eye pain exacerbated by bright light (photosensitivity) can be a sign of uveitis
- Numerous related auto-immune conditions exist with uveitis, and immunosuppression for other reasons can increase the risk of infective causes
- Prompt treatment can prevent vision threatening complications
- Treatment usually involves corticosteroid drops, but may include tablets, injections or other treatments depending on the type and complications
- It can be an isolated one-off event, enter a long term phase or be recurrent in nature
- · It can affect one, both or alternating eyes
- It is typically a unique condition in each patient and is treated accordingly.

Our sincere thanks to Dean for taking the time to answer our questions about uveitis.

Image: An eye affected by uveitis.

DR CUGLEY is an Ophthalmologist, medical retina and uveitis specialist, and cataract surgeon. He is based at the Launceston Eye Institute and has an appointment at the Launceston General Hospital.

After gaining his medical degree from UTAS, Dean completed his resident years at St Vincent's Hospital in Melbourne. He then undertook Fellowship training at the Royal Victorian Eye and Ear Hospital and Centre for Research in Melbourne, and the Bristol and Moorfields Eye Hospitals in the UK.

When not at work, Dean enjoys spending time with his family and making the most of the great outdoors.

Research news

Seeing Feeling Red

For decades there was an urban legend within the anaesthetic community that people with red hair were challenging to anaesthetise. This has since been found to be true! On average, when undergoing painful procedures, redheads need up to 20% more anaesthetic than people with dark or blond colouring.

Researchers ascertained that the genetic mutation that results in red hair (or fur) is also involved in some central functions in the brain including pain processing and also the body's response to different types of pain medications.

Redheads have been found to be more sensitive to certain types of pain including thermal (response to hot and cold) pain, but less sensitive to electrically induced pain. But before you jump to the conclusion that red heads must be wimps, they have been shown to have the highest pain threshold across all of the hair colour groups. It just goes to show how complex pain science is.

Interestingly, they also have a higher incidence of some medical conditions including Parkinson's disease (being twice as likely to develop PD than people with black hair) and endometriosis (women with red hair are 30% more likely to develop this condition).

New research by investigators from the Massachusetts General Hospital in the States is providing further insights into why people with red hair perceive and experience pain differently. According to Dr Lajos V. Kemény, MD, PhD, these new findings "may lead to the identification of novel pain-modulating strategies."



The researchers also make the point that their study validates earlier evidence about pain thresholds and experiences by people with red hair, and they believe that other medical personnel need to recognise that the pain sensitivity in red heads may vary to that of people with other hair colours. They also suggest that people with red hair have a chat to their care team prior to having any potentially painful procedures.

Source: Science Advances (2021). DOI: 10.1126/sciadv.abd1310

Jelly on a joint

Wharton's 'Jelly' (substantia gelatinea funiculi umbilicalis – try saying that three times, fast) is a substance that coats the arteries and vein in the umbilical cord. The jelly-like mucous connective tissue cushions and insulates these blood vessels, protecting them from damage (such as kinking), thus ensuring the blood supply to the developing fetus.

Named for the English physician and anatomist Thomas Wharton (who first described it in his 1656 publication, Adenographia) the substance has been found to have significant regenerative potential, being rich in immature stem cells.

Researchers hope that an injection of these cells, derived from donated cord blood (so regarded as being ethically sourced), could stimulate the regrowth of cartilage in joints affected by osteoarthritis.

These cells are unlikely to be rejected like those taken from donated bone marrow and are a better option than a person's own stem cells, as the process to harvest and prepare these cells is uncomfortable and timeconsuming.

Research using the jelly is currently being trialled in a number of conditions including diabetes and traumatic brain injury. Several groups world-wide are looking at its use in arthritis. One study published in the *Macedonian Journal of Medical Sciences* last year reported that in rats, Wharton's Jelly halted damage to cartilage by blocking key enzymes involved in its degradation.

Clinical studies in humans have been small to date, with several centres currently commencing larger trials.

One such project, being conducted across several US hospitals, will see the jelly injected into the knees of study subjects. These people will



then be followed over twelve months with regular MRI scans to see if cartilage damage is stopped and pain assessments will be conducted to see if pain/discomfort is relieved.

If injections of Wharton's Jelly are found to be safe and effective, this procedure could reduce the need for total joint replacements in people with osteoarthritis (which are increasingly becoming recognised as being a less than an ideal solution to an increasingly big problem).

Source: Journal of Orthopaedic Surgery and Research: Article Number 143 (2021).

