

# Travelling with Inclusion Body Myositis or IBM



**Intro /** Okay, let's face it: IBM is an energy disease. Once you get beyond the glitz of “large populations of clonal highly differentiated cytotoxic CD8+ T-cells”, your life with IBM is all about managing your energy. As your muscles weaken, so does your ability to run, ski, bike or get out of a chair. You have to plan tasks like housework or shopping quite differently. You have to adapt your house and your vehicle, your eating habits and your exercise patterns. Moreover, you also have to re-examine your ability to travel.

Whether you are still grappling with a recent diagnosis of IBM, or you've pretty well accepted a reality that's ten years old, you and your Travel Partner (TP) have probably concluded that the old way of travel is no longer possible. The “where” you travel, the “how” of getting there, and the “what” you can do have all changed dramatically from your days of backpacking across Europe or climbing Kilimanjaro. I sincerely hope that what follows will motivate you to keep travelling – albeit in a slightly different style – but travelling all the same. You'll feel mentally more positive and physically more able when you travel.



**Why & Where /** So, you want to go on a trip. Why? Family reunion? Celebrate an important date? Escape winter? Bucket list? Okay, now where should you go? A local “staycation” or somewhere in Canada? Southern states? Beach destination? Cruise? Europe or Asia?

Ok, you've narrowed it down. Now, do you have a budget in mind? Add 10%. Add another 10%. Now convert it into local currency. That's your new budget! Maybe subtract some airline miles or hotel points, but basically, disabled travel is at least 30 to 50 percent more expensive than able-bodied travel. Why? Because you may need help lifting a suitcase onto an overhead rack, or you're exhausted after a day of sightseeing, and you decide to cab it back to the hotel. You'll make a thousand small decisions to conserve your energy, and some of these may cost money.

**Tip:** Local travel can be as rewarding as flying off to France. The City of Calgary, where we reside, has many local trails and parks that are accessible such as Fish Creek, Ralph Klein and river trails. Alternatively, camp in the Rockies at provincial parks or the William Watson Lodge. Please refer to “Resources” at the end of this article.

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**How Will You Travel?** / Travel by car looks pretty straightforward but can you still handle eight-hour stints sitting down? Can you contribute to the driving or do you no longer trust your legs? Perhaps you need to bring along a cushion, water and snacks for long trips. Plan for bathroom breaks in pretty basic restrooms. Also, always watch for signs that you're getting tired; that's when falls occur.

Travel by rail varies by country. Via Rail, CN, Rocky Mountaineer, Virgin, Amtrak, and private tourist trains do NOT offer comparable accessibility. Always contact the operator and ask: can I access the platform and the rail car? Is there an accessible toilet? Can I sleep comfortably in a bunk? Can I climb up into a dome car? It's better to be informed before you put a deposit down. Talk to friends and review the ratings on travel websites.

European rail travel is amazing: every inter-city line offers handicapped seating. The London-Paris route, for example, puts wheelchairs in first-class at second-class fares AND provides a discounted fare for your TP! However, local routes between towns may be much more complicated: again, contact the rail line or use a specialist travel agent.

**Tip: Check out any city that has hosted the Olympics since 1988. As they also hosted the Paralympics, they've upgraded their subways and sidewalks!**

Travel by plane has its pros and cons. Once you're through security and at the gate, taking a walker or even a folding scooter on board is usually easy if you speak with the gate agent. Wheelchairs and larger scooters must be stowed: find out your carrier's policy about batteries. Always order a wheelchair even if you can stroll. Some airports are enormous and involve 20-minute walks to a baggage carousel or connecting flight. Also, try to avoid switching terminals. Dallas, Pearson and Frankfurt, for example, involve complicated transfers: plan to conserve your energy. Also, remember: compression socks are your friend!

Finally, there's cruising. River cruises (primarily in Europe and Asia) are not recommended unless you are comfortable with staircases between decks. Very few river cruise boats have elevators. Ocean cruising, on the other hand, is perfectly suitable for IBMers. Talk to friends or your travel agent, or visit cruise review websites to see which line is best for you. Many offer different levels of accessibility, but if they're based in the U.S., they must meet all ADA standards.



**Documents, Documents, Documents** / We assume that everyone makes copies of key documents (passport, driver's license, government and private health insurance, prescriptions) and shares them with their TP and leaves one with someone at home. I recommend you also scan a copy and send it to your key contact. In an emergency, he or she can email them to you, the embassy, cruise ship or hospital. Saves looking for a fax machine!

You may also want to talk to your pharmacist and give them the heads up that you're travelling. He or she may give you an extended refill of important meds, or notate your file if contacted by a third party. Finally, we all rely on our phones to keep in touch. If you lost your phone, would you remember your kids' phone number at home and work? Your doctor's? Write down two or three key numbers and keep them handy at all times.

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**Aids to Travel Life /** Whether you fly or cruise, you may want to explore renting equipment (scooters, wheelchairs, oxygen machines, etc.) at your destination. This will eliminate the hassle and worry about taking your own on the plane.

IBM is an auto-immune disease. We recommend carrying anti-bacterial wipes to clean your plane's tray table, or after handling the millions of surfaces you will encounter on your trip.

Based on your particular situation, you may also wish to travel with a foam cushion, a toilet seat riser, shower mat or other "aids to daily living."



## Resources /

- Calgary has lots to offer in the way of accessible day trips: [Calgary-Recreation-Accessibility](#)
- If you want to stay overnight, try the [William Watson Lodge](#), or Alberta Parks at [Alberta Parks - Accessibility](#)
- For cruise websites for key go-to info, go to [Cruise Critic](#) or [Shore Excursions](#)
- Some equipment rental sites include [Special Needs Group](#) and [Scoot Around](#)
- Suggested Specialist travel agents include:
  - Europe: [The Man in Seat 61](#) or [Sage Travel](#)
  - Canada/US: [Travel-for-all](#)
  - Worldwide: [Disabled travelers](#)
- And for general info about accessible travel, try [Wheelchair Travel](#) and [Lonely Planet](#)



**Disclaimer /** We do not endorse any travel agency or travel organisation – caveat emptor.