

ARTHRITIS INSIGHT

Achieving a better life for all those
affected by arthritis



03/ Coronavirus
and arthritis

11/ Prof Chris Scott
on JIA

15/ Managing anxiety
in challenging times



The Arthritis Foundation of South Africa is the only body in the country dedicated to supporting people with arthritis, their families and carers.

We work to empower you to take charge of your health through advocacy, education, support and access to information and resources.

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While uncertainty is unsettling, we shall emerge stronger

“The better you are at making sure you’re doing what you should be doing, the better chance you have for making an impact on others.” – John C Maxwell, *The 360° Leader*

Our foundation, like many non-profit organisations, was grappling with its own changes in leadership and reconfiguring its strategic direction at the time the world was hit by the coronavirus.

These unprecedented times have dramatically changed our daily lives. While the uncertainty can be unsettling, I believe we will get through this together and emerge stronger at the end of this rough phase of our lives.

We recognise there is great responsibility in delivering critical news and information to our members and never has it been more important that accurate and reliable news be at the forefront.

The Arthritis Foundation of South Africa remains committed to its mission of supporting our members and creating trusted content for our magazine – and our resolve is even stronger today.

As we navigate through this new normal we find ourselves in, rest assured that we will bring you relevant and insightful content on arthritis, and at the same time bring you information about the coronavirus and advice on how to do things during this period.

Our members and stakeholders are core to the wellness of our society. We know these are trying times for all of us, so we are also producing content with tips and ideas to support those that may be experiencing increased levels of anxiety and depression.

Although we have missed a number of crucial events during this lockdown period, such as WORD Day (Juvenile Arthritis), Rheumatoid Arthritis Awareness Day and World Lupus Day, because we have had to practice social distancing and follow the rest of the precautionary measures as laid down by the Department of Health, including following guidelines from the World

Health Organisation.

However, we take courage in knowing that everyone is safe at home and that you are still able to access relevant information on these important topics on our online platforms.

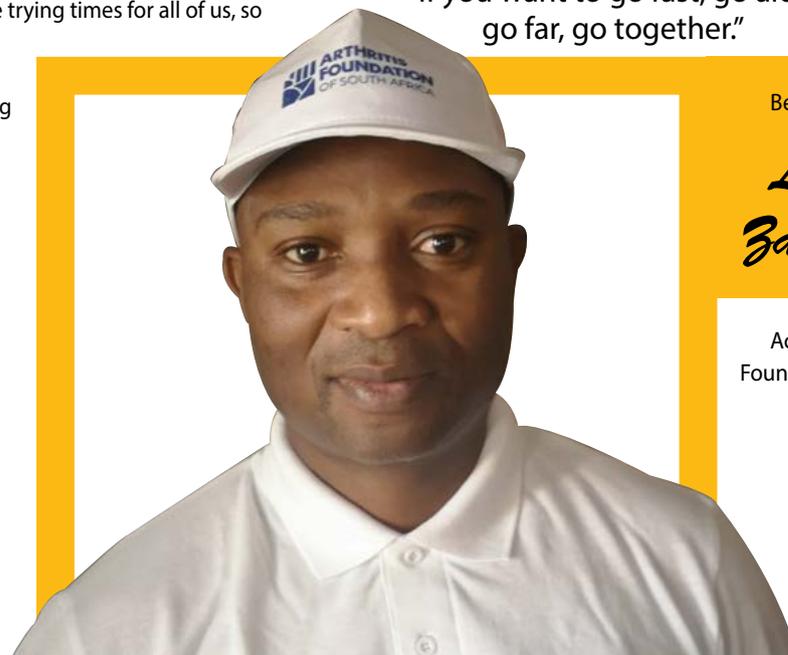
As soon as I start to feel frustrated at the daily challenges that have been brought on by the coronavirus, I think of all the people who are in the forefront of the war against this pandemic. These essential workers are our true heroes as they risk their lives every day to keep us safe. We salute them and their fortitude is an encouragement to all of us, knowing that we have them to count on to ensure our people and our country are safe during this lockdown period.

Please remember you too can play your part to prevent the spread of Covid-19 by: Washing your hands often and with soap or 60 percent alcohol content sanitiser; coughing into your elbow; not touching your face; cleaning surfaces; practising social distancing; wearing a mask and staying home.

Finally, there is no doubt that these are stressful times, but I hope through a sense of community we can not only survive, but also come out of this with more connection and support for each other.

Let me end with an African proverb, straightforward in its saying yet so relevant to the times:

“If you want to go fast, go alone. If you want to go far, go together.”

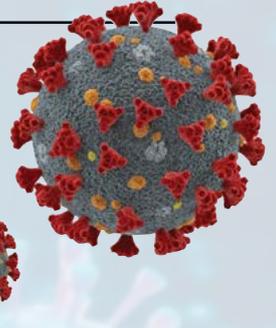


Be well and stay safe.

*Luvuyo
Bahela*

Acting CEO - Arthritis
Foundation of South Africa

CORONAVIRUS AND ARTHRITIS



Having RA and taking some RA medications means a suppressed immune system. Speak to your doctor first, but here's the current view...

If you have rheumatoid arthritis (RA), you're more likely to get certain infections. That means you may have a higher chance of getting Covid-19. If you do get sick, your symptoms could be more serious than someone who doesn't have RA. Some medicines you take might also make infections more likely.

On the flip side, researchers are looking into the benefits of some RA drugs for Covid-19, the infection caused by the new coronavirus. But more research is needed to know if and how they could prevent or treat Covid-19.

“ Experts aren't sure how this coronavirus affects people with RA or those who take drugs that affect their immune systems. That means you shouldn't change your treatment without talking to your doctor. ”

Experts aren't sure how this coronavirus affects people with RA or those who take drugs that affect their immune systems. That means you shouldn't change your treatment without talking to your doctor. For now, the best way to stay healthy is to keep taking your medicine. And try to avoid contact with the virus.

Does Covid-19 trigger RA?

RA raises your chances of getting any kind of infection. You're also more likely to end up in the hospital when you get sick. Your illness is likely to be more serious when your RA is active. You may hear that called a flare.

You may also have other health problems along with RA. Some that can make it harder to fight off an infection include: Chronic obstructive pulmonary disease and other lung diseases; heart disease; diabetes and kidney failure.



There's also some evidence that respiratory infections spread by viruses, like Covid-19, may raise the risk of getting RA. One study showed that women and older people who'd had other kinds of coronaviruses were more likely to get RA after they'd been sick. But more research is needed to know whether Covid-19 can actually trigger RA.

