8 ways to better mornings
How to rise and shine with a smile!

KEEPING ACTIVE THIS WINTER
Easy ways to move more in the colder weather

“Arthritis won’t beat me”
Judd Batchelor on standing up to her condition

Your relationships
How to talk to people about arthritis – and help them understand
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Hello...

...and welcome to the winter issue of Inspire.

Hopefully you’ve had an enjoyable summer – with the endless, sunny days, things could not have been more perfect! Now our thoughts turn to the changing seasons and how to start adapting to winter. The cold often makes joint pain worse, especially in the mornings, which is why we’ve put together a great feature, ‘Eight ways to better mornings’, on page six. We’ve also got an inspiring piece on how to keep active this winter – find out more on page 16.

This is a time of change for Arthritis Care, too. You will have read about our merger with Arthritis Research UK last year – and now the two charities have a new name, Versus Arthritis. Read more about it on page 21.

As ever, please write in or send an email with your stories to tell us what you’d like to see – we love hearing from you! Enjoy the magazine,

Tracey Lattimore
Editor

OUR AWARDS
Institute of Internal Communication National Awards 2014: Best New Publication
Institute of Internal Communication Central Awards 2013: Stakeholder Publication

KEEP IN TOUCH!
Stay up to date with Arthritis Care’s latest news and activities all over the UK. For monthly news delivered straight to your inbox, sign up via the website at versusarthritis.org/newsletter
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There has been very limited progress in the development of new therapies for long-term pain. However, a recent review in *Nature Reviews* suggests three priorities in research that could decrease the number of people living with pain:

- There should be a focus on drug and other forms of therapeutic research. This would allow treatments to be developed that block acute pain and the mechanisms that promote the development of long-term pain.
- Therapeutics should be created that copy or target internal pain-resolution mechanisms. This could reduce, and permanently reverse, long-term pain.
- It is possible that some successful ways of treating short-term pain can interfere with treatments for long-term pain. Future research will try to stop this from happening.

This research agenda will hopefully lead to breakthroughs that will lower the number of people living with long-term pain.

**A high-sucreose diet increased signs of joint inflammation in recent tests involving mice**

*DID YOU KNOW?*

New research suggests that patients with end-stage ankle arthritis can expect enhanced quality of life within six months of surgical reconstruction. Researchers from The Rothman Institute and Thomas Jefferson University Hospital, USA, found that surgical reconstruction boosted patients’ range of motion by more than 60 per cent, reducing pain and increasing function. The improvement in patients continued for at least two years after surgery. The team assessed 100 patients’ range of motion, pain levels and function completing everyday activities before surgery and again at three months, six months, one year and two years after total ankle arthroplasty surgery. The results, published in the *Journal of Bone and Joint Surgery*, found that surgery improved patients’ ankle range of motion by 66 per cent. As range of motion improved, so did patients’ quality of life.

**Great expectations for ankle patients**

**Tackling pain head on**

A grant from Arthritis Research UK has allowed the successful development of a Patient Decision Support Intervention (PDSI) to help patients considering knee or hip replacement. Professor Mark Wilkinson from the University of Sheffield is now looking to pilot this tool.

Another grant has recently been applied for, which, if successful, will allow the pilot to begin in June 2019. This would be the start of a three-year project involving 510 recruits.

The pilot would take place within the Sheffield area, involving people aged 40 to 90 with osteoarthritis of the knee, who are also considering knee replacement.

Two trials would take place at the same time – one would be done by the patient, while the other would be done by a clinician. This is a very exciting development for anyone considering knee replacement – watch this space.
8 ways to better mornings

Living with a condition like arthritis can make it hard to get going in the morning, as stiff joints take time to loosen up. These tips will help you to rise and shine.

WORDS: CLAIRE LAVELLE

1 Try gentle stretching
Heat, regular movement and strengthening the muscles around the joints are key to reducing the pain of arthritis, no matter what time of day it is, says physiotherapist Andy Byrne (pallmallmedical.co.uk). “However, you can make mornings better by gently warming up your body before you even get out of bed,” he says.

“There’s no benefit in forcing things to move – instead, try to coax joints into moving gently, but repeatedly. Try the following stretches:
- Your knees: slowly bend and straighten each knee 15 times
- Your hips: gently pull your knees towards your chest and lower 15 times
- Your back: lie with your knees bent up and feet on the bed, roll your knees from side to side for a minute. If you introduce these exercises at night, too, you’ll find that being as mobile as possible before you go to sleep will make mornings easier,” he adds.

2 Turn up the heat
Once you’re up, have a warm shower or bath, or apply hot pads to very sore joints. “Any kind of heat is great for arthritis,” confirms Byrne. “Heat pads, hot water bottles, warm showers and baths all help improve circulation, relax the muscles and soothe the nervous system, which reduces pain.”

3 Get moving
It may be the last thing you feel like doing, but the stronger the muscles around your joints are, the better supported (and less painful) they will be. Research consistently shows exercise to be beneficial for people living with arthritis, as it can help strengthen your heart, improve your flexibility and mobility, and put you in a better mood. The best form of
exercise is the one you’ll do, so don’t be afraid to try something different in your quest to move more. If you can manage it, going to an exercise class regularly can be a great way to make new friends, too – there’s nothing to lose!

4... and put your best foot forward

“I’m often asked by patients what they can do to help them lose weight, get their blood pressure down and help them feel a bit happier,” says GP Ron McCulloch.

“My answer is always the same – go for a walk!” Indeed, a study by Public Health England found that walking reduces the risk of serious health conditions, such as heart disease, stroke, type 2 diabetes, certain types of cancer (of the breast and colon), Alzheimer’s and depression by between 20 to 60 per cent. Walking also improves mood and quality of sleep, lowers blood pressure and cholesterol levels, and can help to reduce anxiety.

“I do 20 minutes every day without fail,” says Dr McCulloch. Sounds like just what the doctor ordered.