A Gut Reaction to RA Management

Could concentrating on the health of the gut be the next big thing in the treatment of inflammatory arthritis? Researchers from University College London believe so.

The gastrointestinal tract plays a critical role in our health - from influencing our mood, cognition and memory, to being implicated in the development and progression of conditions including depression, obesity and types of inflammatory arthritis including rheumatoid (RA) and psoriatic arthritis.

Now researchers are looking at the gut and its health as a potential way of positively influencing these conditions.

The University College research group identified that people with rheumatoid arthritis had blood markers indicating gut damage when compared to healthy controls, with these markers being higher the more the disease progressed. They were able to demonstrate that the lining of the gut had become 'leaky,' allowing bacteria to cross the gut lining into the body, potentially enhancing inflammation in the joints. They therefore identified the gut as offering an exciting therapeutic target for managing joint inflammation.

"Current treatments for rheumatoid arthritis don't appear to correct the problems in the gut and so may leave the patient susceptible to reactivation of disease from the continuing inflammation in that area" reported Professor Claudia Mauri, co-lead author from the UCL Division of Infection and Immunity. "Going forward, we need to evaluate the therapeutic impact of treating the intestinal lining of rheumatoid arthritis patients in addition to their joints. Maintaining gut health both through diet and pharmacological intervention may be a valuable new strategy."

Source: This study was published in Med, a Cell journal.

Image: Gut Microbes





Reacting to COVID-19

Corona viruses were first identified in humans in the mid-1960s. Initially, they were thought to only affect the respiratory system and there was little, if any, follow-up of patients. Recently, doctors have been presented with a staggering range of symptoms in people who have contracted COVID-19 and for many, ongoing medical issues will remain or emerge. The virus is still relatively new to us, but alarmingly evidence is pointing to a growing number of reports of reactive arthritis being associated with COVID-19. This offers a timely reminder that arthritis can develop as an unwanted 'side effect' of a viral or bacterial infection.

When the body is exposed to a virus or bacterium, our immune system mounts a defence. We can feel this 'battle' within, with symptoms such as fevers, chills, and aches and pain in places including our muscles and joints. This acute phase usually subsides and hopefully, the system clears the virus from the body. However, in some cases the immune system stays primed, still hunting for the 'bug' and mistakenly attacking healthy tissues of the body.

Reactive arthritis is a type that is caused by an infection. It causes pain/swelling or stiffness in joints, in tendons (tissues that join muscles to bones), and pain/redness in the eyes.

It is early days in terms of fully understanding the effects of COVID-19. What we do know is that it makes sense to do everything you can to reduce the risk of contracting and/or spreading the virus – for your general health and that of others and to reduce the risk of developing reactive arthritis.

When/if you can be vaccinated against a virus or bacterial infection (including the flu and COVID-19) do it for your joints (amongst other reasons).

For those who suffer from conditions that have pain, fatigue and malaise as symptoms, including fibromyalgia and chronic fatigue, COVID-19 may have a silver lining. The US Congress has given the National Institutes for Health (NIH) \$9b to better understand and find treatments for long-haul COVID.

The NIH has revealed an impressive, highly integrated approach involving immense databases, biorepositories and hundreds of researchers devoted to following, understanding and treating some 40,000 people suffering the devasting after-effects of this terrible condition (and informing our understanding of others).

Source: Medical News Today and Health Rising



Menzies Institute Musculoskeletal Team Research Update

Tasmanians can be justifiably proud of the research being undertaken in our state. We met with Associate Professor Dawn Aitken from the University of Tasmania's Menzies Institute for Medical Research to find out about current research and the results of recent studies. Dawn leads a team of 20 researchers (including PhD students) undertaking research focusing on improving our understanding of osteoarthritis, and its management.

"We know that Tasmania has the longest wait times in the country for elective surgery and we have the highest rate of prescriptions dispensed for opioid medicines per capita*." explained Dawn. "We are undertaking a program of work aimed at improving the non-surgical management of osteoarthritis. We are particularly interested in improving the management and outcomes for Tasmanians with knee and hip osteoarthritis." A snapshot of three research studies recently undertaken by the Menzies team:

1. A pilot study involving 17 GPs and 10 surgeons

RATIONALE: The recommended first-line treatments for knee and hip osteoarthritis include education and exercise, and weight management where indicated. Yet they are underused. We know that invasive, expensive, and sometimes harmful and ineffective surgical procedures are commonly used to treat OA. Joint replacement surgery is advised only when all non-surgical options have failed¹. However, in Australia, referral rates from general practitioners (GPs) to exercise is only 5%, with opioid prescriptions (20%) and referral for surgery (14%) far more common². We wanted to explore the reasons for this in Tasmania.

