

Education

Living with arthritis

keep doing the things you love to do

When researchers study the impact arthritis has on the lives of people living with it, concrete factors such as pain, mobility, level of deformity, and ability to participate in paid employment are examined. What is often forgotten is the impact arthritis can have on your ability to do the things you love to do—things that are most meaningful to you. Examples of these types of activities include participating in family life, maintaining an active or satisfying social life, and participating in leisure activities, including recreational or competitive sport.

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For many people, losing the ability to participate in these areas is what they fear most when diagnosed with arthritis. Parents are often more concerned about their ability to function with their children than about pain. The loss of ability to participate in recreational activities can be more traumatic than many of the physical symptoms that people living with arthritis face.

Human beings engage in many different types of life activities. These include specific "valued life activities", which vary from person to person. A valued life activity is an activity which has specific meaning or importance to an individual (Backman). Pain, and other symptoms of arthritis, can threaten a person's ability to participate in these activities (Katz et al).

Recently, researchers have taken a closer look at the importance of participation in valued life activities. They are learning what people with arthritis have always known—leisure, or the time spent away from work-related activities, is critically important to overall mental and physical health. Losing the ability to participate in these valued life activities can have a devastating effect on a person's emotional well-being.

When dealing with arthritis, it is extremely important to make the effort, wherever possible, to remain involved in the activities that were meaningful to you before your diagnosis. It might not be easy but trust that persistence will pay off. If maintaining your "pre-arthritis" activities is simply not possible, try to search

out other activities that can be tailored to the challenges your arthritis presents, or modify your participation in those activities to make them more manageable.

Leisure

If you have always loved to participate in a particular activity, be it entertaining at home or travelling abroad, try to think of ways you can modify your participation rather than eliminating that activity from your life.

For example, if you have always been the person to host large dinners for your extended family, consider hosting informal potlucks as opposed to elaborate multi-course "sit-down" meals. Start preparing your share of the meal early enough to allow you to take breaks along the way, and ask family members or friends to give you a hand with any heaving lifting duties. With these simple changes to your routine, you will probably find

"... when at all possible, do whatever you can to keep doing the things you loved to do before you got arthritis."

that entertaining can be just as enjoyable, and substantially more manageable for you.

Perhaps travelling has always been something you have enjoyed; if this is the case, plan trips with your arthritis in mind. Plan for rest as well as activity, and make sure your travelling companions and tour guides understand the physical limitations you face.

Changing or adapting the tools you use can help make your favourite activities more manageable. If you are an avid gardener, try using long, fat-handled garden tools, and make sure they are well-oiled to avoid having to use

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more force than necessary. If you love to cook, look into the many adaptive tools available to make working in the kitchen easier.

The bottom line is this: when at all possible, do whatever you can to keep doing the things you loved to do before you got arthritis. These are the very things that bring joy and meaning to your life, and you really need them when facing a health crisis such as arthritis.

Sports and recreation

If you have always been a physically active or “sporty” person, try to think of ways to prepare your body so that you can keep doing the things you love. Aerobic and strengthening-type activities are very important to keep your body strong and healthy enough to participate in the other recreational and sport pursuits you love.

For example, to keep up your ability to go for long hikes in the forest, cardiovascular and weight-bearing training at a gym will help to prepare or keep your body “at the ready”. But remember to respect what your body tells you, and plan ahead to make sure you will be able to stop when it tells you it is time.

If pain is a barrier for you to participating in physical recreation or sport, there are a number of pain management tools available to help you overcome it. Ice or heat on the joint posing a problem, stretching and range of motion exercises to limber up before hand, taking pain medication before or after the activity, or a combination of these strategies have all proved effective for people with arthritis.

Family participation

The ability to participate in family life is of paramount importance to many people. Being an active parent, grandparent, spouse, or family member can often be some of our most important activities.

For parents with small children, worries about not being able to care for children adequately can be overwhelming. Remember that, often, children are just as happy to spend time cuddling and reading a book with a parent; try not to feel guilty if you're not as able to play in the park and run around as you used to be.

Work on maintaining open communication with your family, so that you can let them know what you need and how they can best help you. Let your family know how you are feeling and what you are able to do and not do on any given day. Roles in family relationships may need to shift to accommodate the new demands arthritis has placed on the family. <

Spotlight on lupus (systemic lupus erythematosus or SLE)

Lupus is the name given to a group of chronic immune diseases. It affects about 15,000 Canadians—approximately one in 2000.