RA Drugs and Covid-19

When you control your disease, you're less likely to get really sick. That's why it's important to take your medicine, even if some drugs slow down your immune system. Those are called immunosuppressants. Examples include some of the drugs in these categories: corticosteroids (prednisone); disease-modifying antirheumatic drugs (DMARDs); biologics and biosimilars.

You may also take a non-steroidal anti-inflammatory drug (NSAID) like ibuprofen or naproxen. You may have seen news reports that NSAIDs could make Covid-19 symptoms worse. But the FDA says there's no scientific evidence right now to back up that warning.

Talk to your doctor about your medicine. It may be safer for you to avoid a flare than to lower your chances of getting an infection. Your doctor will help you decide what's right for you.

Can RA Drugs Treat Covid-19?

There's no vaccine or treatment for the virus yet. But some researchers think that certain RA drugs might help. They include: chloroquine and hydroxychloroquine (Plaquenil). This has led to controversy as some politicians vaunted their use before it has been scientifically validated.

Researchers around the world are studying how these drugs, among others, could prevent or treat Covid-19. **But there's not much scientific information yet.**

How to Stay Safe

If you have active RA or take an auto-immune drug, you should also follow the social distancing and personal hygiene guidelines carefully, and not take risks. You can also help your immune system by preventing infections from other diseases. Talk to your doctor about vaccines for things like the flu, pneumonia, whooping cough, and shingles. - WebMD

Building resilience



Rheumatoid Arthritis (RA) is an auto-immune disorder, which means the body's immune system mistakenly attacks the body, resulting in pain and inflammation. While Covid-19 is around, extra care needs to be taken if you have a compromised immune system.

So, how best can you support your immune system? For those living with RA, an over-active immune system can be just as harmful as a weak one, so the aim is to achieve balance and encourage resilience. Proper immune function is always a balancing act, but even more so with RA – it's vital. Think of our immune system as a garden. First you need to prepare the soil and create the right environment (in your gut) and then plant the best nutrients in it. Then discourage any enemy that wants to disrupt this nurturing environment.

Prepare

Scientists are finding more and more evidence that your gut health affects the development of diseases in the body. A Functional Medical Practitioner can help you to identify what in your environment results in RA, and also discover what triggers yours to flare.

It is essential to find the right balance of good bacteria for the microbiome to flourish. This can be achieved by feeding your gut prebiotics and probiotics.

A prebiotic encourages the growth of good bacteria – eat green bananas, chicory, onions, asparagus, leeks, garlic, apples, legumes, flaxseeds, barley and oats.

By Claire McNulty

Probiotics, on the other hand, are live bacteria and yeast. Boost your levels by consuming fermented foods such as sauerkraut, kefir, kimchi, kombucha and apple cider vinegar. If you can't find these in your supermarket, you should be able to get them at your local health shop. Or, ask Google – there are lots of recipes online that will show you how to make your own!

One other thing, you wouldn't put dodgy chemicals in your soil so don't put dodgy foods into your body. Avoid refined carbohydrates and sugars, as well as artificial sweeteners. Gluten, dairy, corn, soy and eggs can also inflame the gut.

Plant

This is not an exercise in deprivation (I found a delicious recipe for healthy chocolate!), rather see it as focusing on how you can rebuild your home, make it stronger, more stable, and a more comfortable place to live in. A healthy diet is invaluable, preferably consisting of fresh, organic products. The most important vitamins and minerals for RA are:

Vitamin A - Foods include apricots, asparagus, carrot, broccoli, peas, cabbage, spinach, pumpkin, peaches, papaya, mango, tomatoes, watercress, sweet potatoes, eggs, beef and liver from organically raised cattle. If you take a supplement, do it under supervision. Too much can overload the liver.

Vitamin D - fights colds and flu, and enhances the immune system. Sit in the sun early in the morning and late afternoon in summer, and whenever you can in winter

– it's best absorbed through the skin, so no sun block. Food sources are egg yolk, butter, sardines, salmon, fish, liver, green veg, carob, almonds, sesame seeds, figs, hazelnuts and alfalfa. Again, if you use a supplement don't overdose.

Zinc – It is found in seaweed and kelp, wheat germ, chicken, brown rice, eggs, fish, pumpkin seeds, sesame seeds, poppy seeds and asparagus. As a supplement, use zinc picolinate.

Fish oil/omega-3 essential fatty acids help to reduce inflammation too, so include them in your diet (flax seeds, oily fish, avocado, fresh raw nuts and seeds, cold pressed virgin oils) or take a supplement.

There are many herbs recommended for this condition. However speak to a qualified professional. Advice from your well-read friend, well meaning as it is, could be dangerous if they don't have in depth understanding of your condition. For example – you may have heard that Echinacea is excellent for boosting immunity but say no to Echinacea if you have an auto-immune disease.

Maintain

You may be wondering why the gardening analogy, well, getting your hands in the soil actually boosts your good bacteria; so growing your own food helps in oh so many ways. Reduce stress as far as possible, it can stimulate or aggravate RA.

Meditate – no need to get airy-fairy about it. Mindfulness is practical, and proven to reduce stress. Practice yoga. A teacher who has training in therapeutic yoga will know the particular postures that will benefit RA. Go outside, breathe, take care of yourself.



From left are Lorraine Mantini of AF; Verinique Nel and Chantelle de Bruin from JJ Watson, and Julie Martin (AF)



Getting participants involved at an Ikamva Labantu Wellness Centre workshop



Training days

Arthritis Foundation staff travel to outlying areas to bring valuable awareness workshops to those who need it most

By Julie Martin and Lorraine Mantini

“ We covered different themes in the training workshop such as coping with stress, relaxation techniques, laughing exercise, care of the feet, practising good sleep hygiene, ways to manage pain and conserving energy and protecting joints. The key is how to simplify life as much as possible when you have arthritis. ”

Central to the functioning of the Arthritis Foundation are the talks and tours staff embark on to deliver awareness, train healthcare workers and give helpful advice and guidance for people with the disease.

This is where the real value of the foundation comes to the fore, in that staff travel to outlying areas, where help is hard to find, and help make real people's lives easier, in real ways.

Early in February we rolled out a two-day arthritis training workshop in George for 60 participants made up of community carers who service people in Rosemore and Pacaltsdorp, as well as nursing staff from Huis JJ Watson.

Later in the same month we gave a talk called *Living Life and Loving It with Arthritis* to 120 people at the Islamic Seniors Association in Kensington. In this presentation we make all aware of the definition of arthritis and then talk about how the joints in our bodies work.