OUTCOMES:

- Tasmanian GPs and surgeons state that 'out-of-pocket' cost and accessibility to physiotherapy is a major barrier
- Tasmanian GPs expressed concerns about limited allied health networks for onward referral, particularly in more remote areas
- Tasmanian GPs also expressed frustration with having to complete Chronic Disease Management Plans to send OA patients to a physiotherapist.

This study is informing the development of a new program which plans to upscale and evaluate an evidence-based program for osteoarthritis (GLA:D) across Tasmania.

To achieve this, Menzies have partnered with Primary Health Tasmania, Tasmanian Health Service, Arthritis & Osteoporosis Tasmania, Australian Physiotherapy Association, BODYSYSTEM® Physio, Royal Flying Doctor Service Tasmania, RACGP, and the Tasmanian Collaboration for Health Improvement (TCHI).

2. Parkrun® Study: Unlocking the potential of a novel setting to promote physical activity among knee osteoarthritis patients- a parkrun® feasibility study.

This is the first study to assess parkrun® as an intervention in people with a chronic disease. Parkrun® is a short community fun run or walk event that takes place every Saturday morning at locations throughout the country. Seventeen patients with knee OA, who were not meeting physical activity guidelines, were asked to walk in four consecutive parkruns and were supervised by an exercise physiologist or physiotherapist.

OUTCOMES:

- Participants showed significant improvements in knee pain, function and stiffness, and increased their physical activity levels
- They found parkrun® acceptable and safe
- The scalability, accessibility and wide appeal of parkrun® supports efforts to use it to promote physical activity in knee OA patients.
- **3. WALK study:** A pilot randomized controlled trial evaluating community walking for knee osteoarthritis.

This study examined aerobic outdoor community walking for knee OA patients and performed MRI scans to assess changes over 6 months. The walking group trained three days/week (two group supervised sessions and one unsupervised session). 40 patients participated in this trial.

OUTCOMES:

- Walking significantly improved knee pain, function, and stiffness over 24 weeks. The difference observed in pain was considered large and clinically significant.
- Small changes in MRI knee structure were observed, with no between group differences. There was no indication of detrimental effects related to the walking intervention.

Associate Professor Aitken said that results from studies such as these provide further evidence that 'exercise is the best medicine for osteoarthritis.' "Our challenge now is how do we use it more effectively and encourage exercise as a treatment."

*Australian Atlas of Healthcare Variation

 Australian Commission on Safety and Quality in Health Care. Clinical Care Standards. Osteoarthritis of the Knee Clinical Care Standard. May 2017.
 Bennell K, Bayram C, Harrison C, et al. Trends in management of hip and knee osteoarthritis in general practice in Australia over an I I-year window: a national wide cross-sectional survey. Lancet Regional Health. Published June 9, 2021.

Member's *story* — *Living with Sjögren's Syndrome*

Sjögren's Syndrome is a relatively common autoimmune condition that affects the eyes and the salivary glands and can also affect other parts of the body.

The immune system attacks the tear (lachrymal) and salivary glands, resulting in dryness of the eyes, mouth and/or other tissues.

Around half of all people with this condition also have a form of arthritis (conditions affecting the joints), specifically types of inflammatory arthritis such as lupus and rheumatoid arthritis which are also immune system disorders.





If you would like further information about Sjögren's syndrome and ways to help manage symptoms, visit our website or phone our InfoLine to receive a copy of our free Sjögren's Syndrome Information Sheet: call 1800 011 041.

With this issue's focus on eyes, we asked Jennie, our recently retired InfoLine volunteer and Member, about her experience of living with Sjögren's Syndrome, specifically its effect on her eye health.

"Ten years ago, I started having trouble with my eyes. They were really sore and felt gritty a lot of the time, and I was really struggling. Initially, the condition was difficult to diagnose as there are many things that can affect the eyes and there is no definitive blood test to diagnose Sjögren's Syndrome.

I started using eye drops from my pharmacy but soon needed to see an optometrist, who prescribed anti-inflammatory drops. These helped to ease my symptoms for a period of time, but I had to keep going back. My optometrist noted that my eyes were not closing completely at night and suggested that I start using an over-the-counter gel lubricant to help deal with draughts that were contributing to my dry eyes while I slept. They also referred me to an Ophthalmologist (eye specialist) who inserted plugs into my tear ducts to help keep my eyes moist.

