

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.jointhehealth.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

ACE thanks the Arthritis Research Centre of Canada (ARC) for its scientific review of JointHealth™.



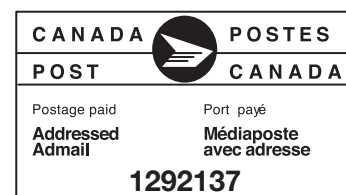
Acknowledgement

Over the past 12 months, ACE received unrestricted grants-in-aid from: Abbott Laboratories Ltd., Amgen Canada / Wyeth Pharmaceuticals, Bristol-Myers Squibb Canada, Arthritis Research Centre of Canada, Canadian Institutes of Health Research, GlaxoSmithKline, Hoffman-La Roche Canada Ltd., Merck Frosst Canada, Pfizer Canada, Schering-Plough Canada, and UCB Pharma Canada Inc. ACE also receives unsolicited donations from its community members (people with arthritis) across Canada. ACE thanks these private and public organizations and individuals.

Disclaimer

The material contained in this newsletter is provided for general information only. It should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Should you have any health care related questions or concerns, you should contact your physician. You should never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter. ☞


Arthritis Consumer Experts™
Suite #200B 1228 Hamilton Street Vancouver BC V6B 6L2



A well deserved vacation...

For many people who live with arthritis, taking a vacation or travelling may seem overwhelming or even impossible; however, with planning and good preparation it can be relaxing, refreshing, and enjoyable. This issue of JointHealthTM monthly is devoted to helping you organize a holiday that is fun and relatively stress-free, tailored to your needs.

JointHealthTM monthly is available in print and online in English and français.


Arthritis Consumer ExpertsTM

Suite #200B 1228 Hamilton Street
Vancouver BC V6B 6L2
t: 604.974.1366 f: 604.974.1377
tf: 1.866.974.1366

e: feedback@jointhealth.org
www.jointhealth.org

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Planning:

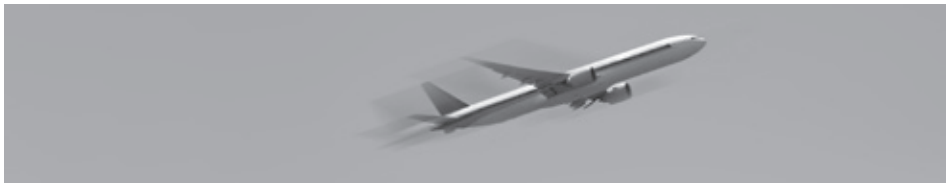
Thorough planning done well in advance of your trip is very important, especially for people with special requirements. A travel agent can be a great resource; if you let them know your requirements, they can do the work of finding accessible hotels, package deals suitable to your needs, and arrange transportation with the services you require. Alternatively, the Internet can be very useful for booking transportation, hotels, and entertainment.

As difficult as it may be, try to leave for your vacation well-rested. While last-minute list-making, shopping, document gathering, and packing are hardly a recipe for relaxation, it is important to not over-stress yourself to the point where you risk a flare.

Here are a few thoughts on planning a vacation that will work for you and your arthritis:

- When you are choosing your vacation, try to tailor it for your interests and physical abilities.
- You may find that bus tours in locales with uneven terrain or cities with cobblestone sidewalks will suit those with mobility issues.
- Boat cruises can be a terrific choice for people with mobility challenges because you can decide how many cities to stop off at, just about everything you need is on board, and you can stay active by swimming in the pool, walking around the jogging track or promenade deck, or exercising at the gym without even leaving the boat.
- When deciding on a cruise or tour package, think about picking one not just for its destination, but also for its pace and lifestyle focus (like adventure, family, or romantic).
- Speak with your doctor or another healthcare professional about things to look for and avoid when planning a holiday.





Booking

- Book tickets as far in advance as possible so that you have lots of time to organize any special assistance you may need.
- If you have mobility issues, make sure you let your travel agent, hotel, airline, cruise line, and/or tour company know.
- If flying, try to book seats at the bulkhead, so that you will have more leg room. Also, you may find that an aisle seat will help provide a bit of leg room and has the added benefit of allowing you to avoid climbing over other passengers. Booking agents can help you figure out which seats offer the most space.
- Try to find hotels that are outfitted with equipment such as grab bars.
- Do what you can to keep your luggage light.
- If possible, pick a room located near an elevator. If you book well in advance, it is more likely that this will be available.
- Consider buying travel or cancellation insurance.
- If possible, get airline tickets that keep the number of layovers to a minimum.
- Especially when booking with an airline, identify your needs so that they will know to meet them. For instance, they may be able to offer certain services such as refrigerating your medication for free or disassembling and reassembling your motorized wheelchair.

Packing:

- Bring a bathing suit if you are able to have access to a swimming pool, so that you can swim.
- Bring comfortable shoes with good support.
- If possible, pack early, so that you can rest the night before you leave.
- Pack UV clothes. They are lightweight and protect you from the sun, which is especially important if your medications or disease cause sun sensitivity. Also, remember to pack sun block, UV lip balm, sun glasses, and a hat.
- Wherever possible, bring any necessary assistive devices.