We explain that there are 150 different types of arthritis. When affected by arthritis, stiffness, inflammation and pain creeps in, making it difficult for our joints to perform

optimally. Arthritis may affect one or more parts in our bodies. In the most common form of arthritis (osteoarthritis) there is a breakdown of the cartilage. The hands, knees, hips and the lower back may be affected. Osteoarthritis affects mainly the elderly.

“ If not diagnosed early and left untreated, RA can be crippling. That's why the foundation advocates for early diagnosis ”

Rheumatoid arthritis (RA), on the other hand, is an inflammatory condition and is auto-immune which means the body attacks itself. One can get RA at any age, even little babies can have this debilitating disease, and if not diagnosed early and it goes untreated, RA can be crippling. That's why we advocate for early diagnosis.

We show the audience how to do specific exercises to incorporate into their



Thank you to foundation funders and supporters



A special thanks to the National Lotteries Commission. We are grateful for your support to the work of Arthritis Foundation. Thank you so much for your generous donation and especially for the funds you gave us towards the purchasing of a vehicle.

Our sincere appreciation goes to the following institutions and persons for their generous contributions:

The Charl van der Merwe Trust, James Rowe, The Mabin Trust, The Kensington Trust, Nussbaum Foundation, Abrams Family Trust, HM Evertsen Trust, T Muller, RA Williams, E/L MA Crisp, Rolag Management, FM Retief Will Trust, Tom Leefrink Trust, The Shill Trust, Fuchs Foundation, AKSA, Hope Promotions, Jose Rodriques, Trudi Moore and Janssen Pharmaceutica.

Thank you so much for your generous donations and bequests to the Arthritis Foundation of South Africa. Your donations have helped us provide much-needed training, awareness, educational support and advocacy to our members and to the various communities in which we offer services.

With support like yours, we are able to build inter-generational programming and a stronger community for all arthritis sufferers. **The world is a better a place with people like you in it, once again thank you.**

daily routine to make life easier when living with arthritis.

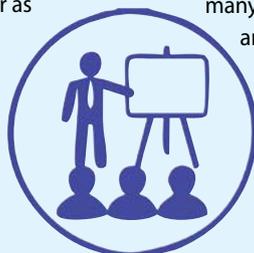
There are always questions from the audience. Namely, does diet cause arthritis and does the weather influence arthritis? We respond that diet can't cause arthritis, however, different foods affect pain levels with people who have arthritis. So this is an individual thing and you have to find out for yourself what may affect you.

Regarding the weather, we respond that when atmospheric pressure changes aches and pains can be felt in the joints.

People really find these talks very interesting and stimulating and always ask us to come back at a later date to learn more about arthritis and its treatment.

At the end of February we held another workshop, this time for assistants and coordinators at the Ikamva Labantu Wellness Centre, which services senior clubs throughout Khayelitsha and as far as Dunoon and Kuils River.

These workshops give comprehensive information on arthritis and teach practical techniques and cognitive skills based on the Kate Lorig Course.



They can then use the skills when working in the community with arthritic people.

The Kate Lorig Course is a self-help course designed to help people with arthritis to cope better with their condition. Professor Lorig came to South Africa, invited by the Arthritis Foundation, to

“ What makes these workshops so special is that we meet so many people but there’s always one person who stands out. ”

train us as trainers, and since then our organisation has used this programme.

We were also invited by the City of Cape Town Municipality to talk at its social development functions for seniors. Once again, our talks were very well received as many people suffer from arthritis and are hungry for information on how to better cope, remembering that there is no cure for arthritis; it is a chronic illness and as such can only be managed.

In the first week of March, we embarked on a week-long trip to the Karoo District starting in Murraysburg and moving along to Beaufort West, Nelspoort, Prince Albert and then Laingsburg where we delivered our training workshops to enrolled nurses, enrolled nurse assistants and community health workers. These health workers are in an organisation called Right to Care, which does community based work. Participants are issued with a certificate of participation.

We covered different themes such as coping with stress, relaxation techniques, laughing exercise, care of the feet, good sleep hygiene, and ways to manage pain, conserve energy and protect joints. The key is how to simplify life as much as possible when you have arthritis.

What makes these workshops so special is that we meet so many people but there's always one person who stands out.

These workshops are made financially possible for us by the generous funding of the National Lottery Commission, and we are certainly grateful. We are so happy with the comfortable vehicle sponsored by the commission that makes things a bit easier over the long distances we travel.



ARTHRITIS FOUNDATION ACTIVITIES

By Nadine Lewis

Despite having some activities curtailed as a result of the lockdown, such as a two-day workshop in March as well as the Rheumatoid Arthritis Awareness day, the Arthritis Foundation has done some valuable outreach work in Gauteng.

For instance, on February 22, says Nadine Lewis of the foundation: "We shared a patient information day with rheumatologist Dr Romela Benitha at Wilgeheuwel Hospital."

The foundation worked closely with her practice nurse, Doreen Mayne to set up the event.

It started with a talk by Refilwe Magano from Janssen Pharmaceutica, who very kindly sponsored the event. Refilwe works in Janssen's patient care division and spoke expertly on PMBs and medical aids.

Then Brenda Spence of the Joburg branch of the Arthritis Foundation got the



Nadine Lewis speaks at an information day

audience going by getting them to do dance and movement either in their chair or standing for those who were able to.

Nadine then presented on "Nutrition and Inflammatory Diseases" followed by Brenda who demonstrated some useful arthritic devices.

Finally George Hensley, a patient, gave a perspective on patients and social media.

Dr Benitha concluded with thanks, then tea and coffee were served giving patients a chance to chat to each other or to the



Refilwe Magano from Janssen Pharmaceutica

speakers. It was a very successful morning altogether.

In November 2019, our Complementary Therapies event included a music therapy morning presented by Yael Gavronsky and we had a lovely song and dance session which was enjoyed thoroughly by all.

Every year-end function, we get a wonderful donation from our chairperson, Dr Anne Stanwix, and we use it to buy gifts. We hold a raffle and draw prizewinners.

Joburg branch run a Wellbeing Workshop twice a year – generally in March and October. It is a two-day workshop where we invite patients to attend, free of charge. We give advice and input on subjects from how to manage your arthritis, to good diet and nutrition, exercise guidelines and tips on visiting your doctor. A primary focus is on diverting one's mind from pain through mindfulness, meditation, games and other techniques.



Getting moving at the Joburg Complementary Therapies workshop



OUTREACH INITIATIVES

In the Eastern Cape, the Arthritis Foundation's Community Liason Officer Vicki Sanan has been putting her all into organising great outreach initiatives.

These include visits to the Dora Nginza Hospital RA Clinic as well as the RA and Orthopaedic Clinics at Livingstone Hospital.