In managing my condition, over time, I have noticed several factors that contributed to my dry eyes including some medications, being in draughty rooms, campfire and environmental smoke from bushfires and burn-offs but by far the worst situation for me is being in air-conditioned rooms and buildings. My eyes are also very sensitive to light, particularly fluorescent light, so I often need to wear sunglasses while working under fluoros."

We asked Jennie to suggest some of the ways she manages her symptoms and any 'top tips' she had to share. She responded that she:

- now uses a pharmacy available gel day and night, as she finds it helps lubricate her eyes
- finds an eye mask helps when it is necessary to sleep in a room where the air conditioning is centrally controlled and can't be switched off
- avoids being in draughts and/or highly heated rooms that can cause additional eye dryness
- wears sunglasses in bright light and a hat as well, winter and summer, for eye protection
- uses the visor in her car, summer and winter, to reduce glare while driving
- sees her Optometrist for regular eye checks at least annually or more frequently, if symptoms arise
- now knows not to rub her eyes, as it will make everything worse.

Jennie recommends that people with eye symptoms take their sunglasses (prescription or non-prescription) with them when they visit their Optometrist and ask them to ensure that the glasses are still appropriate and provide the protection they are designed for.

And, as a final piece of advice she offered "Don't try to treat your eyes yourself. I learnt the hard way that you need to get professional help to steer you in the right direction."

We thank Jennie for sharing her story and management tips, and for nearly a decade of dedicated volunteering, in an air-conditioned office, working under fluorescent lights!

Programs & services

THE INDEPENDENT LIVING CENTRE

The Independent Living Centre Tasmania (ILCT) is a charitable not-for-profit organisation that was established in Launceston in 1991. The service receives funding from both State and Federal Governments to provide information and advice regarding assistive technology. Assistive technology is anything that can help you to do a task throughout the day. This can include very simple devices to help with eating or drinking to more complex mobility aids or communication devices.



It can be a challenge for many people to see how some of these devices work and how they could assist them in their daily life, which is why the ILCT showrooms are so helpful! The showrooms, based in Hobart (just opened this year!) and Launceston, have a range of items that can be sourced from local or interstate suppliers for you to try out for yourself.

ILCT is not a retailer and they do not sell equipment, but their friendly staff can help you find where to purchase.

You can call or drop in to speak with their staff or you can make an appointment to talk with an Occupational Therapist about what you might need. Not all solutions need equipment or technology- sometimes it can be a simple technique or even household items that can be used to make life easier.

ILCT also now provides an Allied Health Service which can be accessed with a Home Care Package, through the National Disability Insurance Scheme (NDIS) or privately. They have Occupational Therapists, Physiotherapists and Speech Pathologists who can support people at home or in the community.

Contact: ILCT Information and Advisory Service on **1300 885 886** or visit their displays at 337 Argyle Street, Hobart or 275 Wellington Street, South Launceston.

Image: New ILC Centre at 337 Argyle Street
Free parking including accessible park available

FORTHCOMING EVENT:

The ILCT is hosting an Expo



When: 14th October 10am - 3pm

Where: At the Door of Hope, 50 Glen Dhu Street, South Launceston

Interactive displays, demonstrations and forums - showcasing the latest developments in assistive technology, smart home technology, building design for independent living, community support services and more.

If you or someone you know may be wondering about independent living options, then this is the event for you!

Register for Free on Eventbrite (www.eventbrite.com.au) or call the ILCT on 1300 885 886

NORTH WEST

Tai Chi for Arthritis

WYNYARD Senior Citizens Centre Contact: Maxine – M: 0419 870 471

Exercise Right for Active Ageing (subsidised program for over 65's conducted by Exercise Physiologist) SMITHTON Wellbeing Indoor Recreation & Leisure

Contact: 6452 4890

NORTHERN TASMANIA

The Joint Movement®

Provided by Martin O'Toole, Licensed Joint Movement Leader

• Group Warm Water Exercise Classes

For details and/or bookings contact: Martin O'Toole – M: 0412 296 694

SOUTHERN TASMANIA

The Joint Movement® Land Based Group Strength Training

CLARENCE, LINDISFARNE, GLENORCHY, KINGSTON, SOUTH HOBART AND OLD BEACH. ONLINE LIVE-STREAMED CLASSES ALSO AVAILABLE.

