

KNOWLEDGE IS POWER...

TRAVELLING WITH ALS

Travelling is the spice of life to some and a necessary evil to others. If you enjoy travelling, there is no reason to let a diagnosis of ALS stop you. As a Canadian hero, General Sir Arthur Currie, once said: "Thorough preparation must lead to success. Neglect nothing." You can do this!

As I write this, I must acknowledge that we are living in unprecedented times. After over two years of the COVID-19 pandemic, people have returned to air travel only to find delays, cancellations and poor customer service. This is almost the rule at the present time, and not the exception. As much as it pains me to say this, if you cannot tolerate these real life issues, travelling by car or train would be a much better tolerated option. It may reduce the distance you can travel, but it also allows for those little side journeys that can add so much to a trip!

Your first thought, after deciding on a destination, should be how to make sure everyone involved in providing services to you during the trip is notified of your diagnosis and your individualized needs. And what might those needs be? Think about how you are accommodated in your own home; what equipment do you use? What medical therapies are required? How much are you able to help yourself? Is your caregiver limited in their ability to help you in any way?

From the moment you leave the comfort of your own home, you are in someone else's hands. Do everything in your power to make sure they are prepared.

Following are some suggestions that could go a long way to making your trip a success:

- When you make your reservations, let them know that you are travelling with a disability. Make sure it is recorded on your file.
- Prepare yourself for the screening process. Disabled persons may be excused from some of the security procedures. Investigate your options before travelling.

- When flying, unless you have the option of Business Class seats, choose the bulkhead seats for the extra legroom and proximity to the airplane door. One cautionary note is the potential distance from your seat to bathrooms. It wouldn't hurt to ask if permission can be given to use the Business class bathrooms. Consider alternatives if the distance to the bathroom is too far or you just cannot manage it – there are devices and wearable items that can serve in a pinch to make your trip more palatable. Ask for an aisle seat. Airlines have a small, narrow wheel chair that is used to transport non mobile patients down the narrow aisles. Make sure that one will be available for you. And moving you from that narrow chair to your seat is best accomplished to an aisle seat. The more information you provide, the better prepared that airline staff can be.
- Documentation is key; be armed with signed documents detailing your diagnosis and travel needs. Leave copies of all important documents with a trusted family member or friend. Carry your medications with you and confirm that your bipap, suction and cough assist machines can be taken on board and not counted against hand luggage. If you are concerned about taking this much "stuff", investigate whether any of it can be obtained at your destination.
- If you are taking your manual or power chair, or a scooter, make sure you find out what the carrier needs to know about the equipment and what options they can make available to you should your equipment be damaged in transit. Ask that your chair or scooter be brought directly to you at your arrival gate or during a layover if you have connections. If this is not possible, request an acceptable option. A good idea would be to make contact with the ALS Society nearest your destination to see what assistance they may be able to offer should something untoward occur. Remember the words of Sir Arthur!
- Wheelchair accessible taxis and vans may or may not be readily available at your destination. Plan ahead. There may be an organization in the destination city that can provide you with information and assistance.
- A travel agent with experience in working with persons requiring travel accommodations can be worth their weight in gold!
- DON'T FORGET TRAVEL INSURANCE. No one needs a big medical bill added to their travel costs.
- Don't assume that all arrangements are set and that everyone is ready for you – confirm all arrangements within 48 hours of your travel time.
- When you are making your plans, don't forget that wherever you may be staying at your chosen destination, you still have accessibility needs. If you forget something, anything, it may not be easily obtained at your destination. Medications in particular may vary between countries, or even provinces. Communication is key, and don't forget those famous words "Thorough preparation must lead to success. Neglect nothing."