

Support for the FM Family

FIBROMYALGIA MAGAZINE

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including

Dealing with the school holidays
when you have fibromyalgia



Getting The Picture Across: Using the Power of Imagination to Cope with Fibromyalgia

by Katarina Zulak

It's almost funny that the single word *pain* is supposed to mean all of the different sensations you feel when you live with a chronic pain condition. I find it hard to describe in words how different pains physically feel, especially to someone who does not have chronic pain. Sometimes a metaphorical image captures it best.

Visual Metaphors Can Improve Communication By Evoking Empathy

Visual metaphors are better able to evoke understanding and empathy in others (G. D. Schott). If I tell you about a large needle being slowly inserted into my eyeball, your reaction is likely to cringe, grimace and/or squint your eyes.

When you hear someone describe an image of something happening to them, your brain will “mirror” that experience – you imagine what it would literally feel like for the same thing to happen to you. In fact, we have neural pathways, called mirror neurons, devoted to empathizing with other people this way: “both mirror neuron and alternative neural networks are likely to be enlisted in the empathetic response to images of pain” (G. D. Schott). Using visual metaphors can help you to describe your pain better to your doctors and your family and friends.

Nerve pain brings to mind intensity, heat and electricity. My sciatic pain can feel like a zap of

electricity – a sudden, searing, mini-bolt of lightning. Pain is often compared to a burning or searing fire. Describing a sharp stabbing feeling, like a hot knife, can really help to get the picture of how your pain feels across.

Muscle pain might be best described as a tool-kit wielded by a sadistic handyman. The drilling in my head referred from spasmed neck muscles, the throbbing ache in my SI joint like a hammer pounding down on the spot. It's also common to describe pain as a tormenting animal, clawing, tugging or squeezing the painful area of the body.

Deep, internal pain can feel like the pressure of a bowling ball, or worse, an anvil, suddenly teleported pressing down on the painful area. Some tools from the sadist's toolkit might join the party, like pliers pinching or an ache that feels like a vice grip being tightened.

Take a deep breath after reading those descriptions. They can be stressful to contemplate, because it may bring to mind all the different pains you feel at once, and/or activate your mirror neurons so that you're imagining many types of pain at once. Luckily, the power of visualization can be used not just to describe pain, but to reduce it as well.

Use The Power Of Your Imagination To Manage Your Pain Better

If you have chronic pain, just reading or hearing descriptions of pain metaphors might start to make you feel tense and stressed. Images can elicit a very physical response, bypassing the analytical parts of our your brain. If I describe the sensation of a dentist drill, whirring away, drilling a hole deep into my hip joint, how do you feel? In contrast, imagine I describe being in a forest, with sunshine streaming through the trees and dappling the forest floor – do you feel more relaxed? That's the power of our imagination to affect thoughts and feelings.

In fact, visualizing can be a potent way to ease pain and shift attention. Imagining a soothing, or more positive mental picture can significantly lower levels of the stress hormone cortisol. When you enter a relaxed state, your brain releases endorphins, which are natural pain-relieving biochemicals. Using your imagination is a helpful way to distract from focusing on pain, which is likely another reason that visualization can help to manage pain. Numerous studies have demonstrated that guided imagery reduces pain and improve physical function.

Guided imagery often involves visualizing tranquil natural settings, like walking on the beach or in a garden. The visualization should incorporate all of your sense. For example, a beach visualization would include the mental image of a beach, but also the sound of the surf and the cry of seagulls, the smell of salt air, the feeling of sand under your feet – you get the idea. There are many websites, CDs and apps that provide sessions you can listen to if you're interested in using this technique.

Another technique involves reframing your original visual pain metaphor or replacing it with a pain reduction visual metaphor. For example, if you feel like your pain sensation is like being pricked by hot needle, then you reframe visual to be a cold needle. After concentrating on that, you can imagine the needle itself becoming soft, like a string of spaghetti.

Guided visualization to soothe pain involves minimizing, distancing or numbing the pain sensation. You can imagine the warm oil being poured over tight muscles, for example, or ice freezing out burning sensations. The secret to success with any visualization technique is practice and repetition – it becomes more effective the more you do it.

A Picture Is Worth 1000 Words: Express Yourself Using Art Therapy

Envisioning pain can also go past physical sensations into describing how the pain impacts your life. If I was going to draw a picture of my fibromyalgia, it would be like a cage. I often feel trapped within limitations of what I'm able to do for the pain flares and I have to stop. Chronic pain can feel like an alarm that is always blaring – like trying to work through a fire drill. I would probably use colours like bread and orange or grey and black to describe The 'feel' of pain.

Not surprisingly, exercises that get you to draw your pain/health condition are also helpful to relieve stress. "Expressing oneself through [art] makes our thoughts, feelings and ideas tangible and communicates what we sometimes cannot see through words alone" (Psychology Today). Creative expression is quite healing, even if it's limited to abstract doodles or colourings. Drawings and collages can also picture positive images that evoke well-being.

What is a visual metaphor for your pain? If you had to draw an image of your chronic pain condition, what would it look like?

Resources

Psychology Today (Picture Of Health: An Art Therapy Guide) <https://www.psychologytoday.com/ca/blog/arts-and-health/201703/drawing-picture-health-art-therapy-guide>

Arthritis (Guided Imagery For Arthritis) <https://www.arthritis.org/health-wellness/treatment/complementary-therapies/natural-therapies/guided-imagery-for-arthritis-pain>

Calgary Neuropathy Association (Visualization And Pain Management For Neuropathy) <https://calgaryneuropathy.com/visualization-pain-management/>

Brain (G. D. Schott: Pictures Of Pain And Their Contribution To The Neuroscience Of Empathy) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4408436/>



The Onerous Healthcare Void for Fibromyalgia Patients

by Brandi Clevinger

Recently, I've had the pleasure of being interviewed by the editor of the Italian edition of *The Fibromyalgia Magazine*. During the interview, questions were asked about how the health system supports me as a fibro mom and the importance to disseminate correct information about fibromyalgia. It was then I realized how much healthcare has failed fibromyalgia patients and the effect of incorrect information from public health organizations has on healthcare.

The lack of adequate care has not been lost on me and is not something I didn't already know. In my own experience, I've been mocked, minimized, and dismissed repeatedly by medical providers. It took me six years to receive a proper diagnosis and even after diagnosis it's been difficult to receive proper medical care. Because of my experience, I started blogging about living with fibromyalgia as a parent and became an advocate.

What renewed my frustration was how the lack of proper medical care affects fibromyalgia patients and their families and just how large this fissure in healthcare has grown in the past decades. The magnitude of it reached out and settled around me in a heavy cloak that I could not ignore or easily shrug off.