Designed for people with arthritis. Supportive, supervised small group environment.

1hr per week for 12 weeks (and opportunity for ongoing classes).

Contact Arthritis InfoLine: 1800 011 041 for an information pack.

New resources

Safe at Home website:



This website shares simple exercises and gives ideas of safe ways for older people to increase their activity levels while at home. Developed by a collaboration of Australian clinicians and physiotherapy researchers from ten universities, institutes and health services, this website which is accessible via desktop or mobile devices, provides information and instructional videos at three different levels of function and fitness, as well as tips on staying motivated and safe while exercising at home.

This resource provides exercise advice with easy-to-follow videos to help you keep mobile, ease pain and build flexibility. It also provides the choice to start with some simple exercise programs and then allows you to choose more challenging programs to build up your strength and balance.

Visit: www.safeexerciseathome.org.au



Understanding & Managing Scleroderma (6th Edition)

scleroderma

Scleroderma Australia have recently updated their excellent information booklet designed to help people with scleroderma, their families and interested others, to

better understand this condition, what effects it may have and what people with scleroderma can do to help themselves and their doctors manage the condition.

They have also recently released a new series of information brochures for people living with scleroderma and their health professionals on a range of topics including: helpful tips when having blood taken; eating well; and a checklist for hospitals and nursing guide.

All publications are freely available from their website: www.sclerodermaaustralia.com.au or, if you don't have access to the Internet, our friendly Arthritis Tasmania InfoLine Team will be able to help you source a copy: Tel. 1800 011 041.

Volunteers Wanted:

Scleroderma Australia is currently seeking Tassie volunteers.

What better way to connect with the scleroderma community than by becoming a volunteer!

You can make an impact in people's lives, do fun and rewarding work, and build your personal support networks. There are a range of interesting roles available.

Curious about how you can help Scleroderma Australia? Get in touch with Amanda on 02 9990 5159 or email:

hello@sclerodermaaustralia.com.au

NEW website for Australians living with Psoriatic Arthritis (PsA)

Arthritis Australia recently launched a new website MyPsA. Psoriatic arthritis is an autoimmune condition which affects around 200,000 Australians.

MyPsA offers information about the psoriatic arthritis, as well as a range of links for treatment options and ways to improve the management of the condition. It will provide tips about lifestyle changes that can make living with psoriatic arthritis more manageable.

Visit: www.mypsoriaticarthritis.org.au

FREE COMMUNITY WEBINARS

Musculoskeletal Australia's FREE community webinars are a great way to hear from experts about conditions and how to manage them. Coming soon:

Wednesday 13 Oct 2021, 7pm INFLAMMATORY ARTHRITIS

Presenter: Dr Marie Feletar, Rheumatologist

Thursday 11 Nov 2021, 7pm HANDS AND ARTHRITIS Presenter:

Ms Josephine Gibbs-Dwyer, Occupational Therapist, Working Hands Therapy

Visit their website to register and/or watch recordings of past sessions: www.msk.org.au/community-webinars

Clinical Trials



Do you suffer from knee pain?

The Menzies Institute for Medical Research is recruiting for **three studies** to evaluate different treatments for knee osteoarthritis.

STUDY 1: A clinical trial to test the effectiveness of a new anti-inflammatory medication (diacerein).

STUDY 2: A study where participants will get to participate in a free supervised **YOGA** or **STRENGTHENING EXERCISE** programme.

STUDY 3: A 24-month study investigating the effect of intra-articular **STEM CELL INJECTIONS** compared with **PLACEBO** (The SCUlpTOR study).

All studies are looking for people aged 40 years and over, who can attend study visits at Menzies in Hobart.



If you are interested in taking part or would like more information, please contact:

STUDY 1.

Kathy Buttigieg 6226 6909 or Kathy.Buttigieg@utas.edu.au

STUDY 2.

Vinah Anderson 6226 4633 or vinah. anderson@utas.edu.au

STUDY 3.

Kirsty Carmichael 6226 4215 or sculptor.trial@sydney.edu.au or access www.tinyurl.com/sculptor-trial



IBJR – Institute of Bone and Joint Research Study



DO YOU HAVE LOW BACKPAIN?

Researchers from IBJR are conducting an innovative study using text messages to support recovery of people suffering from low back pain.

Participating in the study will involve completing online surveys and receiving text messages.

People living anywhere in Australia can participate.

If you have back pain, please follow the link to find out more about the TEXT4myBACK Study: bit.ly/text4myback