5Dress smart

Arranging your clothes for the morning the night before can help you get dressed with minimal pain and discomfort, says Katie Ellis, director of the Able Label (theablelabel.com). “Choosing slip-over and zip-up tops, or Velcro fastenings over fiddly buttons, will help if you have stiff fingers, and it can help to lay items out before putting them on – for example, fully open a wrap skirt onto a chair, sit back into the skirt, wrap and fasten,” she says. “You can also choose coats with slippery linings to make it easier to get them on and off,” she adds.

6Practise gratitude

You can do this at any time, but doing it first thing helps set up a positive mindset for the rest of the day, says health psychologist Dr Meg Arroll. “Think of three separate things to be grateful for – they only need to be small, but it puts us in an appreciative mindset for where we are in our lives now rather than ruminating on the past or worrying about the future. It can be hard to focus on the positives when you have a long-term health condition, but it helps you appreciate the good days and keep the bad ones in perspective.”

7Keep your morning routine the same

Doing the same thing in the same order every day gives consistency and reduces stress – as humans, we find unpredictability stressful. “I leave the curtains open so that I wake up naturally as the day breaks, do my stretching exercises while I’m still in bed, and then put my dressing gown and slippers on and have a cup of tea in the garden before tackling the day ahead,” says June Hazeltine, 59, who has rheumatoid arthritis. “It wakes up my body and calms my mind. Some days are better than others, but I’ve learned over time that the bad days are just that – days – and they do pass.”

8Finally... prioritise sleep

To be at your best for the day ahead, you need to prioritise sleep. Whether that means going to bed earlier, or staying in bed later if you’re able to, your body will thank you for it. “If you push your body when you’re already fatigued, you’re adding more stress and not allowing yourself time to recover,” says Dr Guy Meadows, clinical director of The Sleep School (sleepschool.org). “Remember, being sleep-deprived makes you more susceptible to coughs and colds, too. So, while it’s great to have a morning routine that sets you up for a positive day ahead, don’t try to push through if you’re not getting the rest you need. There’s no shame in prioritising sleep.”
When I mention the word ‘gout’ to patients, many think of fat kings like Henry VIII, or old men too fond of port and red wine. However, despite alcohol and being overweight potentially increasing your risk of gout, there are other – perhaps more surprising – risk factors.

Given that the translation for the medical term arthritis is ‘joint inflammation’, gout definitely qualifies. However, gout tends to occur in attacks and you are likely to feel completely well in between these. About one in five people with gout find that it runs in their family, and it tends to start in middle age, although symptoms can begin earlier. Men are affected more often than women.

What is gout – and who gets it?
Gout occurs when crystals made of uric acid are laid down inside the joint. Most people who develop gout have high levels of uric acid in their bloodstream. The level of uric acid in your system depends on how much your body makes, and how much it gets rid of through your kidneys. More often than not, people with gout have kidneys that don’t filter uric acid very efficiently.

The classic symptoms are rapid onset of redness, swelling and sometimes agonising pain – most commonly in the joint at the base of the big toe, although other joints can be affected. Without treatment, the symptoms will usually take five to 10 days to settle down. However, more than three in five people will have another attack within a year and, in some people, repeated attacks can lead to long-term joint damage.

Short-term treatment is to give anti-inflammatory tablets, which should ease symptoms within 12 hours. If you can’t take these for any reason, colchicine tablets may be recommended. If you have repeated attacks, your doctor may suggest you take allopurinol tablets regularly. Allopurinol works by lowering the level of uric acid in your system. It takes several months to do this, so won’t help relieve an acute attack: in fact, it can make symptoms worse, so they shouldn’t be started until a few weeks after an attack has settled. The dose – usually 100-300mg a day – can be adjusted, depending on the level of uric acid in your system.

What changes can I make?
The good news is that lifestyle changes can often dramatically cut your risk of further attacks. In particular, reducing the level of purine in your diet may be useful, since this naturally occurring chemical is broken down into uric acid.

Foods high in purine include:

- Liver, kidneys and game (including rabbit and venison)
- Trout, sardines, mackerel, anchovies, whitebait, shrimps and crab
- High-fructose corn syrup and glucose-fructose corn syrup (found in sugary drinks, cakes and biscuits, but also in some yoghurts, cereal bars, ready-made sauces, ketchups and bread)
- Yeast extract (Marmite is the most popular UK version)
- Beer

Other types of alcohol can also increase your risk of gout, so it’s important to limit how much you drink and certainly not to exceed the UK guidelines of 14 units a week for both men and women. Alcohol is surprisingly high in calories, too, so cutting down can also help if you’re overweight, which is another major risk-factor for gout. For alcohol advice, visit drinkaware.co.uk.
I am 85 years old, and I have never been on any kind of medication, until now. I have a pacemaker and have had arthritis in my hands and one of my feet for a few years, which made them stiff, but not really painful.

I have been put on Xarelto and my arthritis has suddenly become painful. This might be a silly question, but is this natural, or could it be the drug? My doctor offered to switch me to apixaban, but the side effects sound worse, and they mention osteo joint pain.

Should I try another drug, or soldier on and try to treat the side effects myself?

Pearl Hazel, via email

In trials, about one in five people taking rivaroxaban were thought to have at least one side effect caused by treatment. Common side effects include anaemia, dizziness, headache, low blood pressure, indigestion and feeling sick. Pain in at least one joint or limb is described as a common side effect.

I suggest you discuss all of the options with your doctor. They may recommend an alternative anticoagulant, which may not carry the same side effects – but could have different ones.

For some people, side effects settle with time and people often assume a drug has caused a side effect when it’s a coincidence.

I would urge you not to stop taking your tablets before speaking to your GP, as anticoagulants are very effective at reducing the risk of life-threatening complications.

Whether it’s a health niggle or emotional problem, DR SARAH JARVIS gets straight to the point

Dr Sarah Jarvis answers:

All drugs carry a risk of side effects, as anyone who reads the information leaflet that comes with medicines will know. But they also have benefits, and drugs can only be licensed on the basis that, for a whole population, those benefits outweigh the risks.

However, if you’re the one in 1,000 who experiences a very severe side effect, this may not be the case for you.