In these technological times, there should be no reason for the shortage of information on a condition that was first extensively studied by German and British physicians in the late 1800s¹. Even after the more accurate and accepted name of 'fibromyalgia' was determined by the medical community in the 1990s, not much has changed in terms of diagnosis and treating.

What I want to know is *why*. How come a condition that has been around for over a century (with references to it during biblical times) still has not had the medical research necessary to help patients manage their symptoms? Why isn't the origin of fibro more definitive? For these answers, we must dive into the condition itself.

Fibromyalgia is a syndrome that mainly affects the central nervous system. It also affects the digestive, endocrine, immune, muscular, and respiratory systems. The disruption in function of the organs within those systems manifests as a multitude of symptoms. Symptoms include muscle pain and/or muscle spasms, difficulty remembering or concentrating, abdominal pains, sensory sensitivities, chronic pain, and fatigue, to name a few. It also leads to emotional and mental distress.

With a condition so extensive affecting various body systems, it's difficult to pinpoint how it develops or where it originates. What triggers it? Is it caused by genetic makeup? Does a malfunction of a bodily system trigger it? Perhaps a different condition or disease leads to the development of fibro? There's strong speculation that trauma of any kind can induce the onset of symptoms. There are possibilities and theories, but that's all it is: possibilities and theories.

Because it is largely unknown what definitively causes it or where it originates, there's no definitive way to diagnose or treat it. At best we are treating the symptoms and not the condition in and of itself. Furthermore, because fibro affects multiple systems and the origin is unknown, it's an ongoing debate as to which medical provider or specialist would be responsible for diagnosing, administering treatment, and continuing care. As a result, patients are passed from one specialist to another.

The harsh reality is that little fibromyalgia-specific research is present in the medical community and the information available through public health organizations is widely inconsistent. Most providers will not bother themselves with inquiring more about it because it's overwhelmingly lacking. They are exhausted and overloaded with patients as it is, so taking the time for a complicated condition such as fibro is highly improbable.

There are some patients 'lucky' enough to find marginal care through their primary care provider (PCP) in an effort to sustain their current condition and prevent it from worsening. Fibromyalgia itself is not progressive, but symptoms can worsen over time if not properly treated. It's not uncommon for a PCP to prescribe pain narcotics, antidepressants, or other medication in a vain attempt to provide some relief to the patient's discomfort. (And in today's opioid crisis, even that option has rapidly closed with little options taking its place.)

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opioid crisis, even that option has rapidly closed with little options taking its place.)

In many instances, fibromyalgia patients are abandoned, falling into a gap where medical care is insufficient and, in many cases, nonexistent. And it is in this onerous healthcare void for fibromyalgia patients their health deteriorates. No longer able to turn to a medical expert for help, patients begin to doubt their suffering. We sit in our mental anguish and physical discomfort for so long that we believe there is no end to it. Some lose hope. And in some cases, patients have taken their lives to end their suffering.

The absence of healthcare has devastating effects on fibromyalgia patients. Their caregivers and loved ones suffer as well, and families become disconnected and torn apart. I reached out to the fibromyalgia community to ask how they are affected by their current healthcare. The responses were crushing, but their stories need to be heard.

The following truths were gathered from readers' responses from the Being Fibro Mom social media accounts. I also collected experiences from the members of the Fibro Parenting group on Facebook. These are real stories gathered by real fibromyalgia patients around the globe.

The onset of symptoms usually begins with unexplained pain and/or chronic fatigue. An initial physical examination (sometimes accompanying bloodwork) will show no indicators as to why the patient is experiencing pain and fatigue. But when the pain and fatigue continue with no real cause that can be measured, tested, or seen, fibromyalgia is diagnosed. In many cases, it takes several years for them to arrive at this diagnosis.

Sometimes primary providers will order lab tests to check on deficiencies in the blood. And if there are any found, they will defer to those deficiencies as the cause of symptoms. No further testing required. And if the levels are normal, we are told everything is fine and to either get more sleep, eat healthier, or exercise more.

With no solid explanations from a provider, we are labeled as 'lazy', 'attention-seekers', and a hypochondriac. These labels become synonymous with fibromyalgia, and future medical appointments (especially the ones landing us in the emergency room or urgent care) will be cut short upon seeing that diagnosis of fibro.

Many patients are referred to multiple specialists in search of an answer only to leave empty-handed aside from yet another expensive medical bill. Eventually, the medical bills pile up, and seeking additional help is no longer an option as they struggle to pay for all the repeated emergency room visits, extensive testing, and the costs of specialists. For those parents living with fibro, we are unable to properly care for ourselves let alone our children. What should be a time of making memories with our children is instead filled with guilt and grief because we are unable to play with them. Our days consist of pacing our activities and energy levels so as not to become depleted of all energy (which means not a lot of physical activity otherwise it will result in being bed-bound for days). Oftentimes children do not have the capacity to understand why we are unable to interact and engage with them, so it's translated as a form of rejection. It's disheartening and disappointing.

A majority of fibromyalgia patients have to file for disability due to their inability to work caused by debilitating issues such as chronic muscle pain/weakness, frequent headaches/migraines, and chronic fatigue. Many of these cases are denied as a result of not having 'enough proof' of having fibro. In other cases, the request is denied because 'pain is not objective'. As a result, the patient is unable to financially provide for themselves and their families causing further health issues.

In some instances, the afflicted is an adolescent or younger child. The parents of these children are told the symptoms are caused by growing pains or allergies. Medications are prescribed and the child is expected to 'start feeling better soon'. Even upon the parents' insistence of it being more than growing pains or other dismissive causes, the provider is hesitant to run more tests and will assure the parent is worrying too much.

Because patients fall into the healthcare aperture, some of them are taking their health into their own hands. They are learning to advocate for themselves (which I believe all patients should do to an extent) and figuring out what helps their symptoms and what worsens it. They become both the patient and provider striving to improve their well-being to the best of their ability. Some are successful and others are not.

Those that are failing at handling the management of their symptoms are met with hopelessness and

confusion. They can't imagine a life in which they are healthy and able to enjoy themselves. They suffer mentally as well as physically becoming depressed and dejected. Dispirited, they hide in their homes and suffer in silence.

To conclude, patients do not deserve to be cast out of the medical community to lead a poor quality of life simply because we live with a condition that is under-researched and many providers do not readily understand. We know all too well the overwhelming confusion fibromyalgia inflicts. All we are asking for is compassion and a willingness to help.