Important is a visit to the Dora Nginza Paediatric Unit in early November 2019 when Vicki put up posters, which led to being approached by the Senior Social Worker.



“ Arthritis had not been represented on the Health Promotion Forum previously and they welcomed the Foundation on board ”

Also in November the support groups at the Buffelsfontein Retirement Village in Walmer and the Mater Dei Catholic Church in Newton Park were continued. These were wrapped up for the year in November with happy Christmas meetings.

Towards the end of November Vicki visited the 14th Avenue Clinic in Walmer to introduce the foundation, which led to a valuable referral to the Eastern Cape Health Department (ECHD) where it was the foundation's turn to be introduced to the Health Promotion Forum (HPF), managed by Ms Fikile Sohuma, who invited her to join the forum's 113 members dedicated to various conditions, disabilities, and institutions of learning.

Arthritis had not been represented there previously and the forum welcomed Vicki. The relationship continues to blossom.

Staying with November, a Senior Social Worker from Dora Nginza Hospital invited Vicki to visit the Paediatric Unit to do a presentation to mothers in the ward.

She was asked back to the unit in December with a request that if she was think-

ing of bringing anything for the children to please make it fresh fruit.

Vicki says: “This was a humbling and most rewarding suggestion and I have carried it through to other groups.”

The morning concluded with a presentation to the Senior Social Worker and three juniors.

Three further visits to Ms Sohuma followed before Christmas helping to consolidate the foundation's fledgling relationship with the forum. This led to Vicki giving a brief introduction to the Foundation's work during the forum meeting in January, as well as a presentation in February.

During February, Vicki's support groups continued but with a difference - she would conclude meetings with an introduction to the coronavirus, its symptoms and precautions.

Vicki visited the Dora Nginza Hospital RA Clinic for adults where she did a presentation from the foundation's *Living Life and Loving It* programme.

March brought the theme of proper diet (accompanied by fruit boxes) which always generates lively discussion.

Vicki says: “One scorching Wednesday I elected to take bottles of chilled water for doctors, staff and patients at Livingstone Hospital. What a coup that was.

“And then came lockdown. However, I maintain contact with most of my groups via WhatsApp for those who have access to it and the HPF on a virtually, 24/7 on-call basis, which enables me to translate the goodwill of the foundation into action in these extraordinary times. An additional benefit is that it often gets early official notifications which she can pass on.”

Vicki adds: “Ms Sohuma and her team are doing incredible work in the Metro with the homeless, needy and destitute through members of the HPF and we have donated dry ingredients as well as fresh produce to various soup kitchens.

“However, its major thrust is in offering training sessions in Screening and Testing



Monthly support groups

The Buffelsfontein Retirement Village support group in Walmer happens on every 1st Monday of the month at 2pm in the chapel.

The Mater Dei Catholic Church group takes place on the 2nd Wednesday of the month at 2pm in the community centre in Newton Park.

These groups are open to the public.

to the community on an ongoing basis. This is an enormous task co-ordinated by Ms Sohuma and the team; she is to be saluted for making a difference here!”

Living life to the FULLEST with RA



Arthritis Insight speaks to adventure hiker Zan-Mary Dockrall about how she discovered she has RA and the way in which she lives her life well despite her diagnosis.

I am 36-year-old mom, wife, international sales manager and adventure hiker living with rheumatoid arthritis. I was diagnosed at the age of 33.

Growing up in a small town, I remember I had this consistent pain in my feet, and was told that it was growing pains. Throughout high school I did karate and hockey. My feet were always sore when walking far. My parents tried to assist and their way was to make sure I had good and comfortable shoes.

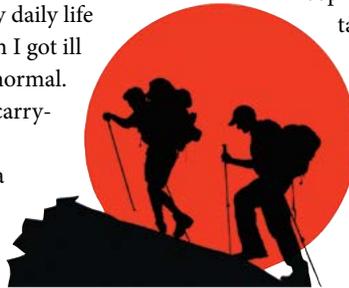
At varsity I continued with karate. Training was more intense and the pain in my feet increased. I remember waking up in the middle of the night crying of pain in my little hostel room.

The South African Student Sport Union championship was coming up and I just could not compete with my feet in the state they were in. So I went for physiotherapy and ended up getting a foot operation. Then, after a while, I had another foot operation.

Time moved on, I got married and had two difficult pregnancies. By now the pain was part of my daily life and I had gotten used to living with it. When I got ill I got very ill; it was always a bit worse than normal.

Even simple things like opening a jar or carrying groceries became a difficult task.

In 2016, I got very sick again and was at a point that I could not take it anymore. I ask the doctor to test for everything.



This was when I was diagnosed.

It was a shock at first but soon it was to become a blessing in my life. The blessing was: I realised that I needed to live for today, tomorrow is not guaranteed and I don't know how my body is going to feel and if I will still be capable. Tick my bucket list now, and live life to the fullest.

My dream was always to one day climb Mount Kilimanjaro. Well, that one day turned into the next six months. A year after I was diagnosed, I climbed Africa's highest mountain. It was such an amazing journey and experience.

This made me realise that I needed to get the word out there. Help people and make a difference in the life of other patients.

People who are living with this disease can get medical assistance that can ensure that they can still have a full life, and the sooner you get help the better. Exercising helps me to keep mobile and helps preserve my strength.

I do not want my next experience to be only for myself and thus want to do it to spread awareness of arthritis. My goal is to climb Mount Elbrus in the Caucasus Mountains in southern Russia, giving patients the hope to keep moving.

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LONG WALK TO PAEDIATRIC RHEUMATOLOGY

Arthritis Insight speaks with inspirational Professor Chris Scott about how he found his vocation in Juvenile Arthritis.

AI: Tell us a little about who you are and how JIA became your subject of interest?

CS: I am 45-year-old paediatric rheumatologist and a person living with a rheumatic disease. I work at the Red Cross War Memorial Hospital and at Groote Schuur and am an Associate Professor at the University of Cape Town.

A series of life events guided me down this path but in retrospect it appears that I was destined to work in this field. I had many joint and back problems in high school, which I put down to my sporting activity at the time.

My first year after medical school was especially tough, but I put my back pain and fatigue down to lack of sleep and excessive working hours. I was even booked off for a month due to the fact that I had “injured” my back.

The penny didn’t drop until I developed severe plantar fasciitis as a medical officer in the UK and someone suggested that I see a rheumatologist. I was promptly diagnosed with Ankylosing Spondylitis. In retrospect, it was incredibly obvious, as both my father and grandfather had been diagnosed with the condition.