Xarelto (also called rivaroxaban), is an anticoagulant medicine used to reduce the risk of stroke and clots on the leg or lung. Other medicines used for the same conditions include warfarin, apixaban and dabigatran.

All these conditions can be life changing or even fatal and, if you have atrial fibrillation (the most common abnormal heart rhythm in the UK, affecting more than one million people) you’re five times more likely to have a stroke than someone who doesn’t have it.

Anticoagulants dramatically reduce that risk and are now routinely advised for pretty much everyone with atrial fibrillation. The most common side effect of all anticoagulants is bleeding – hardly surprising since they’re used to counter a higher risk of abnormal clotting.

I suggest you discuss all of the options with your doctor. They may recommend an alternative anticoagulant, which may not carry the same side effects – but could have different ones.

For some people, side effects settle with time and people often assume a drug has caused a side effect when it’s a coincidence.

I would urge you not to stop taking your tablets before speaking to your GP, as anticoagulants are very effective at reducing the risk of life-threatening complications.

If you want to read more about treatments for arthritis, go to versusarthritis.org/about-arthritis/treatments

FIND OUT MORE

Ask the doctor

Whether it’s a health niggle or emotional problem, DR SARAH JARVIS gets straight to the point

I have been diagnosed with osteoarthritis and am feeling increasingly low and anxious. I am becoming more isolated as I try to deal with the condition. I exercise and have a good GP. Is there anything I can do differently? Do other people feel like this?

Rose, 71, via email

Dawn Smith answers: The emotional effects of arthritis can have just as much of an impact on you as your physical symptoms. Living with a long-term condition may knock your confidence, and you may experience feelings of anxiety or isolation. This is completely normal and there are many other people that feel the same as you.

Do you have any hobbies or activities you like doing? Many people find reading, gardening or going for walks enjoyable. Some libraries or community centres hold regular clubs or social get-togethers. Arthritis Care has local branches and groups all over the UK, where you can meet people with arthritis and related conditions. Many hold coffee mornings, activity groups and other social events.

You can also find support through our Online Community, where you can talk to others with arthritis – go to arthritisforum.org.uk. And tell your GP how you are feeling – they may recommend some support services.

To find out more, call the free Arthritis Helpline on 0800 5200 520. We’re open weekdays, from 9am to 8pm. You can also call us if you’d like a chat with one of our helpline advisers, whether it’s about your condition or something else.
"I’ve never competed with anybody else but my inner self"

After a long, theatre-based career, acting coach Judd Batchelor, 50, faced a new challenge – and found new motivation – when she was diagnosed with arthritis in 2016

"I’ve been involved in the creative arts since the age of 16, when I started at Mountview Theatre School in London. From then on, I definitely felt I was going to be an actor. My life as an actor was audition after audition. Whether I looked anything like the part or not, I would put myself up for roles. It was a life of castings, directors, agents and theatres. From there, I branched out and found more success in playwriting, while also establishing a career as an acting coach.

It was a gradual transition – I found there was more power behind writing and producing my own plays. One of my plays, A Mother Speaks, is a one-woman play exploring the impact of knife crime, which I performed around the UK in 2007-08. But I gradually stopped acting around 2009 to concentrate on the other areas of my work.

Coaching has been a big part of my life – it’s something that I really enjoy and am so passionate about. I’ve worked for agents and theatres that have agencies within them, selecting and training talent. A number of students have progressed to TV and big-screen movies. But because of my condition – osteoarthritis in my knees and rheumatoid arthritis in all my other joints – I’ve had to take a step back."

As told to: Phil Lattimore  Photography: Kevin Nixon

http://arthritis.org.uk
Early signs
There were signs of my arthritis several years before I was diagnosed, though I didn’t realise it at the time. Around 2007, when I was performing, I found myself getting tired quicker and having really bad knees. I thought jogging was causing it, as I was forever trying to lose weight to look good for parts. I changed from pavements to running on grass, but it didn’t make much difference.

It got worse. From around 2012, I spent three years working for Warner Bros doing administrative work. My wrists started to hurt a lot, and I thought it was possibly from typing. But it wouldn’t go away – it was a constant dull ache. I was consuming painkillers, such as ibuprofen and codeine, like they were sweets, simply to deal with the pain. It was quite a pressured, busy and stressful job, and I felt like I just had got through it.

At the time, I was working to get a mortgage on my first property. I got through the buying process and the hassles of getting the property sorted. But as soon as that was over and I’d relaxed, it hit me like ‘WHAM’. I had pain everywhere. I wasn’t even able to close my hands into a fist.

That drove me to the doctors in 2016, and I was referred to a rheumatologist. I was told I had rheumatoid arthritis and osteoarthritis in my knees. At the time it was most prominent in my wrists and I felt it in my shoulders, but now it’s spreading all over.

Shock reaction
I hadn’t expected the diagnosis at all – I felt shocked and confused. I didn’t know what was happening to my body, and I thought it shouldn’t be happening to me. As far as I knew, there was no history of arthritis in my family so, at the age of 48, it was something completely new to me.

After my diagnosis, I did lots of research and tried to read uplifting articles about people who have the condition, but have tried to push past it. I’ve picked myself up; since my diagnosis, I’ve looked at myself many times in the mirror and said: ‘This is not where you stop.’ I never used to look in the mirror as much as I do now and question who I am and where I’m going in life.

Audition for life
My diagnosis has had a major impact on the way I approach the creative arts. What I’m doing now has a different meaning, as I’m passionate about using the arts to show how arthritis impacts so many people’s lives.

In 2017, I lost a friend – Elaine Delaney – to cancer. She was 38 years old. I looked at her and thought: ‘It’s like an audition, it’s like constantly having to keep asking life if I can get a part’. So I came up with the idea for the ‘Audition for Life’ event, to raise awareness and money for three conditions that have had an impact on people in my life: sickle cell disease, cancer and arthritis.

The first event was held in October 2018 – a 5k fun run/walk at Hackney Downs Park, London, combined with a live performance from a local artist, panel discussions on health, and a cool-down party for participants at the Hackney Empire. I would never have thought of it before my diagnosis.