For the medical community, fibromyalgia is a small blip on the radar, but for those living with it, it is our lives. We are not a numbered chart within our providers' offices to be slid onto a shelf and be passed over purely because it's easier to do. We ask for more, for the sake of our humanity and for the sake of our well-being.

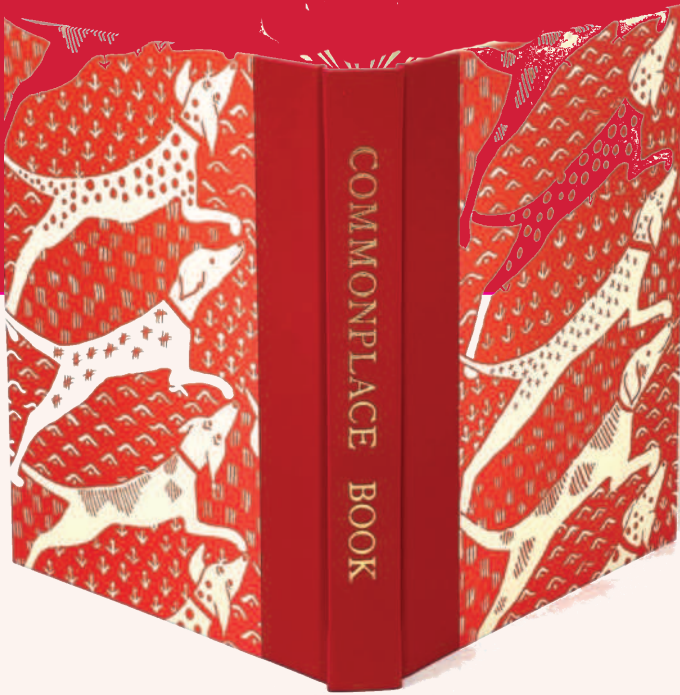
There are ways to improve this collapse of healthcare and to begin closing the aperture. Hope can and should be restored to all of those living with fibromyalgia. In the next month's issue, we will explore the ways to be able to climb out of this medical mess and into a better state of health.

Sources:

1. Marek, C. C. (2003). *The First Year - Fibromyalgia: An Essential Guide for the Newly Diagnosed*. Da Capo Press.

Making your own Fibro Manual (or Commonplace Book)

by Sarah Warburton



It was a gloomy November afternoon during lockdown 2 and I was idly browsing through some of the items in the British Library's online collection when I came across the manuscript of the poet John Milton's commonplace book. Created between 1630 and 1650, the book contains page upon page of handwritten notes and quotations on topics as diverse as politics, marriage and divorce as well as details of the books that Milton had read. Back in 17th century Britain, commonplace books were a popular way for owners to jot down anything and everything, whether informational or inspirational in nature.

All of this made me think of my humble, red fibro folder which I call my fibro manual and how, in essence, this is my own version of a commonplace book. My folder is not so different from the scrapbooks I kept as a child, although these were mainly focussed on either horses or the fortunes of Liverpool Football Club!

I've gathered reams and reams of fibro related information ever since I was presented with a handful of Arthritis UK leaflets by my rheumatologist during my initial diagnosis consultation which were duly read before being filed in my red folder. Fast forward seven years and that same (now rather battered) red folder is full to bursting with the notes I've taken from the myriad fibromyalgia and chronic pain books I've read during the intervening years, course materials from chronic pain and mental health classes attended, poems, physical exercise diagrams, recipes, information on natural

supplements and even one line retorts that I can use in response to all those spiteful comments from fibro doubters. In short, my folder has become my go to place for everything I've learned about fibro, my own personal bible, if you will.

So what are the benefits of creating your own fibro manual or commonplace book?

It's a reminder of how much we've learned since diagnosis - I'd never even heard of fibromyalgia when I was diagnosed and so some of the information in my folder relates to basic facts, figures and management tips about the condition. Reviewing this reminds me that I now have a lot of practical knowledge about living with fibro and that I've come a long way on my own health journey.

It acts as a pick me up when things aren't going so well - now that I'm fully versed in life with fibro, this is probably the main reason why I pick up my red folder these days. I find that 20 minutes leafing through the information in my folder does give me a boost, motivation when I sorely need it or kind words of encouragement that this too will pass.

It can give a quick hit of pertinent information - there is so much information about chronic illness available and not all of it will resonate with everyone. Keeping what's meaningful to us in one place means we can quickly access what's relevant.

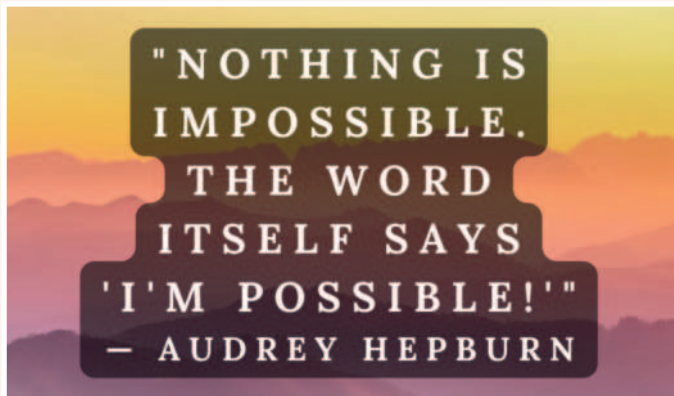
It's a place for useful stuff for future reference - sometimes we come across information that we think will be useful but for whatever reason, be it time, season or finances, we can't take further right now. The commonplace book is a good place to store information for the future.

And finally, it helps with fibro fog - having a book or folder can help us to remember information or suggestions which we can so easily forget if fibro fog strikes. It can also save us from leafing through pages of information, trying to recall where we read such and such a thing.

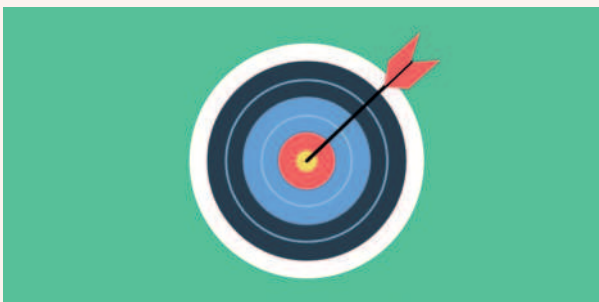
What could be included?

The bottom line is that anything and everything which you may find useful could be included, but here are some ideas to get started with:

- Course / book notes – from any chronic pain management / mental health courses attended or books read.
- Inspirational Quotes – these could be connected with fibromyalgia, chronic pain or not - anything that inspires you.