Things came to a head in my second year of paediatric training. My condition progressed and the gruelling hours and stressful work made matters intolerable. By now I had been on non-biologic therapies without much success. Regular steroid injections into my feet and knees were a feature of life.

By my 30th birthday I was just not able to carry on. I had great difficulty walking and I was so incredibly tired that I felt like a shadow of myself. My dear wife decided enough was enough and encouraged me to take time off work. I resigned and spent a year not working.



Professor Chris Scott

With only one breadwinner life was tough and we had to relocate to Johannesburg for my wife to be able to take up more permanent employment. All this was very very difficult.

Biologic medications were new on the market and while we knew I needed one we could not afford it. The cost was about a quarter of my salary at the time I left work and with two small kids in the house funding the medication was not an option.

“ Well, let me tell you normal was great. So great that I was suddenly intensely angry that I had to suffer so long because of misdiagnosis ”

After a protracted battle with medical aid, my biologic agent was approved. I went for my first infusion and I felt like a new man within days. It was only then that the reality of what I had been going through became apparent to me. I had been unwell for so long that I had no idea what normal was like.

Well, let me tell you normal was great. It was so great that I was suddenly intensely angry that I had had to suffer for so long because of misdiagnosis, inadequate (and sometimes totally incorrect) treatment, as well as my own lack of insight into what this condition was doing to me. Somehow the system had a blind spot for people with arthritis.

I then went back to work and it slowly dawned on me that there were in fact many children with rheumatic disease, struggling to get a correct diagnosis and onto the best available therapy.

I set my mind toward changing that and started looking for a fellowship to study paediatric rheumatology. I am deeply grateful to wonderful Professor Carine Wouters from Leuven, Belgium, who offered me a training position and the rest, as they say, is history.

AI: What are the treatments you find to be most effective?

CS: Juvenile Idiopathic Arthritis (there are seven different subtypes) happens in children from as young as eight months up to the age of 16 and so there is no one-size-fits-all therapy.

We use many medications that adult rheumatologists use and also some that they do not use. Some children require intra-articular injections with corticosteroids and others may need hospital admission and daily IV therapy with sophisticated biologic drugs to control their disease. Methotrexate is probably our most widely used and available agent (also very effective) but it doesn't work equally well for each subtype or for each patient. Fortunately our bag of tricks is very big, but can only be used safely by trained paediatric rheumatologists.

AI: Which treatments in development most interest you?

CS: I think one of the most interesting aspects of research at the moment, in all types of rheumatic diseases, is research on the microbiome. Our bodies are filled (and covered by) bacteria and other organisms that play an important role in controlling our immune systems (and other parts of our physiology).

We are learning that there may be potential to improve our health by making sure we 'cultivate' and protect the right kinds as well as the appropriate diversity of organisms that live in and on us. It's not likely to be the answer to everything but it will likely be a huge step forward once we understand this system completely.

I am also very interested in the repurposing of drugs that we use to treat HIV to manage conditions such as systemic lupus erythematosus by suppressing the expression of virus components within our own DNA. My colleague Dr Kate Webb is leading an international group of researchers in this endeavour.

AI: How did Cape Town mark WORD day, it being so close to the start of the lockdown?

CS: There were numerous plans for WORD day (World Young Rheumatic Diseases day) in Cape Town and Johannesburg. Dr Dee Abraham had arranged an absolutely massive media event with the Arthritis Foundation and various VIPs and celebrities at Tygerberg.

Unfortunately this was cancelled due to the lockdown. We did, however, manage to arrange a group of volunteers to hike up Table Mountain in honour of the day.

I joined forces with Zan-Mary Dockrall, an RA activist who leads hikes for foundation members and who plans to climb mount Elbrus in Russia next year to raise awareness for arthritis sufferers.

We wanted to let people who have never had arthritis understand how it would feel to do an activity with just one (or two) joints not functioning optimally. So we all met on Table Mountain and casted up various limbs and joints before tackling the mountain. What an experience.

I had a knee cast up and found it incredibly challenging to get to the top. One of our team, Dwayne from the Red Cross, had casts on both his knees and still managed (but I think he must

have suffered). Zan and her team had the opportunity to connect with many people on the mountain and tell them about WORD day, including the fact that children can develop Juvenile Arthritis.



AI: As you have mentioned, WORD day had to be cancelled as a result of the lockdown. What are the main themes you intended to cover in your talk?

CS: I was going to talk about the a broad range of conditions that cause arthritis in children, as well as a global response to the challenges we face. While JIA is fairly common (between one and four per 1000 children) there are hundreds of more rare conditions that also cause arthritis and together they cause a lot of disability (in fact the leading cause of disability in most parts of the world).

The problem is that in Africa and South Africa we have very few paediatric rheumatologists. In order to treat all these kids appropriately we would need at least 60 in SA and we have 10.

The rest of Africa is even worse off. There are fewer than 20 paediatric rheumatologists for nearly a billion people. We need thousands more. That is why I have joined forces with the Paediatric Rheumatology European Society and my co-chair Prof Helen Foster from the Global Task Force for Musculoskeletal Health, to raise the profile of these conditions and to organise and support initiatives on many levels (including education, awareness, treatment guidelines and international collaboration) to improve the management of rheumatic diseases on a global level.

“ In children, there is a window of opportunity to change the outcome of the disease and this window is early on. ”

AI: Let's talk about early diagnosis. Why does this help, and what are the early warning signs to look out for?

CS: In all rheumatic diseases there is much to be gained from early aggressive intervention. There is a window of opportunity to change the outcome of the disease and this window is early on. If children are ill for a long time without a diagnosis the chances that they will suffer permanent damage and disability (such as blindness and joint destruction) is much higher if they come to a diagnosis late. Disease activity equals damage. We follow a targeted approach to reducing disease activity and the earlier we get the kids the better it works.

Most people do not think that children get arthritis and so symptoms are often disregarded (as in my case) or dismissed as growing pains. We have to stop this and we have to make people think about arthritis to get the kids to an early diagnosis and to support training for more paediatric rheumatologists.

How the Arthritis Foundation has helped me

Member of foundation's Khayelitsha support group tells of how she has learned to have courage and act with confidence



Mrs Mary Nkosi (known as Mankosi), is a member of the Arthritis Foundation support group in Khayelitsha. She has Rheumatoid Arthritis. Here is her story:

My name is Mary Nkosi, 62 years. I have been living with Arthritis since the age of 10 years.

I did not know that there were people who care about people living with this sickness until I met two ladies from the Arthritis Foundation (Lorraine Mantini and Julie Martin) who came to our club and taught us how to take care of ourselves.

This has changed my life and given me

the courage and confidence to see myself differently. It has taught me how to speak freely in front of an audience without any fear.