Being resilient
Since my initial diagnosis, my condition has progressed. But it’s made me stronger inside. I also think I’m much more compassionate – I try to see the other side of things, not taking anything for granted and being happy with the little things in life. And, if I see people with an ailment walking by, I quickly send a prayer out for them.

I’m being positive that my knees will get better, and I’ve started going back to the gym. I enjoy stationary cycling and low-impact exercise, including cycling in the swimming pool. I’m determined to graduate soon to biking on London’s streets.

Dealing with setbacks as an actor has helped build my resilience – I’m determined to prove people wrong. Actors are vain, and I’m happy I’ve got the vanity to say: ‘I’m not going to look like this or appear to people in this way!’ That attitude has really helped me. That’s why it won’t beat me. I’ve never competed with anybody else but my inner self – and that’s what’s happening now. I’ve even given this arthritis another ‘character’ inside me.

I’ve got five older sisters, who came with me to Hollywood for my 50th birthday in June. We had an amazing time, with a helicopter tour on my birthday. I said a prayer to myself; then I said to this arthritis character inside me: “This is the second half of my book. It’s going to be written the way I want – and you’re not coming with me.”

WHAT WORKS FOR ME
“Exercise is tremendously important to me. It’s one of the key weapons in the arsenal I’ve put together to help me, alongside nutrition. If I’m not able to get out, I walk around inside my flat. I do something I call a ‘Standing O’, where I stand upright and as correctly as possible, pushing my knees back, chest out, shoulders square, getting my posture right. In the morning, sometimes I put on powerful music to give me ‘the power’, and I’m also inspired by watching people on TV doing extreme sports such as parkour. They really push themselves to their limits.

On down days, I accept that I will be emotional, and allow myself to have a good cry. I put on a funny movie or remind myself that this isn’t the end – this isn’t it. It’s a mixture of songs, attitude and going through my routine to get going. It’s about getting my head in the right place – because the mind is a very powerful thing.”

If you’d like to know more about Judd’s campaign, go to auditionforlife.com
To join the movement pushing against arthritis, or discover ways to help manage your condition, visit versusarthritis.org
For me, it’s the stories told by young people with arthritis that are the most moving. I’ve had the privilege of meeting a handful of the estimated 12,000 children in the UK with juvenile idiopathic arthritis and, in every case, I’ve been humbled by what I’ve heard. Children with juvenile idiopathic arthritis have significantly lower physical wellbeing and psychosocial health (mental, emotional, social and spiritual wellbeing) compared with those without. Often the levels of pain are hard to contemplate.

What’s more, it’s an interruption to their lives. At a time when they ought to be carefree, taking in every new experience they can, and – yes – doing a bit of schoolwork, too, they’re tied to medical appointments and, in some cases, serious surgical procedures.

I’ve spoken to people who seem to have grown up so quickly when faced with all those challenges and, in all of those cases, the support of family and friends has been vital.

I just wonder sometimes about the ones I haven’t met – the ones who, maybe, don’t have the parents or schoolmates to provide them with the understanding they need on the bad days.

I mention this because I was reading the story of a 13-year-old with JIA recently. A teenage girl who talked about not being able to walk the family dog, about the friends’ birthday parties she was missing, about the schoolwork she couldn’t keep up with.

But she wrote this about her time in hospital: “Even in my hardest moments I’ve been so well looked after. I’ve not only been given the ability to walk again, but I’ve also had so many hours of happiness and laughs with everyone here”. I’m humbled once again.

Making an impact
As our newly merged charity, Versus Arthritis, looks to increase awareness of arthritis, it will be people’s stories that will really resonate with the public.

I know from my own experience that my story is more unusual because I developed psoriatic arthritis in my late thirties rather than my late sixties. I developed psoriatic arthritis in my late thirties rather than my late sixties. Imagine someone’s story creating lots of talk on social media, demanding a response from health organisations, even from members of parliament.

If that story ends up prompting lasting change – improved provisions in the workplace for people living with long-term pain, for example, or better design of everyday household items – then that’s something we could all celebrate. Young and old.

Julian Worricker has psoriatic arthritis. He is a TV and radio presenter and journalist, and currently presents the BBC News channel’s rolling news and the BBC World Service’s Weekend World Today.
Findings from a survey conducted by Versus Arthritis – the new name for Arthritis Care and Arthritis Research UK – suggest that people with arthritis across the UK are missing out on support to stay in work. Arthritis can have a huge impact on someone’s ability to work. Our survey respondents shared that they had experienced pain (95 per cent), fatigue (86 per cent) and stress (53 per cent) at work as a result of their condition.

Access to Work is a government-funded scheme available in England, Scotland and Wales, designed to support those in work who have a disability, or a physical or mental health condition. A similar scheme is available in Northern Ireland. The grants can be used to pay for practical help to address some of these issues. They can fund specialist equipment, support workers, taxi costs, mental health support services or disability awareness training for colleagues.

However, of almost 1,600 survey respondents with arthritis and related conditions – such as back pain – 59 per cent said they had never heard of the scheme. Of those respondents that hadn’t accessed support from the scheme, 69 per cent said they believed these forms of support could have helped them in the workplace.

This is particularly worrying considering 35 per cent of respondents had reduced their working hours, 26 per cent had changed the type of work they do, and a further 19 per cent had given up work completely or taken early retirement. In fact, national statistics show that only 63 per cent of the UK’s working age adults with a musculoskeletal condition are currently in work, compared with 81 per cent of people without a health condition.

**Improving access**
We believe support for people with arthritis to be in work must be improved. That’s why we need you to get behind our campaign calling for improvements to the Access to Work scheme. You can find out more on our website, and send our powerful new report *Working It Out* to your local MP to draw attention to this issue.

Morgan Vine, campaigns manager at Versus Arthritis, says: “We know what a huge impact it can have when someone is forced to give up a job they love. To support more people in the workplace, we believe the government-funded Access to Work scheme needs improvement. People with arthritis must understand the employment support on offer to them.”