- Poems – my own personal favourite which is so relevant to my life with fibromyalgia is Portia Nelson's poem "Autobiography in Five Short Chapters".
- Recipes
- Exercises – e.g. yoga for fibromyalgia.
- Leaflets from charities / organisations supporting those with chronic conditions.
- Magazine Articles – fibromyalgia crops up quite often in general interest magazines which carry health features and these can contain some useful information.
- Information on associated conditions – e.g. migraines, costochondritis, mental health conditions etc.



- Goals – documenting goals can show how far we've come in our journey. Some of my first goals were, staying awake 2 afternoons

per week and walking for 30 minutes, both of which I routinely manage these days but years ago, they were major challenges for me.

- Things to research in the future – anything which interests us but we're not able to pursue at this time.

The actual format of a commonplace book can vary too. My folder is somewhat utilitarian in nature but I like to keep leaflets and printed sheets as well as as my own handwritten notes, so wanted something with plastic sleeves to keep everything in one place. But if you're intending to hand write everything, then you could purchase a decorated book which feels special to use.

In short, there are infinite options for what to include and how to collect information about our condition and it really depends on what motivates and inspires each person. For me though, the key benefit is having my own personal fibromyalgia handbook which I can dig out from the drawer knowing that I'll almost always find just the words or pictures I need to give me a boost.

Sources:

<https://www.bl.uk/collection-items/john-miltons-commonplace-book>

The Impact of Fibromyalgia on Grandparents: Nurturing Relationships with Grandchildren

Fibromyalgia, a chronic condition characterized by widespread pain and other debilitating symptoms, not only affects individuals directly but also has an impact on their immediate family members. For grandparents with fibromyalgia, managing the condition while maintaining a meaningful relationship with their grandchildren can be challenging. In this article, we will explore the unique dynamics between grandparents with fibromyalgia and their grandchildren, as well as strategies for nurturing these relationships while coping with the condition.

1. Communication and Education: Open and honest communication is crucial when explaining fibromyalgia to grandchildren. Depending on their age, it is important to use age-appropriate language and explanations. Here are some suggestions:

a. Simplify explanations: For younger grandchildren, use simple language to explain that grandma or grandpa has an illness that causes pain and fatigue. Assure them that it is not contagious and that it is not their fault.

b. Encourage questions: Create a safe space for grandchildren to ask questions about fibromyalgia. Answer their inquiries honestly and without judgment, helping them understand that it is a real condition that impacts their grandparent's daily life.

c. Provide educational resources: Offer books, articles, or online resources that explain fibromyalgia in a child-friendly manner. This can help children grasp the concept and feel more informed and involved in their grandparent's experience.

2. Modify Activities and Routines: Fibromyalgia symptoms can limit a grandparent's ability to engage in certain activities or maintain regular routines. However, with some adjustments, it is still possible to create meaningful experiences with grandchildren. Consider the following:

a. Plan low-energy activities: Choose activities that are less physically demanding but still allow for quality time together. Examples include reading books, doing puzzles, watching movies, or engaging in crafts or board games.

b. Create a restful environment: If hosting grandchildren at home, make sure the environment is comfortable and accommodating. Create a quiet area where the grandparent can rest or nap when needed.

c. Pace activities: Break activities into smaller, manageable segments, allowing the grandparent to rest in between. This approach helps conserve energy while still participating in enjoyable activities.

3. Seek Support from Family and Friends: The support of loved ones can make a significant difference in the lives of grandparents with fibromyalgia. Encouraging family and friends to understand and assist in managing the condition can help foster positive experiences with grandchildren:

a. Share responsibilities: Communicate openly with family members and distribute caregiving responsibilities. This can provide grandparents with much-needed rest and ensure that they have the energy to engage with their grandchildren.

b. Coordinate schedules: Work with family members to coordinate visits and activities around the grandparent's energy levels and limitations. Planning ahead and considering the grandparent's needs can help create more enjoyable and manageable interactions.

c. Support groups and counseling: Encourage the grandparent to seek support from fibromyalgia support groups or professional counseling services. These resources can provide emotional support and practical advice on managing the condition while maintaining family relationships.

4. Practice Self-Care: Self-care is essential for grandparents with fibromyalgia to maintain their overall well-being and effectively engage with their grandchildren:

a. Prioritize rest and relaxation: Encourage the grandparent to listen to their body and take regular breaks to rest and recharge. Practicing relaxation techniques, such as deep breathing or meditation, can also help manage symptoms.

b. Maintain a healthy lifestyle: Promote healthy habits, including a balanced diet, regular exercise (as tolerated), and sufficient sleep. These factors can contribute to better symptom management and overall energy.

For Robert

Some friendships end way to soon,
And some people burn to bright.
I guess the fire that was you,
Burned so much it killed the light.
I hope you know you were never out of mind,
Even with years out of sight.
Those that don't understand old friendships,
We never found that bright!

The outrageous stories that I tell,
you know that they were true!
Because all the best and funniest were
the ones with me and you.
We were a bunch of lawless bohemians,
me with poetry you with sound.
We did as we pleased, when we pleased,
using England as our playground.

I miss making stories with you,
being so wild and free.
But I'm sure you know that those stories
will forever be part of me.
Like that time you marched naked
up and down a bus,
Then we chatted with three women,
and of course they left with us!
Or in one day we seen more police
then I've ever seen in my life.
And yet somehow we were let go
without even a little strife!

I hope you know that you were loved,
In my heart you still are!
And your passing has not changed my heart
only now it has a scar!

I guess it's goodbye old friend,
But I'll see you when this life is through.

So say hi to Mother Mary for me,
And know we still all love you

For

Robert James Selby

23 July 1985 – 06 April 2023



You Mon frere were born before your time,
You my friend found your answers inside wine,
You my brother layed beneath a weeping willow,
You my prophet used kerouac as a pillow,
You my poet gained illumination from Rimbaud,
Rob you troubadour found yourself
at desolation Row,
You my wounded soldier fought
every losing battle,
You my legend gave me lease from my shackles,
You my comet burnt out way too soon,
You my artist painted light inside gloom,
You my jester gave me a smile a mile long,
You're love for music echoed a nightingales song,
And now your evanescent spirit will live on
through forever and rewrite any wrong.