Systemic lupus erythematosus (SLE) occurs when the body's immune system begins to malfunction and attack healthy tissue in various parts of the body, causing inflammation and damage. Tissues affected can include the skin, joints, muscles, kidneys, lungs, heart, blood vessels, and brain.

Like many other forms of arthritis, lupus occurs more commonly in women than in men—women develop lupus approximately ten times more often than men do. While it can strike at any age, it tends to occur most often between the ages of 15 and 45.

While the exact cause or causes of lupus remain unknown, there are a number of factors which researchers believe may trigger the disease, either alone or in combination with one another. These include genetics, hormones, certain types of antibiotics and other medications, prolonged and severe stress, viruses, and sun exposure.

Diagnosis of lupus

Because lupus can affect so many different areas of the body, the disease often presents very differently from patient to patient. For this reason, lupus is a disease which is often difficult to diagnose. If you experience three or more warning signs of lupus, you should speak with your doctor about looking into the possibility that you may have lupus.

Warning signs include:

- Swollen or stiff and painful joints
- Fever
- Loss of appetite and weight loss
- Fatigue and low energy
- Skin rash, especially if brought on by sun exposure
- Ulcers in the mouth and/or nose, usually painless
- Pain in the chest while lying down or taking deep breaths
- Low blood counts, including anemia

While there is no single test for lupus, several blood tests are available which assist doctors in diagnosing lupus. These, combined with other factors such as physical symptoms and sometimes family history, can assist doctors in diagnosing lupus.

Treatment of lupus

If your doctor believes you may have lupus, you will usually be referred to a

rheumatologist—a specialist in the treatment of arthritis. Rheumatologists have many years of extra training on top of their regular medical schooling, and are experts at diagnosing and treating lupus.

Once your rheumatologist has diagnosed lupus, there are effective treatments available. While there is no known cure for lupus, treatments focus on controlling symptoms.

There are five major groups of medications which are used to treat lupus. These are:

- Non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (for example Advil® or Motrin IB®), naproxen (or Naprosyn®), diclofenac (or Voltaren® and Arthrotec®)
- Hydroxychloroquine (Plaquenil®)
- Methotrexate
- Corticosteroids, such as prednisone
- Immunosuppressive medications, such as cyclophosphamide (Cytoxan®, Procytox®) and azathioprine (Imuran®), and mycophenolate mofetil (CellCept®)

Most often, lupus can be controlled using one or a combination of the first four groups of drugs. For milder cases, hydroxychloroquine or NSAIDs are sometimes enough alone to control symptoms. Corticosteroids are highly effective in controlling lupus, but hydroxychloroquine, methotrexate and azathioprine may be safer over long periods of time. For very severe cases of lupus, corticosteroids and an immunosuppressive agent may be required.

Good news for people with lupus and their rheumatologists: new medications are under investigation. Two biologic response modifiers – abatacept (Orencia®) and rituximab (Rituxan®) – are under active study; both of these medications are currently used to treat rheumatoid arthritis and may prove to benefit people with lupus, too.

The goal with any medication used to treat lupus is to bring symptoms under control and bring about remission of the disease. Early treatment minimizes tissue damage, and may also lessen the amount of time a patient needs to stay on high doses of medication.

One simple form of lupus “treatment” often overlooked is using sunblock with a skin protection factor (SPF) of 30 or above. Applying appropriate amounts of sunblock on the face and all areas of skin (the sun goes through thin layers of clothing) 30 minutes before exposure to the sun reduces lupus flares as well as skin cancer.

And finally, maintaining a healthy lifestyle is also a critical part of any lupus treatment plan. Poor diet, lack of exercise, and high levels of stress may encourage flare-ups of disease activity, so healthy eating, gentle exercise, and relaxation are highly recommended.

For more information about Lupus, visit the Lupus Canada website at www.lupuscanada.org. <

Getting physical

sports, recreation and arthritis

Those who have been through it know

that receiving a diagnosis of arthritis can be devastating, especially when facing the prospect of losing the ability to participate in activities we love. For many people, recreational exercise is an incredibly important and valued part of life. Learning that you have a disease which could compromise your ability to participate in the activities you love can feel overwhelming.

One of the most important things to understand at the time of diagnosis is that many treatment options are available for most forms of arthritis. Getting your disease and related symptoms under control through treatment is a crucial first step towards learning to live well with it.

Jay Fiddler is a person living with adult Stills disease, a form of inflammatory arthritis. When she first developed arthritis several years ago, she was a physically active woman in her late 20s who enjoyed rock climbing, mountain biking, kayaking, snowboarding, and a host of other physical activities. In the space of several months, she went from being an active, healthy person to being unable to stand and move unaided.