Find out more about the Access to Work scheme at gov.uk/access-to-work

**Dan’s story**

“My rheumatoid arthritis causes my ankles and knees to swell up, making it difficult to stand, walk and drive. As a chef, my symptoms have caused me major problems. Before doing the Versus Arthritis survey, I’d never heard of the Access to Work scheme, but I think it could have helped me.

“Equipment that eases the pressure on my hands when my thumb joints flare up could make opening bottles and jars easier, which is essential for my job.

“Help for travelling to and from work could also have been very useful. I’m only in my thirties, so I want to carry on working – but it’s getting harder.”
Letters
You’ve been busy writing to us, tweeting and having your say in our Online Community

Write in
Get in touch! Send your letters to: Inspire magazine, 1 Cambridge Technopark, Newmarket Road, Cambridge CB5 8PB or email inspire@arthritiscare.org.uk

Reasons to be cheerful
Had I been told in younger days that old age and various resulting degrees of malaise would leave me in pain, virtually housebound and unable to contemplate travel, holidays or even outings, I would have been very anxious about the years ahead. But this attitude would have been totally unjustified. Yes, at 85 and living alone with no nearby relations, life is not easy. Inevitably, I am on a downward slope with multiple problems – arthritis being just one of them – but life remains full of interest, variety and mini-incidents that can be translated into enjoyable small-scale events.

Just before I was 80, I bought an iPad and spent a year wrestling with its complexities unaided. Eventually, I was able to regard my tablet as a source of friendly communication and chat, without ever trying Facebook or learning how to use Twitter.

The NHS gives me amazing attention, with an average of two hospital appointments a week. I am provided with free hospital transport and wheeled from one department to another by friendly volunteers. I have become familiar with monster hospital tunnels and heart machines and, in the process, I have fun trying to remember the names of attending medics. In waiting periods, you sometimes get chatting to other patients and even hear their life stories.

On my return from hospital visits, a magnificent ramp – installed free by the council – awaits me. The ambulance men unload my four-wheeled walker, and I negotiate the ramp with ease.

I have had to sell my car for safety reasons, but there’s a voluntary lift service where I live, or a friend will help. I can also book a ride on the wonderful Bustler bus, and the friendly drivers carry your shopping.

Yes, I live alone – but I don’t lack company. I have a marvellous chatty home help who also whizzes through the jobs I can no longer manage. In addition, I host various U3A groups in my home. The people, in turn, offer to shop for me.

Best of all, my brain is still ticking over. I realise how fortunate I am in many ways. The loss of mobility is so gradual that there is no shock factor. It’s just a case of adjusting and being glad there is such a lot that you can still enjoy.

I used to be an impatient person, always in a rush. Now, I have learnt acceptance and even tranquillity. Life is still good.

Wendy Sturges, via email

Finding peace in the arts
I’ve attached a piece of my writing that helps me keep as strong and focused as possible to rise above my pain and deal with life’s challenges.

I have a number of chronic health conditions, including osteoarthritis and fibromyalgia, with daily pain and fatigue, but have found my passion and the magic that arises from my love of art, literature and the theatre.

My poem ‘How to eat an elephant’ was published in CBT Good Habit Journal: A mindful journal for replacing anxiety and stress with clarity and calm by Christine Wilding and Gill Hasson. I have attended a number of Gill’s self-development courses in Brighton and found my voice, thanks to her wonderful teaching and mentoring. Gill helps to empower people to live their best life – regardless of any ‘barriers’. With her support, I was offered the opportunity to realise a life-long ambition, which I hope to take up next year.

Beyond pain there is magic
Find your passion and you will find your strength
Find your strength and you will find your power
Beyond pain there is magic
Go and find it – it’s waiting for you.

Julie, via email

Waste not
Having just read a letter in the autumn 2018 issue of Inspire, I have to agree with Heather Gorton regarding trying to return items no longer needed after surgery. I have had the same experience.

I had a total knee replacement last year and found the loan equipment very helpful. However, when I’d recovered, I tried to return everything: crutches, walking frame, toilet frame, and grabber. I was told the same thing as Heather – throw them away!

What a total waste of NHS money. Surely these can be disinfected and re-used, as there was absolutely nothing wrong with them. I wonder who made this silly decision – and for what reason.

Marlene Steudel, via email
The majority of people who have arthritis are of working age

Maureen McAllister, manager of Working Well with Arthritis in Scotland, on why it’s crucial to support people to stay in work

AS TOLD TO: PHIL LATTIMORE

I run the employability service to help people with arthritis remain in or return to work. We offer people guidance, information on their rights, help raise their confidence to manage their arthritis in work, improve employability skills, and direct them to services that can make a difference.

I lost the sight in one eye when I was a teenager and now have around 25 per cent useful vision in the other eye, so I’m registered blind. I was born with a genetic condition – Marfan syndrome – which is a connective tissue disorder that can affect your joints, heart, sight, and so on. I’ve got fairly good central vision in my good eye and manage well.

I love interior design and art, and hoped to pursue a career in this field. At school in the 70s, my career choices and pathways were limited because of my sight loss. Thankfully, this has changed for today’s disabled students. I got a ‘safe’ job in the civil service instead.

I worked in the benefits office in Glasgow for 18 years. When my eyesight deteriorated, I left due to a lack of information and support on adjustments and adaptations. After studying and volunteering, I got a job with the Royal National Institute of Blind People. I helped people with sight loss get back into or stay in work, delivered IT training on specialist equipment to improve employability skills, and advised employers on visual awareness and supporting disabled staff.

My sisters had been volunteers with Arthritis Care several years before I joined in 2013. They delivered the self-management programme. My daughter volunteers for the charity, too.

When the 2014 Commonwealth Games came to Glasgow, I was on the accessibility group. Our role was to make sure the stadiums were accessible to everyone with disabilities, that the planning, travel and marketing material was accessible and fully inclusive. I had been working for Glasgow Access Panel since 2012, and we worked with the Games for well over a year on this.