By James Craig

CATS OF PERE LACHAISE

By Robert James Selby

One morning I went walking out among the dead
Cos the sun just about kicked me out my bed
And trying to recover what was left of my head
Down the rue avenue of the Pere Lachaise
O' we're all gonna' die
But you can come back as a bird
You can fly the sky, getting high
Just you be careful, where you build your nests
Or you will be killed by the cats of Pere Lachaise
They walk among the tombstones, climb the trees
They listen to the songs of ghosts coming on the breeze
No nothing that you or I have ever heard or read
Compares to that of the cats of Pere Lachaise
O' we're all gonna' die
But you can come back as a bird
You can fly the sky, getting high
Just you be careful, where you build your nests
Or you will be killed by the cats of Pere Lachaise
When the moonlight comes shining down on every casement
It opens like a key, the window of enchantment
The silvery shadows the cats and the bats
They dance to the death and at mortality laugh
O' we're all gonna' die
But you can come back as a bird
You can fly the sky, getting high
Just you be careful, where you build your nests
Or you will be killed by the cats of Pere Lachaise
You're gonna' be killed by the cats of Pere Lachaise
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You're gonna' be killed by the cats of Pere Lachaise





Natural Remedies for Fibromyalgia: Holistic Approaches to Alleviate Symptoms

Fibromyalgia is a chronic condition characterized by widespread musculoskeletal pain, fatigue, sleep disturbances, and cognitive issues. While there is no known cure for fibromyalgia, various natural remedies can help manage its symptoms and improve quality of life. In this article, we will explore a range of holistic approaches and lifestyle modifications that can provide relief for individuals with fibromyalgia.

1. Diet and Nutrition:

Proper nutrition plays a crucial role in managing fibromyalgia symptoms. A well-balanced diet can help reduce inflammation and promote overall health. Here are some dietary recommendations:

a. **Anti-inflammatory foods:** Incorporate fruits and vegetables, whole grains, lean proteins, and healthy fats into your diet. Avoid processed foods, refined sugars, and saturated fats, which can exacerbate inflammation.

b. **Omega-3 fatty acids:** Increase your intake of omega-3 fatty acids found in fatty fish, flaxseeds, and walnuts. These essential fatty acids possess anti-inflammatory properties and may help reduce pain and stiffness.

c. **Elimination diet:** Some individuals with fibromyalgia may benefit from identifying and eliminating trigger foods. Common culprits include gluten, dairy, caffeine, and artificial additives. Experiment with eliminating these foods one at a time to identify potential sensitivities.

2. Exercise and Physical Activity:

Regular exercise is essential for managing fibromyalgia symptoms. While it may be challenging to engage in physical activity due to pain and fatigue, starting with gentle exercises and gradually increasing intensity can be beneficial. Here are some recommendations:

a. Low-impact exercises: Opt for low-impact activities such as walking, swimming, yoga, tai chi, or water aerobics. These exercises can improve cardiovascular fitness, reduce pain, and enhance flexibility without placing excessive stress on the joints.

b. Strength training: Incorporate strength training exercises to build muscle strength and improve overall function. Start with light weights or resistance bands and gradually increase intensity under the guidance of a qualified professional.

c. Stretching and flexibility exercises: Include stretching and flexibility exercises to alleviate muscle stiffness and improve range of motion. Activities such as Pilates or gentle stretching routines can be particularly helpful.



3. Stress Management Techniques:

Stress can worsen fibromyalgia symptoms. Therefore, adopting stress management techniques is vital for managing the condition. Here are some strategies to consider:

a. Relaxation techniques: Practice deep breathing exercises, meditation, progressive muscle relaxation, or guided imagery to promote relaxation and reduce stress levels.

b. Mind-body therapies: Consider complementary approaches like acupuncture, massage therapy, or chiropractic care. These therapies can help alleviate pain, reduce muscle tension, and promote overall well-being.

c. Cognitive-behavioral therapy (CBT): CBT can help individuals with fibromyalgia develop coping mechanisms, manage stress, and improve their overall mental outlook. It focuses on identifying and modifying negative thought patterns and behaviors.



4. Sleep Hygiene:

Fibromyalgia often disrupts sleep patterns, leading to fatigue and increased pain. Establishing good sleep hygiene practices can help improve sleep quality:

a. Consistent sleep schedule: Maintain a regular sleep-wake cycle by going to bed and waking up at the same time each day, even on weekends.

b. Create a sleep-friendly environment: Ensure your bedroom is dark, quiet, and at a comfortable temperature. Use a supportive mattress and pillow to optimize comfort.

c. Relaxation techniques before bed: Engage in relaxing activities before bedtime, such as reading, taking a warm bath, or practicing gentle stretching.

Fibromyalgia in the elderly - an overlooked issue?

By Dr D. Mantle FRSC FRCPath, Medical adviser, Pharma Nord (UK) Ltd and
Dr I. R. Hargreaves FRCPath, Senior Lecturer, Liverpool John Moores University



As readers of this magazine know only too well, fibromyalgia is a disorder that can occur at any age in both men and women. However, fibromyalgia may be considered by some medical practitioners as a condition primarily affecting middle-aged women.

As a result, fibromyalgia in older patients has tended to be understudied, and because of the likelihood of other age-related problems, diagnosis of fibromyalgia in the elderly may be overlooked.

Study shortage

Only six clinical studies relating specifically to fibromyalgia in the elderly have been published in the medical literature over the past 30 years. In 1988, Yunus et al first reported that fibromyalgia in the elderly was often unrecognised, and treated with inappropriate medications such as steroids.

The most recent study by Jacobsen et al (2015) found that more than 80% of older (55 to 95 years) patients with fibromyalgia were subject to pain, lack of mobility and sleep disruption resulting from under-treatment; in addition many of these patients were using ineffective and potentially harmful opioid or steroid type medications.

What can help older fibromyalgia sufferers?

Two non-pharmacological interventions known to benefit fibromyalgia are exercise and nutrition (Busch et al, 2011; Bjorklund et al, 2018).

Exercise is an important part of the treatment in fibromyalgia, and it also helps keep weight down, which reduces the stresses on the joints; however older individuals may find taking part in such exercise regimes challenging.

With regard to nutrition, supplementation may benefit the primary symptoms or co-morbidities associated with fibromyalgia, as described in previous issues of Fibromyalgia magazine. Thus supplementation with coenzyme Q10 may benefit the cardinal symptoms of muscle pain and fatigue (December 2017 issue), as well as headache and migraine (April 2019 issue). In addition, nutritional supplementation can benefit co-morbidities such as gastrointestinal dysfunction (probiotics; May 2018 issue), osteoporosis (calcium, vitamin D3, vitamin K2; March 2018 issue), sleep problems (melatonin; August 2018 issue), and thyroid dysfunction (selenium; February 2019 issue).