Medications:

- When you are booking your plane tickets, find out what the airline and airport security regulations are for travelling with liquid medications, ice packs and/or sharps.
- Speak with your doctor about adjusting your medication schedule for travel in other time zones.
- If your medications are given to you by infusion, make sure to schedule your trip between doses so that you will not need to take medication while you are away.
- Try to pack all of your medications in your carry-on luggage so that if your other luggage gets lost or delayed you will not be without.
- Bring enough medication to last the duration of your trip.
- Carry a copy of your doctor's medical prescription.
- Ensure that all of your medications are labelled with the name of the drug, your name, and your doctor's name.
- Remember to declare all of your medications to security and ensure that you have a letter from your doctor explaining your need for medications, ice packs, sharps, and other related supplies.
- Try to book a room with a refrigerator if you need to keep your medications cold. Or, confirm that your hotel will be able to make a refrigerator available to your room.

Useful accessories:

- A portable stool for waiting in long line ups or when you need a break. Try to get one that is light and compact enough to strap to your backpack or see if you can find a walking stick that converts to a stool.
- A waist harness for your camera.
- Lightweight luggage with wheels or backpack with wheels.
- A backpack that can be used as your carry-on luggage and double as your daypack when you go out touring.
- Neck pillows for long drives and bus rides. The inflatable type is lightweight and good for keeping your carry-on luggage light when you fly.

Car

- Try to stop often—hourly if possible—to stretch your legs and reduce stiffness. Taking lots of breaks from driving will also help prevent fatigue.
- When idling at intersections, do neck stretches or shoulder rolls.
- Put a sheepskin cover on the steering wheel. It will make it easier to grip the wheel.
- If possible, try to travel in a car with power features, such as power brakes, steering, chairs, mirrors, windows, and locks, as well as heated seats and a tilted steering wheel.
- Outfit your vehicle with cushioned seatbelts for greater comfort and wide-angle mirrors to reduce the need for craning your neck.
- You may find it useful to have a lumbar pillow for helping to provide back support.

Airplane

- Take advantage of early or advanced boarding and deplaning.
- If you can, try to avoid travelling on weekends and holidays so that you are travelling when the airports are less busy.
- Try to get a seat near the washrooms.
- Try to get a seat near the bulkhead or emergency exit, where there is typically more leg room.
- Find out in advance how far check-in is from the gate. At the airport, use a wheelchair or get a ride on a chauffeured cart. Both are usually provided by airlines.

Train

- Take opportunities to move around and stretch regularly.
- Pack snacks to eliminate the need for walking to the food car, or try to book a seat near the food car.
- Find out in advance whether there are accessible washrooms and aisles.

Bus

- Find out how many stops there are. When stopped, do range of motion exercises and stretches.
- As with car travel, whenever you can, do neck stretches and shoulder rolls.
- In advance, determine whether equipment, such as wheelchairs, needs to be collapsible.
- Pack snacks if you have difficulty getting on and off the bus for stops.





While there:

Living with arthritis can cause a good deal of physical and emotional strain. Coping with joint pain, fatigue, and mobility issues can feel exhausting over time. If at all possible, use at least some of your vacation time to relax and recharge.

You may find it helpful to keep to your home schedule (as much as is practical) because that can help reduce the stress of travel and keep you on track in terms of your medications and exercise routines. As much as is practical, plan for rest and try to stick to a fairly regular sleep schedule. As well, if your type of vacation allows, try to maintain your exercise regimen. Sticking to your exercise routine will help to keep your energy up and reduce stiffness in your muscles and joints. Some hotels will have exercise facilities or a pool, and walking or cycling may

provide a fun way to sightsee and get exercise at the same time.

While it goes against the grain for some of us, try to remember to ask for and accept help when you need it. For example, consider taking advantage of some of the luxuries that hotels have to offer, like porters to carry your luggage.

While on vacation, remember to pay attention to fatigue as a symptom of arthritis. Do as much as you can or wish to do, but try to pay attention to your body's signals.

Above all, when you feel tired or worn out, remind yourself that all the "work" of travelling, such as standing in line-ups at airports, waiting for taxis or buses, or even touring through art galleries or spending a full day of sightseeing is exhausting for everyone, so be patient with yourself.

Other resources for travellers with arthritis or related conditions:

- Try the Internet. There are lots of sites that give excellent travel tips. Also, the Internet is a great resource for researching travel destinations that will be suitable for your interests and needs.
- Online blogs dedicated to travellers with physical limitations may be useful for you. You can read about other people's experiences, ask questions that are specific to your situation, and get advice on accommodating hotels, how to handle airport security, etc.
- Friends and family who have travelled may be useful for advice.
- Some travel guides indicate accessibility and you may find travel guides specifically for people with limited mobility. Go online or contact a library or a book store to help you find one.
- Travel magazines may also be useful, and can be really enjoyable to read.



DVT

Deep vein thrombosis (DVT) or blood clots of the legs are much more common with long distance travel. They can cause pain and swelling of the legs, damage to the vein and complications such as a pulmonary embolism where the blood clot breaks off from the leg vein and travels to the lung. This is a life-threatening emergency that can result in sudden death. Factors that can predispose to blood clots include arthritis, cancer, heart failure, obesity, older age, pregnancy, and a previous history of blood clots or pulmonary embolism.

Tips to prevent DVT while travelling include frequent stops to walk around, getting an aisle seat and getting up frequently, ensuring that you are getting enough fluids, leg/calf exercises while in the seat, avoiding tight undergarments and clothing and avoiding crossing your legs for long periods. There are pressure stockings that can be worn while travelling.

Some medications may predispose patients to getting more blood clots. These include birth control pills and certain osteoporosis medications called SERMs (selective estrogen receptor modulators - raloxifene). Other medications may reduce the risk of getting blood clots such as aspirin and warfarin. Your physician may recommend adjusting your medications before long travel. It may be prudent to bring up the subject with your physician.