For Jay, one of the most upsetting things about becoming ill and her subsequent diagnosis was the thought that she would no longer be able to participate in the activities she loved. "I would say that heartbroken and distraught describe how I felt when I thought I would have to give up being active" she says now.

A proper diagnosis and comprehensive treatment plan, however, have allowed Jay to return to many of the activities she participated in before she got sick. Today, she is able to rock-climb, mountain bike, and kayak. She says that an aggressive treatment plan incorporating rehabilitative exercise and physiotherapy, a healthy lifestyle, strong community support, and a willingness to modify her activities have allowed her to get to a point where she is able to participate again in many of the activities she loves.

While it is true that arthritis changes many things, and people living with arthritis often need to accept that certain activities are no longer possible or advised, there are steps you can take to increase your chances of being able to participate in physical recreation.

"I would say that heartbroken and distraught describe how I felt when I thought I would have to give up being active"

Treatment and rehabilitation

Once arthritis is diagnosed, finding the right medication is often key. Once the right treatment has been identified and started, many people living with arthritis will often regain enough of their health to begin moderate exercise.

Exercising at this point in a treatment program is crucial, as it helps to prevent weight-gain and muscle loss. Even moderate physical activity can help to improve health outcomes.

Jay remembers that once she received her diagnosis and started treatment, she was able to begin to visit the gym and start doing some light cardiovascular and weight-bearing exercise, as well as low-impact water-aerobics. She credits these with allowing her to regain her fitness and keep her muscles toned.

Then, once she found the right medication, in her case a biologic response modifier, she was

healthy enough to return to many of the activities she enjoyed before her diagnosis.

Healthy lifestyle

One challenge people living with arthritis often face is maintaining a healthy lifestyle. Eating well and exercising can be a real challenge while living with the effects of arthritis, and often the result can be weight gain and muscle loss.

Try thinking of food as "fuel" for your body. The right kinds of fuel allow your body to work at optimum capacity, and give you the energy you need to stay active. As well, maintaining a healthy body weight takes pressure off load-bearing joints.

Community support

Often, it can be helpful to find others who are also living with arthritis, to work on regaining physical strength and fitness together. Local community centres and arthritis groups can help to connect you with others who are in a similar situation. Local classes may include water-based aerobics, low-impact cardiovascular classes, and yoga.

Seeking out people who have already walked the path you are currently navigating can also be a source of inspiration and comfort. Jay Fiddler remembers meeting a person living with rheumatoid arthritis who was an active tennis player, and feeling inspired and reassured that it was possible to continue participating in sports after an arthritis diagnosis.

Modifying activities

While you may not be able to do everything you once did, once your arthritis is controlled through treatment you are likely to find that it is possible to get back to many of the activities you once enjoyed. You may need to be willing to modify what you do; Jay notes that today, she chooses gentler slopes while mountain biking, and rock-climbs for several hours at a time instead of a full day.

As always, speak with your doctor about what types of exercise and recreational activity may be beneficial, and what to avoid. If your doctor recommends against doing something you've always enjoyed, look for alternatives that will allow you to stay active without compromising your health. <



Jay Fiddler—ready to climb

Arthritis Consumer Experts

Who we are

Arthritis Consumer Experts (ACE) provides research-based education, advocacy training, advocacy leadership and information to Canadians with arthritis. We help empower people living with all forms of arthritis to take control of their disease and to take action in health care and research decision making. ACE activities are guided by its members and led by people with arthritis, leading medical professionals and the ACE Advisory Board. To learn more about ACE, visit

www.arthritisconsumerexperts.org

Guiding principles and acknowledgement

Guiding Principles

Health care is a human right. Those in health care, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the

influence of any specific constituency and a practical necessity. Any profit from our activities is re-invested in our core programs for Canadians with arthritis.

To completely insulate the agenda, the activities and the judgments of our organization from those of organizations supporting our work, we put forth our abiding principles:

- ACE only requests unrestricted grants from private and public organizations to support its core program.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization.
- ACE discloses all funding sources in all its activities.
- ACE identifies the source of all materials or documents used.
- ACE develops positions on health policy, products or services in collaboration with arthritis consumers, the academic community and health care providers and government free from concern or constraint of other organizations.
- ACE employees do not engage in any personal social activities with supporters.
- ACE does not promote any "brand", product or program on any of its materials or its web site, or during any of its educational programs or activities.

Thanks

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