The importance of nutritional supplementation

Nutritional supplementation may be of particular importance in the elderly. The body requires a range of nutrients to maintain normal functioning. Some of these, such as coenzyme Q10 and glucosamine, are manufactured within the body, whilst many (such as vitamins) are obtained from the normal diet.

As people age, their bodies become less efficient at manufacturing nutrients such as coenzyme Q10, or absorbing dietary nutrients from the digestive tract. As an example, optimum production of coenzyme Q10 occurs around 25 years of age, production then gradually declines with increasing age, such that production at age 65 is approximately half that at 25. Thus, supplementation with coenzyme Q10 in older individuals with fibromyalgia addresses two issues: a deficiency known to occur in fibromyalgia, and a deficiency known to result from the normal ageing process.

The nutrients you may be missing out on

Similarly, the elderly are at risk of the potential deficiency in a wide range of other essential nutrients, and a study by Borg et al (2015) identified deficiencies of:

- vitamin D3
- vitamins B1, B2 and B12
- calcium
- magnesium and
- selenium

as being of particular public health concern. As noted above, many of these nutrients have been found to be depleted in fibromyalgia, with a corresponding benefit on symptoms following supplementation, so again supplementation addresses two issues: deficiency due to fibromyalgia and deficiency due to ageing.

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Dealing with the school holidays when you have fibromyalgia

Coping strategies for managing fibromyalgia symptoms during school holidays

Fibromyalgia is a chronic pain condition that can make even simple tasks difficult to manage. For parents with fibromyalgia, the school holidays can be an especially challenging time.

Dealing with the school holidays when you have fibromyalgia can present unique challenges, as the change in routine and increased demands on your time and energy can exacerbate symptoms. However, with the right coping strategies in place, you can manage your fibromyalgia symptoms effectively during this period. Here are some strategies to consider:

1. Plan and pace activities: Create a schedule for the school holidays that includes a balance of rest, leisure activities, and responsibilities. Pace yourself by spreading out activities throughout the day, allowing for breaks and time to recharge. Prioritize activities that are meaningful to you and align with your energy levels.

2. Set realistic expectations: Communicate your limitations and needs to your family and loved ones. Help them understand that fibromyalgia is a chronic condition characterized by fatigue and pain, and that you may need to modify or decline certain activities. Setting realistic expectations can reduce stress and prevent overexertion.

3. Practice self-care: Make self-care a priority during the school holidays. Engage in activities that promote relaxation and well-being, such as gentle exercises like yoga or swimming, meditation, warm baths, or listening to soothing music. Ensure you get enough sleep and maintain a balanced diet to support your overall health.

4. Seek support: Reach out to support groups or online communities for individuals with fibromyalgia. Connecting with others who understand your challenges can provide valuable emotional support and practical advice. Consider seeking professional help from healthcare providers who specialize in chronic pain management.

5. Utilize assistive devices: Explore the use of assistive devices or aids that can help alleviate strain on your body. For example, using ergonomic chairs or pillows, wrist supports, or mobility aids can reduce physical stress and discomfort during activities.

6. Practice stress management techniques: Stress can worsen fibromyalgia symptoms, so it's important to incorporate stress management techniques into your daily routine. This can include deep breathing exercises, mindfulness, journaling, or engaging in activities that bring you joy and relaxation.

7. Take breaks when needed: When living with fibromyalgia, rest is crucial. It's important to listen to your body and take breaks when needed. If you're planning a full day out, make sure to schedule in rest breaks throughout the day. This can help to prevent fatigue and reduce the risk of a fibromyalgia flare-up.

8. Consider childminding services: Childminding services can be a lifesaver for parents with fibromyalgia during the school holidays. This can include grandparents, family members, or trusted friends who can look after your children for a few hours at a time. This can give you the time you need to rest and recharge, and can also help to reduce your stress levels.

9. Adapting activities to suit your needs: If you find that certain activities are too challenging due to your fibromyalgia symptoms, it's important to adapt them to suit your needs. For example, if you're planning a day out at a theme park, consider renting a wheelchair for the day or using a mobility scooter to help you get around. This can help to reduce fatigue and make the day more enjoyable for both you and your children.

Remember, it's essential to listen to your body and adjust your plans accordingly. Be kind to yourself and prioritize self-care. By implementing these coping strategies, you can better manage your fibromyalgia symptoms during school holidays and make the most of your time with loved ones while preserving your well-being. Planning activities and outings during school holidays when living with fibromyalgia

Planning activities and outings during school holidays when living with fibromyalgia

When living with fibromyalgia, planning activities and outings during school holidays requires careful consideration and preparation to ensure that your

symptoms are managed effectively.

Here are some tips to help you plan activities that are enjoyable and accommodating for your condition:

1. Research and choose suitable activities: Look for activities that are low-impact, flexible, and allow for breaks when needed. Consider activities such as visiting museums or art galleries, going to the movies, or exploring nature parks with accessible trails. Avoid high-energy or physically demanding activities that may trigger or worsen your symptoms.

2. Plan in advance: Give yourself ample time to plan and prepare for outings. This includes considering factors such as travel time, accessibility, and any accommodations you may need. Making reservations or purchasing tickets in advance can help alleviate stress and ensure smoother experiences.

3. Break activities into manageable segments: Instead of planning long, uninterrupted outings, break them into smaller, more manageable segments. For example, if you plan to visit a theme park, consider splitting your time into shorter sessions with rest breaks in between. This way, you can pace yourself and prevent overexertion.



4. Communicate your needs: Inform your family and friends about your condition and any specific requirements you may have. Let them know about the importance of pacing yourself and taking breaks. Open communication will help them understand and support you during outings, making the experience more enjoyable for everyone involved.

5. Consider accessibility options: If you anticipate that certain venues or activities may pose challenges due to mobility issues or other symptoms, inquire about accessibility options. Many venues offer wheelchair access, seating accommodations, or alternative arrangements to make the experience more comfortable for individuals with disabilities.

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6. Have a backup plan: Despite careful planning, unexpected challenges may arise. It's important to have a backup plan in case you need to change or modify your original plans. This flexibility allows you to adapt to your symptoms and still enjoy the school holidays without undue stress.

Remember to listen to your body and prioritize self-care throughout the planning and execution of activities. Be prepared to make adjustments as needed to ensure that your well-being remains the top priority. By planning thoughtfully and being mindful of your limitations, you can create enjoyable and manageable experiences during school holidays while living with fibromyalgia.