AF supported me with my bead work by providing me with beading material so I can exercise my joints. When you have Rheumatoid Arthritis you do not have to sit at home and feel sorry for yourself, you should get up and work with your hands, eat healthy and do exercises.

God gave us minds, hands and feet, so that we should work for ourselves and be confident.



In memoriam

It is with great sadness that we heard of the passing of Aysha Manjra.

Aysha was a member of the Johannesburg branch and she and her husband Hanies were regulars at our lectures held throughout the year.

She always put on a brave face despite her pain and discomfort and did all she could to help her condition. She was a regular at the gym and worked hard to keep fit and active. Her husband Hanies was a great support to her and was always seen at her side. In fact in 2014, we published an article on the couple in our winter edition, which demonstrated Hanies' loyalty and support for Aysha.

We wish Hanies and the families our deepest and sincerest condolences and may Aysha's memory be a blessing to them all. From Nadine Lewis and Brenda Spence of the Johannesburg branch and from all the staff at the Arthritis Foundation.



NEW

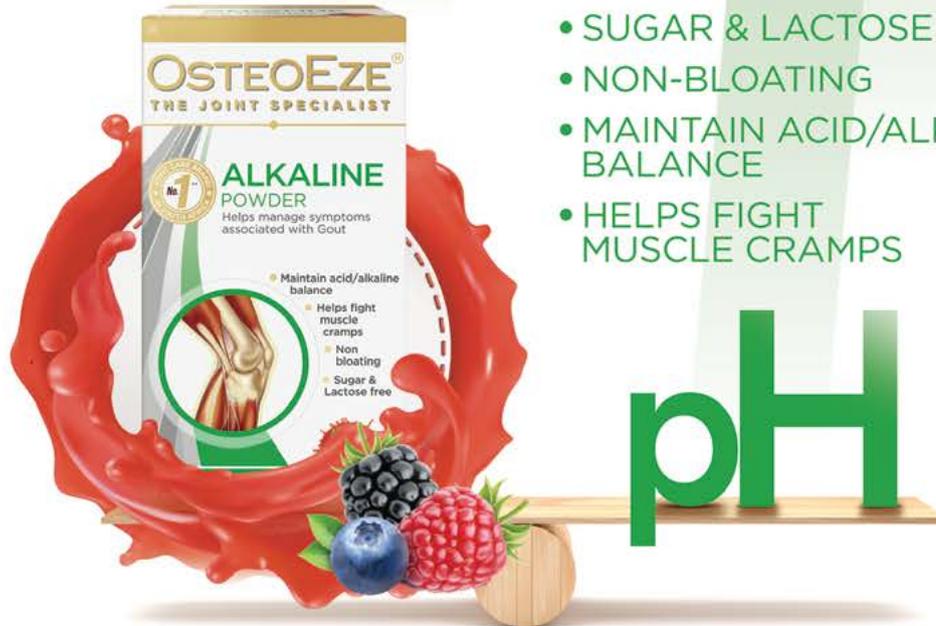
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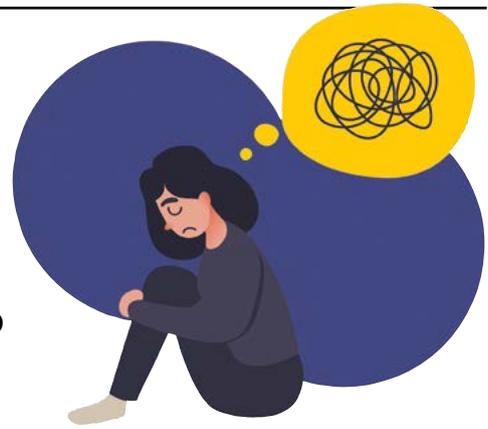
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References: 1. No.1: Nielsen MAT Sept 2019. Marketed by Nativa (Pty) Ltd. 260 Cradock Avenue, Lyttelton, Centurion, South Africa. Tel: 0860 628 482. YA05T028/03

Managing **ANXIETY** is key right now

The healthiest response to the coronavirus is to stay calm; here's how to navigate your stress levels in this uncharted territory



The novel coronavirus has created unprecedented levels of stress for most of us. Some are actually battling the virus now, but the vast majority of the harmful effects are coming from the fear of the unknown, disruption to our routine, loss of productivity, and financial concerns.

As most of us are in uncharted territory, here are some tips that can provide a bit of comfort.

Be Calm and Smart

Try to optimise your mental health by activating the calming part of your nervous system. This is called the parasympathetic nervous system nicknamed "Rest and Digest." It is the opposite of our nervous system that is in overdrive now; the arousal side known as the sympathetic nervous system and nicknamed "Fight or Flight."

We need the arousal side when we face emergencies. It kicks in to prepare us for battle and to stay focused. The situation now is highly unusual in that to fight effectively, we must stay home. Our best defense paradoxically is to relax. If we stay in an aroused state for too long, we can actually damage our health.

Tend to Yourself First!

Make sure you are getting enough rest. Sleep is the base of the wellness pyramid. Many people are feeling very tired from spending so much of the day in a state of anxiety.

Eat Well

One defense against the coronavirus and most diseases is proper nutrition. Eat fruits and vegetables in a balanced fashion. Avoid empty calories, as eating should be a

By Dr Eva Ritvo

way of nourishing ourselves. Avoid eating out of boredom. Talk to your doctor about vitamins or other supplements. Stay properly hydrated.

Reduce Alcohol and Other Intoxicants

It's easier for us in South Africa with the ban, but even though alcohol might make you feel calmer for a short period, it is better to use and develop other tools to relax during this crisis.

Go on a News Diet

Limit the amount of upsetting information to what you need to know. Get info from accredited sources only, then turn off the news. Avoid watching or reading news or social media, especially fake news, where facts can become blurred. Listen to what acknowledged experts are saying.

Exercise

Although most of us can't work out the way we used to, we must find safe alternatives. Use YouTube to help you find ways of staying fit in your own home.



Have Some Fun

Give your brain an outlet to have fun. Puzzles, magazines, humour provide much-needed respite from the stress.

Families are enjoying the extra time together and are playing board games and cooking.

Befriend

Reach out to those important to you. Everyone reacts differently to stress and it is important to know that those people you value are making good choices. Use this time to tell people how important they are to you and reach out to those you care about. Take advantage of the myriad resources online to get support.