One of the highlights of my job was the invitation to present at the European League Against Rheumatism (EULAR) Congress in Madrid last year. I delivered a presentation on ‘Young People in Work’. It was a real highlight of my time with Arthritis Care, as it emphasised the importance of our work and why we should be doing more in this area.

My typical day is pretty varied. It could include referrals from the NHS, the Jobcentre or someone who has got in touch directly – they may be struggling to maintain their job or get into work, and don’t know where else to go. I’d arrange to meet them or speak to them on the phone, and check they’re making the best use of pain and NHS resources. Alternatively, I could be giving a talk at a Jobcentre about arthritis, or visiting an employer.

I offer training and support to staff across the UK on employability services to make sure they understand the issues that people come across. I’m also involved in lots of different groups – looking at devolved benefits in Scotland, but also working with our own workplace health group within the organisation.

Most people I see are in their mid-40s, so they still have a large chunk of their working lives ahead. The majority of people who have arthritis are of working age. The government has pledged to halve the disability employment gap and make employment more accessible for disabled people.

People sometimes come back to us to volunteer. This might be a year or two down the line, when they’ve got themselves on their feet, and they want to give something back after realising how much our support has helped them.

If you would like to know more, contact volunteering@arthritiscare.org.uk about volunteering opportunities

“Maureen McAllister, manager of Working Well with Arthritis in Scotland, on why it’s crucial to support people to stay in work.”
Keeping active this winter

The nights might be drawing in, but that doesn’t mean you have to hibernate! Here are some ideas on how to keep moving this winter

Words: Georgina Maric

It’s very tempting to make the cold and darkness of winter an excuse not to exercise, but in the UK the winter seems to last a very long time.

After a few months of hibernating in your home, you may find that your lack of movement has made your joints stiff or sore, so now’s the time to think about an exercise or movement plan that will suit you all winter long.

Regular, gentle exercises at home or as part of a suitable class are a brilliant way to keep your joints supple – and who knows, you might even enjoy it!

Why should I move more?
“There are lots of reasons to keep moving when you have arthritis, although pain and stiffness can make it feel like an effort,” says Dr Anna Lowe from The Chartered Society of Physiotherapy. “Staying active keeps muscles strong, and muscle strength is really important in keeping people mobile and independent.”

Movement helps to keep bones and joints healthy, which can keep you active and help prevent falls, explains Dr Lowe. “Every time you do something that makes you a little bit warm and a little bit out of breath, you are challenging your heart and lungs – and this is what keeps you fit.”

Keeping active also lifts our spirits, she says. Even though it might feel like an effort to get going, you will feel better afterwards.

Can activity help joint stiffness?
“General activity is a great way of staying supple,” says Dr Lowe. “Gentle mobilisation exercises can help joints to feel looser and can be a good way to warm up before you start exercising.”

If you’re not used to exercise
“If you can’t walk comfortably, you can still benefit from being more active – there’s plenty that you can do,” explains Dr Lowe. “Arm exercises can strengthen your muscles and also get your heart working a bit harder, too.”

Try these movements below – you can even do them sitting in a chair. Do eight sets of one exercise, have a short rest, then repeat. Try this with each exercise in turn.

- Shoulder press: sitting with your hands by your shoulders, slowly raise your hands until your arms are straight and up above your head. Lower down to the starting position.
- Lateral raise: with your hands by your sides, keep your arms straight and raise them out to the side until they are level with your shoulders. Lower them back down again.
- Modified triceps dips: sitting in an armchair, with your hands on the arms, press down though your hands and try to lift your bottom off the chair. It doesn’t matter if you can’t – just trying is really good practice.

“If your muscles aren’t tired after this, you need to work harder,” advises Dr Lowe. “Try adding a small hand weight, or a small bottle of water if you don’t have hand weights.”

If you’re more active
- If you can walk comfortably, then aiming for a 10-minute brisk walk during the day will be great for your health
- Start with a few minutes per day and build up slowly
- If you are getting warm and a bit out of breath, you are on target
- Smartphone user? Try the free Active 10 walking app to help motivate you – find out more at nhs.uk/oneyou/active10

The important thing is to aim to do a bit more exercise than you do already. For classes and groups near you, call our free helpline on 0800 5200 520.

Try an exercise class
While exercising at home might be easier, joining a group – however nervous you may feel – can often push you out of your comfort zone, in a good way.
“Do what you enjoy,” says Dr Lowe. “Exercising is often easier to stick at if you go with a friend or join a group.

“Making it as easy as possible is also important, so finding somewhere local that’s simple to get to will help. Chat to the instructor before the day, and explain any concerns you have.”

Here are some classes you might enjoy:

If you’re more active

- Yoga
- Pilates
- Swimming
- Aqua aerobics
- Water walking (walking in a swimming pool)
- Nordic walking (cross-country walking using poles)
- Tai chi
- Cycling

- Walking in a gym (elliptical/cross training)
- Light weight training

If you’re not used to exercise

You can still join a class, but make sure it’s suitable for you. “Some areas will have classes particularly for older adults and people who are less mobile, such as chairobics, for example,” explains Dr Lowe. “You may find that swimming is comfortable and manageable – many people feel more mobile in water than on dry land.” However, breaststroke should be avoided if you have arthritis in your hips or knees, or if you have had a knee or hip replacement.