Communicating your needs to family and friends during school holidays with fibromyalgia

Communicating your needs to family and friends during school holidays when you have fibromyalgia is crucial for ensuring understanding, support, and a more enjoyable experience for everyone involved. Here are some tips for effectively communicating your needs:

1. Educate them about fibromyalgia: Start by explaining what fibromyalgia is and how it affects you. Provide information about the symptoms you experience, such as chronic pain, fatigue, and cognitive difficulties. Help them understand that these symptoms can fluctuate and that you may have limitations that require accommodations.

2. Share your specific needs: Clearly communicate your specific needs during the school holidays. Let your loved ones know about activities or situations that may exacerbate your symptoms. For example, explain that loud or crowded environments can be overwhelming or that physical exertion may lead to increased pain and fatigue. Be honest about what you can and cannot do, and express any concerns you may have.

3. Set realistic expectations: Help your family and friends understand that your energy levels and capabilities may vary from day to day. Set realistic expectations by explaining that you may need to modify plans or take breaks to manage your symptoms effectively. Encourage open and honest communication so that everyone can work together to find solutions and alternatives when necessary.

4. Provide practical suggestions: Offer suggestions for activities that are more suitable for your condition. For example, propose low-impact activities like going for gentle walks, engaging in arts and crafts, or having movie nights at home. By providing alternatives that align with your energy levels and limitations, you can still participate and enjoy quality time with your loved ones.

5. Ask for support and understanding: Request support and understanding from your family and friends. Let them know that their understanding, patience, and flexibility are invaluable to you. Emphasize that their support can make a significant difference in managing your symptoms and overall well-being during the school holidays.

6. Offer resources for further education: Provide your loved ones with resources, such as articles or websites, where they can learn more about fibromyalgia. This empowers them to gain a deeper understanding of your condition, fostering empathy and compassion.

Remember that effective communication is a two-way street. Encourage your loved ones to ask questions and express any concerns they may have. By fostering open and honest communication, you can create an environment of support and understanding, enabling you to navigate the school holidays with fibromyalgia more smoothly and harmoniously.

In conclusion, the school holidays can be a challenging time for parents with fibromyalgia. However, with some careful planning and self-care strategies, it's possible to make the most of your time with your children and reduce the impact of your symptoms. Remember to listen to your body, take breaks when needed, and prioritize rest and self-care activities throughout the holiday period.



Benefits of Swimming for Fibromyalgia

Swimming can be a beneficial exercise for individuals with fibromyalgia due to its unique properties that can help alleviate the symptoms associated with the condition. Here are some of the key benefits of swimming for fibromyalgia:

1. Low-impact exercise: Swimming is a low-impact activity that puts minimal stress on the joints and muscles. For people with fibromyalgia, who often experience widespread pain and sensitivity, this is particularly advantageous. Unlike high-impact exercises like running or weightlifting, swimming provides a gentle form of aerobic exercise without placing excessive strain on the body.

2. Reduced pain and stiffness: The buoyancy of water reduces the effects of gravity, allowing individuals with fibromyalgia to move more freely without experiencing as much pain or stiffness. Water's buoyancy also provides a supportive environment that can alleviate pressure on the joints, resulting in less discomfort during and after exercise.

3. Increased flexibility and range of motion: Swimming involves a wide range of movements and engages various muscle groups throughout the body. This can help improve flexibility and increase the range of motion in joints, which are often restricted in people with fibromyalgia. By promoting better joint mobility, swimming can help alleviate the stiffness and muscle tightness associated with the condition.

4. Improved cardiovascular fitness: Fibromyalgia is often accompanied by fatigue and reduced endurance. Swimming is an excellent cardiovascular exercise that can improve overall fitness levels, enhance circulation,

and boost energy levels. Regular swimming sessions can help individuals with fibromyalgia build stamina, allowing them to better cope with daily activities and reducing feelings of fatigue.

5. Stress relief and relaxation: Swimming has a calming and meditative effect on the mind and body. The rhythmic movements, coupled with the water's soothing properties, can help reduce stress and promote relaxation. Fibromyalgia is known to be exacerbated by stress, so incorporating swimming into a regular exercise routine can have a positive impact on both physical and mental well-being.

It is important to note that individual experiences may vary, and it's always advisable to consult with a healthcare professional or a physical therapist before starting any new exercise regimen, including swimming. They can provide personalized recommendations based on an individual's specific condition and needs.

Swimming Techniques for Fibromyalgia Patients

When it comes to swimming techniques for individuals with fibromyalgia, there are a few considerations to keep in mind to ensure a safe and effective exercise routine.

Here are some swimming techniques that can be beneficial for fibromyalgia patients:

1. Start slow and gradually increase intensity: It's important to ease into swimming if you're new to the activity or haven't exercised in a while. Begin with shorter swimming sessions and lower intensity, and then gradually increase the duration and intensity of your workouts as your body adapts. This approach helps prevent overexertion and minimizes the risk of post-exercise flare-ups.

2. Focus on proper form and technique: Maintaining proper form while swimming is crucial to avoid straining or exacerbating any existing pain or discomfort. Consider working with a swim coach or trainer who can provide guidance on the correct swimming techniques and help you develop a stroke that minimizes stress on your muscles and joints. This can help you maximize the benefits of swimming while minimizing the risk of injury.

3. Incorporate different strokes: Varying your swimming strokes can help engage different muscle groups and prevent overuse of specific areas. For example, freestyle stroke (front crawl) primarily works the upper body, while backstroke engages the back muscles. Alternating between strokes can provide a balanced workout and reduce the likelihood of muscle imbalances and strain.

4. Use swimming aids or equipment: Depending on your specific needs and limitations, using swimming aids or equipment can be beneficial. For example, flotation devices or pool noodles can provide additional support and help maintain proper body alignment during swimming. Additionally, hand paddles or fins can be used to vary the resistance and intensity of your workout.

5. Warm-up and cool-down: Just like any other exercise, warming up before swimming and cooling down afterward are essential. Prior to swimming, perform gentle stretching exercises to prepare your muscles for the activity. After swimming, engage in some light stretching and relaxation exercises to help prevent muscle stiffness and promote recovery.

Remember, it's important to listen to your body and adjust the techniques and intensity of your swimming sessions according to your comfort level and any guidance from your healthcare provider. Swimming can be a valuable exercise for fibromyalgia patients, but individual needs and abilities may vary.

Risks and Precautions for Swimming with Fibromyalgia

While swimming can offer numerous benefits for individuals with fibromyalgia, it's important to be aware of potential risks and take necessary precautions to ensure a safe and effective exercise routine. Here are some risks to consider and precautions to take when swimming with fibromyalgia:

1. Overexertion: Pushing yourself too hard or overexerting during swimming can lead to increased fatigue, muscle soreness, and a potential flare-up of fibromyalgia symptoms. It's crucial to start with low-intensity workouts and gradually increase the duration and intensity of your swimming sessions as your body adapts. Listen to your body and take breaks when needed.