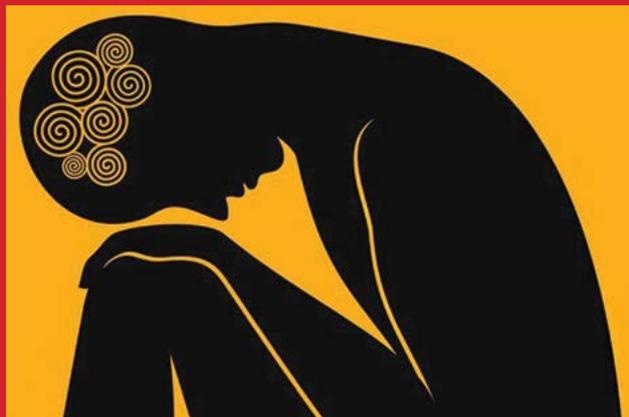


Express emotions

It's beneficial to let your feelings out with a friend, family member or professional. A wide variety of feelings are coming up for people now and they should be acknowledged to ourselves or with others. Many therapists are available for online consultation.

Be Kind

Everyone could use a kind word right now. When we help others, we also help ourselves. Since it is difficult to donate time right now, consider donating money to relief efforts.



The South African Depression and Anxiety Group (SADAG) Are providing support through:
Online Toolkit on the SADAG website (www.sadag.org) with online videos, reliable resources, coping skills, tools and info on social distancing, self-isolation, and more.
Chat online with a counsellor 7 days a week from 9am to 4pm via the Cipla WhatsApp Chat Line 076 882 2775.
SMS 31393 or 32312 and a counsellor will call you back – available 7 days a week, 24 hours a day.
SADAG Helplines providing free telephonic counselling, information, referrals and resources 7 days a week, 24 hours a day – call 0800 21 22 23, 0800 70 80 90 or 0800 456 789 or the Suicide Helpline 0800 567 567 .

Limit Interactions with Negative People

Limit the number of people you interact with that will distress you. If you find conversations with friends and family are very upsetting, limit them to daytime hours and make them brief. Remember most everyone is upset and it does feel good to lend a helping ear but it shouldn't be at the expense of your mental health.

Meditate

If you haven't found the time to start, find it now. You can begin very simply with an app called HeadSpace or Calm. You can simply sit in a quiet spot and focus on your breathing and let thoughts pass through your mind and drift away. Make sure your exhale is longer than your inhale as this triggers your parasympathetic nervous system and helps you relax.



Secrete Oxytocin

Humans are designed to connect via touch, so being apart is unnatural. If you



are home alone or social distancing in your own home, you can simulate touch by wrapping yourself in a warm blanket or taking a hot bath or shower. Hugging a pet has the same effect.

Clean and Organise Your Home

We can counteract our distress over our loss of control by straightening up what we can. Catch up on your mail, work, taxes, or other chores that might have fallen behind. Completing tasks gives your brain a boost of dopamine, so even simple tasks like folding laundry can give us a quick boost.

Create New Routines

Many find comfort in the predictable. With your routine gone, it can help to try to create a new one. For example, stick to

the same bedtime and wake-up time. Try to be productive during certain hours and relax at other times.

Engage in Positive Activities

Read a book. Listen to soft music. Dim the lights. Watch the sunset or be in nature if you can do so safely. Take a deep breath. Journal. Think about and express gratitude.

Avoid Big Decisions

Right now, your thinking might not be the clearest due to the excess cortisol. Try to stay away from conflict with others. We need one another now more than ever. Postpone any decision that can wait.

Reflect

Even in the darkest times, there is always light. In the words of author James Carroll, "There are times when we stop, we sit still. We listen and breezes from a whole other world begin to whisper."

We are collectively experiencing a very unusual time. Try to think about how you want to go forward when the pause button is removed. What activities are most important to resume, and which ones are you better off not resuming? Are we treating ourselves, one another, and our planet with enough kindness and compassion? What can we learn from the challenges of the novel coronavirus? How can we come together to face this and future challenges more effectively?

The Triple-F method

Fight Fatigue with Food to overcome arthritis-related tiredness

Your arthritis illness may well mean you live with chronic pain, depression and sleep deprivation, resulting in fatigue, but it's possible that some of your eating habits may also be sapping your energy.

Culled from *Arthritis Today* the Arthritis Foundation magazine in the USA, are the following eight simple ways to fight fatigue with food.

1. Don't go hungry

The body needs energy to expend energy. That's why when you skip meals, or wait too long to eat, you can feel unfocused or lethargic. When you don't eat regularly, you're simply not fueling your body enough, and when you haven't eaten you are more likely to feel irritable, and that can exacerbate fatigue.



2. Eat Breakfast

People who eat breakfast tend to eat healthier. In one large study published in 2008 in the *American Journal of Clinical Nutrition*, researchers found that breakfast eaters tend to eat healthier meals and fewer calories over the course of a day. Women in the study who ate breakfast weighed less.

3. Say no to the sweet stuff.

Sugary cereals, sweet pastries and high calories-coffee will give you a quick jolt of energy, but at a cost. The sugar burns off quickly leaving you lethargic. These simple carbohydrates can cause a tremendous

increase in serum insulin followed by a falling rapid blood sugar that contributes to a downward swoop in energy and then eventual burnout.



4. Fill Up on Fibre

Several studies show fibre's many benefits, potentially helping people live longer and with less inflammation. But eating fibre-rich foods, such as veggies and whole grains play a role in energy too. Fibre helps the body slow the absorption of carbohydrates, which will smooth out energy highs and lows.

5. Pump Iron

Iron helps your body build healthy red blood cells, which carry oxygen to the organs and muscles. When the brain, for example, isn't getting enough oxygen, you may not feel as mentally sharp as usual; you may also feel fatigued. Non-steroidal anti-inflammatory drugs (NSAIDs) can cause low iron levels in the blood, as can having rheumatoid arthritis (RA). So get plenty of lean protein, beans and dark, leafy greens.

6. Ask your Doctor or Pharmacist about Vitamin B

You may benefit from a vitamin B supplement, as many seniors and people with RA are deficient in certain forms of this vitamin. B vitamins help the body convert carbohydrates into fuel, which is why being low in one or more may cause you to feel

drained. Most pharmacy sisters can give Vitamin B injections.

7. Drink Plenty of Water

When you are even just a little bit dehydrated, your body isn't functioning properly and will feel fatigued. How much liquid should you drink? That depends on you. Water needs vary considerably from person to person and most research suggests you use thirst as a sign you need to drink. But try to drink water to rehydrate rather than any other beverage. Avoid sugary cooldrinks and energy drinks, which are high in sugar and caffeine.