“With support, you may be able to use much of the equipment in your local gym,” says Dr Lowe. “Gyms have specific sessions where they will give people one-to-one support from a qualified instructor, advising on suitable exercises that will work for you.”
Keep it simple

We loves these easy yet tasty recipes by Yotam Ottolenghi

Bridget Jones’s pan-fried salmon with pine nut salsa

Serves 4

Ingredients
100g currants
4 salmon fillets, skin on (500g)
100ml olive oil
4 celery sticks, cut into 1cm dice, leaves kept for garnish
30g pine nuts
40g capers, plus 2 tbsp of their brine
40g large green olives, pitted and cut into 1cm dice (about 8)
A pinch of saffron threads, mixed with 1 tbsp hot water
20g parsley, roughly chopped
1 lemon: finely grate the zest to get 1 tsp, then juice to get 1 tsp
Salt and black pepper

Method
1. Cover the currants with boiling water and set aside to soak for 20 minutes.
2. Mix the salmon with 2 tsps of oil, ½ tsp of salt and a good grind of pepper. Set aside while you make the salsa.
3. Put 75ml of olive oil into a large sauté pan and place on a high heat. Add the celery and pine nuts and fry for 4-5 minutes, stirring frequently, until the nuts begin to brown. Remove the pan from the heat and stir in the capers, brine, olives, saffron and its water and a pinch of salt. Drain the currants and add these, along with the parsley, lemon zest and lemon juice. Set aside.
4. Put the remaining 1 tbsp of oil into a large frying pan and place on a medium-high heat. Add the salmon, skin side down, and fry for 3 minutes until the skin is crisp. Reduce the heat to medium, then flip the fillets over and continue to fry for 2-4 minutes.
5. Arrange the salmon on four plates and spoon over the salsa. Scatter the reserved celery leaves on top.
Puy lentil and aubergine stew
Serves 4 as a starter or side, 2 as a main

**Ingredients**
- 3 tbsp olive oil, plus a little extra to serve
- 3 garlic cloves, finely sliced
- 1 large red onion, finely chopped (160g)
- ½ tbsp picked thyme leaves
- 2 small aubergines, cut into chunks, (about 5 x 2cm)
- 200g cherry tomatoes
- 180g Puy lentils
- 500ml vegetable stock
- 80ml dry white wine
- 100g crème fraîche
- ½ tsp regular chilli flakes
- 2 tsp picked oregano leaves
- Salt and black pepper

**Method**

1. Put 2 tbsps of oil into a large, high-sided sauté pan and place on a medium high heat. Add the garlic, onion, thyme and ¼ tsp of salt and fry for 8 minutes, stirring often, until soft and golden. Tip into a bowl, leaving the oil behind. Set aside.

2. Place the aubergines and tomatoes in a bowl and season with ¼ tsp of salt and plenty of pepper. Add the remaining oil to the same pan (don’t worry about wiping it clean) and, once very hot, add the aubergines and tomatoes. Fry for 10 minutes, on a medium-high heat, turning them often until the aubergine is soft and golden brown and the tomatoes are beginning to blacken.

3. Return the garlic and onion to the pan, then add the lentils, stock, wine, 450ml of water and ¾ tsp of salt. Bring to the boil. Lower the heat to medium and simmer gently for about 40 minutes, until the lentils are soft but still retain a bite.

4. Serve warm, or at room temperature, with a dollop of crème fraîche, a drizzle of oil, and chilli flakes and oregano on top.
Plum, blackberry and bay friand bake

Serves 6, generously

**Ingredients**

200g blackberries  
4 ripe plums, stones removed, cut into 1cm wide wedges (approx. 380g)  
1 tsp vanilla extract  
60g caster sugar  
3 fresh bay leaves  
1 tsp ground cinnamon  
60g plain flour  
200g icing sugar, sifted  
120g ground almonds  
⅛ tsp salt  
150g egg whites (from 4-5 large eggs)  
180g unsalted butter, melted and slightly cooled

**Method**

1. Place the blackberries and plums in a bowl with the vanilla extract, sugar, bay leaves and ½ tsp of cinnamon. Set aside for 30 minutes. Don’t be tempted to leave them sitting around for longer than this, as the fruit will become too juicy.

2. Preheat the oven to 210°C/190°C fan/gas mark 6.

3. Mix the flour, icing sugar, ground almonds, the remaining ¼ tsp cinnamon and salt in a separate large bowl. Set aside.

4. Lightly whisk the egg whites by hand for 30 seconds, so they just start to froth. Stir into the flour mixture, along with the melted butter, until combined.

5. Tip into a 20 x 30cm parchment-lined baking dish and top evenly with the fruit and juices. Bake for 40 minutes, covering the dish with foil for the final 10 minutes, until the batter is golden-brown and the fruit is bubbling. Set aside for 10 minutes before serving.
Get involved!

Arthritis Care works with – and for – people who have any type of arthritis. We are here to help you manage your condition better, and stay active, independent and connected.

Standing up to arthritis

Honouring a life

A plaque commemorating the life and achievements of Arthur Charles Mainwaring-Bowen was unveiled 16 August, in Pontyberem, Llanelli.

Mainwaring-Bowen, better known as Waring, was diagnosed with ankylosing spondylitis at the age of 19, bringing his time at university to an end. Seeing a need for support for those with inflammatory arthritis, he founded the British rheumatic Association in 1947. This later became known as Arthritis Care, who Waring worked with until he died in 1980.

The plaque was unveiled at Pontyberem Memorial hall by Waring’s widow, Helen Barbour, with the tribute organised by Llanelli Community Heritage.

Kids in control

The Take Control Programme is a part of Arthritis Care’s Young People & Families Service, offering free workshops for those aged 10-18 with arthritis and related conditions.

On 17 November, the Take Control team will deliver a communication, happiness, assertiveness and transition (CHAT) workshop in Aberdeen. This will cover how to talk about arthritis with people in our lives, such as friends, teachers and doctors, and how to prepare for and manage change.

The workshop will be a safe space for young people to share and discuss their experiences and learn from each other, with the topics tackled in a fun and approachable way.

For more information, contact Izabela on 0141 251 0300 or email IzabelaM@arthritiscare.org.uk

Getting Powys active

Arthritis Care’s Get Active project has been hugely successful in Powys, Wales. Newton, in particular, has seen the project’s popularity soar, with the launch of an activity support group in July 2018.

The group meets weekly for structured and accessible activities, including boccia and yoga. A regular support group is also held once a month. Since the launch, it has welcomed an additional six people, and membership is set to increase.

Dates for your diary:
Newton Methodist Church, Back Lane Newtown, Powys. Fridays 4.30pm-5.30pm

2 November: Chair-based exercise
9 November: Monthly support group.
The topic will be ‘Healthy eating and the party season’

For more info, email Helen Saxon-Jones at getactive@arthritiscare.org.uk or call 0800 756 3970.