2. Temperature sensitivity: Fibromyalgia can heighten sensitivity to temperature changes. Ensure that the pool water is at a comfortable temperature for you, as extremely cold or hot water can exacerbate symptoms. If needed, consider using a heated pool or adjusting the pool temperature to suit your preference.

3. Slippery surfaces: Be cautious of slippery surfaces around the pool area, as individuals with fibromyalgia may have balance issues or increased sensitivity to falls. Use non-slip footwear and take your time when entering or exiting the pool to prevent accidents.

4. Joint strain: While swimming is generally a low-impact exercise, certain swimming strokes or improper technique can strain the joints, especially if you have existing joint pain or inflammation. Focus on maintaining good form and technique, and consider seeking guidance from a swim coach or physical therapist to ensure proper body alignment and minimize joint stress.

5. Dehydration: Engaging in water-based activities can make it easy to overlook hydration needs. Remember to drink plenty of water before, during, and after swimming to stay hydrated. Dehydration can worsen symptoms and lead to muscle cramps and fatigue.

6. Sun protection: If swimming outdoors, protect your skin from excessive sun exposure by applying sunscreen, wearing protective clothing, and using a hat or sunglasses. Sunburn can cause additional discomfort and aggravate symptoms.

It's always recommended to consult with your healthcare provider or a physical therapist before starting any new exercise regimen, including swimming. They can provide personalized guidance, considering your specific condition, symptoms, and any limitations you may have. By taking proper precautions and listening to your body, swimming can be a safe and enjoyable exercise option for managing fibromyalgia symptoms.

Swimming is an excellent exercise for people with fibromyalgia, and it can provide numerous benefits for managing symptoms and improving overall health and wellbeing. By starting slowly, focusing on proper technique, warming up and cooling down, and listening to your body, you can get the most out of your swimming workouts and enjoy the benefits of this low-impact exercise. Speak to your doctor about starting a swimming program and creating an exercise plan that's safe and effective for your individual needs.

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How Does Hot Weather Affect Fibromyalgia?

According to the National Fibromyalgia Association, when the weather is humid, fibromyalgia symptoms worsen. Many patients who suffer from rheumatological conditions have a condition known as temperature sensitivity, which means any extreme temps, hot or cold, can lead to worsened symptoms or pain.

Temperature changes are also commonly reported as triggers of migraines and tension-type headaches. In addition to temperature fluctuations, the heat of a summer day can lead to dehydration, which can trigger a headache or migraine attack.

Imagine waking up to an excruciating pain in your muscles and joints. Every step you take, every movement you make, causes a groan of agony. The heat outside is unbearable, and you've got a headache that feels like someone's hammering nails into your skull. This is what a person with fibromyalgia experiences on a daily basis, especially during hot weather.

Fibromyalgia is a medical condition that causes chronic pain and fatigue in the muscles and soft tissues of the body. Although it is still not fully understood how and why fibromyalgia occurs, researchers have found that there are several factors that can trigger the condition, including changes in the weather.

In this article, we will explore how hot weather affects fibromyalgia and what you can do to manage your symptoms during the summer months.

How Does Hot Weather Trigger Fibromyalgia Symptoms?

Hot and humid weather conditions can worsen the symptoms of fibromyalgia due to various reasons. For starters, high temperatures can cause dehydration, which can lead to fatigue, headaches, and increased muscle pain.

When the body is dehydrated, the muscles and soft tissues become stiff and inflexible, making it difficult to move around and perform everyday activities.

Heat exhaustion is another common problem that people with fibromyalgia face during hot weather. This occurs when the body is exposed to high temperatures for an extended period, causing the body's cooling mechanism to break down. Symptoms of heat exhaustion include

dizziness, weakness, fatigue, nausea, and muscle cramps, which can mimic the symptoms of fibromyalgia.

The heat can also disrupt the body's sleep-wake cycle, which can affect fibromyalgia patients who already have trouble sleeping.

When the body temperature rises, it triggers a response in the hypothalamus, the part of the brain that regulates body temperature. This response can interfere with the production of melatonin, a hormone that helps to regulate sleep, leading to insomnia and other sleep problems.

Hot weather can also cause increased inflammation in the muscles and soft tissues, which can worsen the pain and stiffness associated with fibromyalgia. When the body is exposed to high temperatures, it triggers an inflammatory response, causing the immune system to release cytokines, which can amplify pain signals and cause more damage to the muscles and soft tissues.

Managing Fibromyalgia Symptoms During the Summer Months

Although you can't control the weather, there are several things you can do to manage your fibromyalgia symptoms during the summer months.

Here are a few tips:

1. Stay Hydrated: One of the most important things you can do to manage your fibromyalgia symptoms during hot weather is to stay hydrated. Drink plenty of water and other fluids throughout the day to replenish lost fluids and prevent dehydration. Avoid alcohol and caffeine, which can dehydrate your body even further.

2. Stay Cool: It may seem obvious, but staying cool during hot weather is essential for managing your fibromyalgia symptoms. Wear loose, lightweight clothing made of breathable fabrics such as cotton and linen. Use fans or air conditioning to keep your home or office cool. Take cool showers or baths to help lower your body temperature.

3. Get Enough Sleep: Getting enough restful sleep is crucial for managing fibromyalgia symptoms. Stick to a regular sleep schedule and create a sleep-friendly environment by minimizing noise, light, and distractions. Use a fan or air conditioning to keep your bedroom cool, and use comfortable bedding that does not trap heat.

4. Avoid Triggers: Identify and avoid triggers that can make your fibromyalgia symptoms worse. For example, if you know that heat and humidity trigger your symptoms, try to stay indoors during

the hottest parts of the day. Avoid strenuous exercise or activities that can cause excessive sweating.

5. Use Medications and Therapies: Your doctor may prescribe medications or therapies to help manage your fibromyalgia symptoms during hot weather. Antidepressants, pain relievers, and anti-inflammatory medications can help relieve pain and stiffness. Physical therapy, massage therapy, and acupuncture can also help improve your mobility and relieve pain.

Conclusion

Hot weather can trigger the symptoms of fibromyalgia, but with some lifestyle modifications, you can manage your symptoms and enjoy the summer months. Stay hydrated, stay cool, get enough sleep, avoid triggers, and use medications and therapies as recommended by your doctor. By taking a proactive approach to managing your fibromyalgia symptoms, you can enjoy a more comfortable and fulfilling life.



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