8. Choose Wisely at Bedtime

Make sure the food you're eating isn't causing you to get less sleep. Spicy foods or high-fat foods, as well as orange juice and carbonated beverages can cause indigestion and heartburn, especially if consumed too close to bedtime. Also try to avoid evening treats like chocolates that contain caffeine. Drinking alcohol may well make you fall asleep faster, but it is also likely to disrupt your sleep. Even perfect sleeping habits won't solve all your energy problems, but adopting better practices may help you feel better and put some pep back in your step.

The many faces of arthritis

Glossary to understanding the various types



There are more than 200 different forms of arthritis and related diseases. Learn more about the various conditions.

Osteoarthritis (OA)

A degenerative form of arthritis found mainly in older patients, resulting from general wear and tear, overused or from previously damaged joints, or hereditary factors. It can involve knee and hip replacements to restore mobility and reduce pain and inflammation. It is the most common form of arthritis.



Rheumatoid arthritis (RA)

A systemic form of inflammatory arthritis affecting one's general health as well as a variety of joints. If left untreated it could affect any anatomical part of the body. RA is the most common of the auto-immune arthritis diseases, found in about 1 in 100 people worldwide.

Lupus / systemic lupus erythematosus (SLE)

An auto-immune disease primarily affecting the skin and vascular system, as well as joints and organs. Many with lupus develop a butterfly-shaped rash on the face. It affects mainly young women aged 15 to 40. In South Africa, people of mixed lineage are often affected.

Ankylosing spondyloarthritis

An umbrella term for inflammatory diseases that involve both joint and the

entheses (the sites where the ligaments and tendons attach to the bones). The most common is ankylosing spondylitis (AS). Others include reactive arthritis, psoriatic arthritis (PsA) and enteropathic arthritis. In most cases it primarily affects the spine. Some forms can affect joints in the hands, feet, arms and legs.

Sjögren's syndrome

A systemic auto-immune disease that affects the entire body. Symptoms include extensive dryness, fatigue, chronic pain, major organ involvement, neuropathies and lymphomas. Sjögren's often occurs in the presence of RA, lupus or scleroderma. Nine out of ten people with Sjögren's are women.

Gout

A form of inflammatory arthritis in people with high levels of uric acid in the blood. The acid forms needle-like crystals in joints and causes severe episodes of pain, tenderness and swelling. Chronic gout can be partially managed with adjustments to diet, exercise and alcohol intake.

Scleroderma

A group of diseases that causes the hardening and tightening of skin and connective tissues. Scleroderma can affect only the skin, but may also impact blood vessels, organs and the digestive tract (systemic scleroderma). Women are diagnosed more often than men and it commonly occurs between the ages 30-50.

Infectious arthritis

Also called septic arthritis, this is an infection in a joint that causes arthritis-like symptoms. It is a type



of inflammatory arthritis but much more severe. Infectious arthritis occurs when bacteria or a virus enters the joint and multiplies, causing painful symptoms in and around the joint.

Juvenile idiopathic arthritis

The most common type of arthritis in children under the age of 16. JIA can cause persistent joint pain, swelling and stiffness. Some children experience pain for only a few months, others have symptoms for the rest of their lives. Some types of JIA cause serious complications, such as growth problems, joint damage and eye inflammation.

Polymyalgia rheumatica

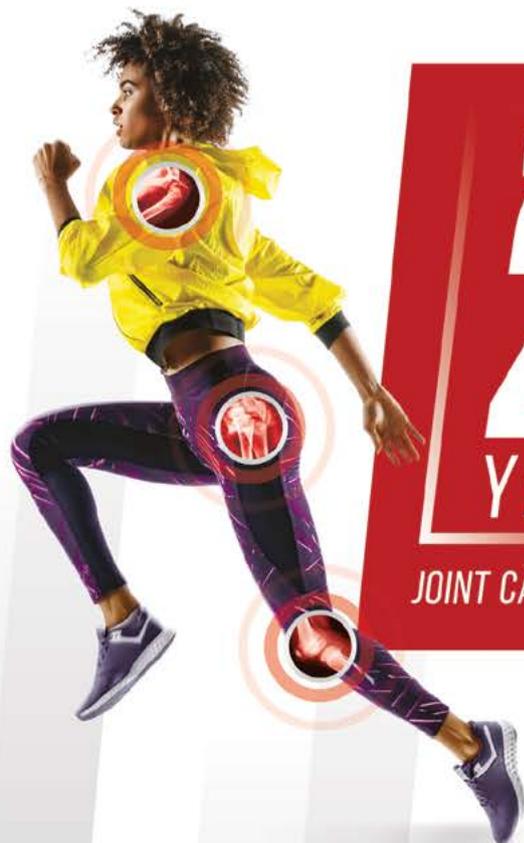
An inflammatory disorder that causes muscle pain and stiffness, especially in the shoulders. Signs and symptoms usually begin quickly and are worse in the morning. Most patients are Caucasians older than 65.

Scoliosis

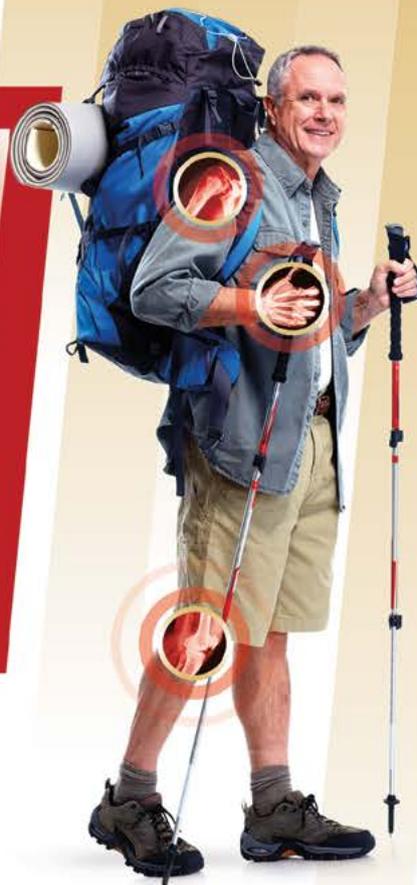
Instead of running straight up the center of the back, a spine with scoliosis twists to one side. Scoliosis can be classified as true (meaning it has to do with abnormal development of the spine) or functional (meaning its cause is not directly related to the spine). Functional scoliosis may occur when a discrepancy in the leg causes the pelvis to tilt to one side to compensate. The cause of true scoliosis is largely unknown, although doctors suspect that it may be the result of

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References: 1. Lugo et al. *J Int Soc Sports Nutr.* 2013;10(1):48. 2. Bagchi et al. *Int J Clin Pharmacol Res.* 2002;22(3-4):101-10. 3. No. 1: Nielsen MAJ Sept 2018.

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