Friends reunited

Were you a patient of the Canadian Red Cross Memorial Hospital, Taplow? If so, we would love to hear from you. We are a friendship and support group formed by ex-patients with juvenile idiopathic arthritis, who have kept in touch for more than 50 years.

We have more than 40 members and are planning a reunion for 2019. We keep in touch using our Facebook group, reminiscing about our years on the wards, sharing photos and offering support. We would love to hear from you and see you at the reunion.

Call Lynda on 07828 571952, email taplowites@gmail.com, or join facebook.com/groups/taplowites. It’s a closed group, so only group members can see content.

For more information, contact Lynda on 07828 571952, email taplowites@gmail.com, or join facebook.com/groups/taplowites. It’s a closed group, so only group members can see content.

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Managing your relationships

Discovering you have a long-term condition can feel as if your world has come crashing down. Here’s some tips on how to manage the rollercoaster of emotions and maintain your closest relationships

WORDS: LOUISE PARFITT

“When I was first diagnosed with arthritis, I was both elated and shocked – at last I had a name for what I had been experiencing. Mistakenly, I thought arthritis only affected older people,” says civil servant Donna Roberts. Now aged 49, Donna was diagnosed with psoriatic arthritis in 2002, after months of tests to find out what was causing the pain in her hands, wrists, hips and knees.

This feeling of relief at pinning down your symptoms can quickly fade into anger and fear, as your thoughts turn to the future and how arthritis will affect your life. “Our thoughts tend to run away into worst-case scenarios,” explains pain management counsellor and mindfulness teacher Kim Patel (counsellinginwrexham.co.uk). “Our minds and bodies are connected, so any negative emotion causes us to tense up, which increases pain.”

Patel explains that mindfulness and counselling can help us to take a step back and work through our feelings, rather than blocking them or carrying on regardless. “Research shows that when we accept where we are with a long-term condition, we
have a better quality of life and our pain reduces,” she says. “Acceptance is not about resignation or giving up. It’s about taking hold of our condition and working with it, not against it.”

**Telling others**

Deciding who to tell – and when – is a very personal decision. Remember that you don’t have to tell everybody all at once. “Think about who really needs to know, such as your closest family and your line manager at work, to avoid becoming overwhelmed as you get used to your diagnosis,” says Counselling Directory member Simone Ayers (counselling-directory.org.uk).

Choose a time when you don’t feel rushed. It can be useful to have the conversation when you are occupied with an activity – such as going for a walk or washing up – because it allows you both some space to think. “Be aware that the person you are telling may not be able to process everything at once, so letting them know where to find more information after they have digested the news is helpful,” says Ayers.

They are likely to experience similar feelings to those you had first – and naturally their thoughts will jump ahead to the future and the impact on them, which is quite normal. “Use simple language to reduce the chance of confusion,” advises Patel. “Say what it is, what you understand by it, and what isn’t helpful for you to hear, because it can be really hard on you to break the news as well.”

**Shifting sands**

Over time, your feelings and emotions towards living with arthritis may change dramatically – and may even vary from day to day. Accepting that there will be good days and bad days can help make life with arthritis more bearable, and it is important to understand what you can do and recognise your achievements.

“When I feel arthritis is hampering my life, I remember that if it had manifested as a broken limb I would have to take it into account,” says Roberts. “If arthritis has taught me anything, it is patience – and that all those to-do lists can be redone.”

Support groups can be a great outlet, as you can talk about how you’re feeling to others who may be in the same position. “There may be times when we experience grief for our ‘old body’, but talking about these feelings can help us find hope and even humour in our situation,” explains Ayers.

**Your relationships**

Ayers believes it is important to maintain contact with those you are closest to, even if that means swapping late-night dinner dates for lunches when you are less tired. “Cherish simple moments like a chat over coffee or a phone call to stay connected to others,” she says. Intimate relationships can take time to settle down, because roles change and you may need to lean on others for support. “Partners will have their own emotional response, so giving them space to share these feelings will help you support each other as a team,” says Ayers.

Patel advises having weekly or even daily check-ins to chat with each other about how you are feeling and keep the lines of communication open. She says that for friends and family who take on a caring role, it is important to maintain intimacy – hugs, hand holding, sharing things together – to avoid the relationship becoming purely functional. “It is really important to maintain that sense of self – you are not your condition, you are still you,” she explains.

For Donna, living with arthritis means she has learned to put herself first. “Saying no to invitations can seem harsh, but there’s no point going along and feeling worse,” she says. “I still socialise, I’m still a friend, an auntie, a great-aunt and a colleague – but I make me a priority.”

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**COPING WITH CHRISTMAS**

1. Don’t do too much beforehand, as you may exhaust yourself and cause a flare-up. “People tend to get caught in a cycle of ‘boom and bust’ around Christmas as they try to do what they always did, but their body has different ideas,” says Kim Patel. Pace yourself. If you are cooking, do it in short bursts and freeze what you can. You might want to buy desserts rather than making things from scratch.

2. Plan some rest periods for Christmas Day – and let people know in advance. “Take time out to have a nap or recharge,” says Simone Ayers.

3. Explain to people that you may need help. “People need to know how best to support you – they cannot read your mind,” says Patel. If you are spending Christmas alone, or need to talk to someone other than friends and family, there are a number of free helplines you can call. These include Samaritans – open 24 hours, 116 123; Age UK – 8am–7pm, 0800 055 6112; and Silverline – open 24 hours, 0800 470 80 90. All these helplines are open over Christmas – even on Christmas Day.
Call us today, we’re here for you.

Arthritis Care’s friendly helpline is free and confidential. Whether you need information, support or just a listening ear, we’re here to help you live well with arthritis.

Contact us Monday to Friday, 9am-8pm by phone 0800 5200 520 or email helplines@arthritiscare.org.uk

Arthritis Care is a registered charity in England and Wales (207711) and Scotland (SC041156)