

Travelling with Huntington Disease

Everyone enjoys the opportunity to take a break from their normal routines and travel. With any illness including HD, it can be more challenging to travel – especially as the disease progresses. Careful planning can help manage new surroundings and make travel easier. This fact sheet provides some tips and strategies for making travel more enjoyable.

Have A Plan

- If travelling is new for your family, starting out with a shorter trip may be a good idea to get accustomed to travel before going on a long journey.
- Because people with HD often have difficulty regulating their body temperature, it is important to consider the weather for the time of the year that you plan to travel. It is also advisable to not travel in high tourist season so as not to overwhelm the person with HD.
- If possible, request quiet and safe spaces for the person with HD to relax and re-group.
- Caregivers should also remember to take time out for themselves to rejuvenate.
- Before the trip, include everyone in the planning of where you will go and what you will see and do. Once the trip is planned, make an itinerary available so the trip details can be reviewed whenever necessary.
- Learn as much as you can about the place you are visiting, so you can anticipate what you will need for the trip.
- Consult with your health care team before your trip about your travel plans and ask about contingency plans and strategies that could be helpful in an emergency situation.
- Establish and practise relaxation techniques to help with stress and anxiety related to flying if that is an issue for anyone in your travel group; over the counter medications and/or prescriptions may also be available to help with anxiety associated with travel.
- Ask your doctor or pharmacist about safe anti-nausea and other medications to help with controlling nausea and other travel-related illness.
- Carry 4-5 days of medications in your carry-on baggage just in case your luggage is lost.
- Ask your pharmacist for a list of all medications with the generic names of the drugs and proper dosages in case your luggage is lost or there is an emergency; locate a local pharmacy at your destination ahead of time, so you have a plan to replace any lost medications needed. In some countries, this may require a visit to a local clinic to get a new prescription.
- Consider taking extra medication with you that may be difficult to get in the country – especially if travelling overseas.
- Educate people travelling in the group about the symptoms, changes in behaviour and potential severity of symptoms. *Understanding Behaviour in Huntington Disease: A Guide for Professionals* is a good resource to learn more.

Simplify

- Try to maintain the regular schedule of eating, sleeping, exercise, rest and other routines as much as possible.
- Use a medication reminder system (there are apps available for cell phones that provide an alert) to help with remembering to take medications as there will be some inevitable disruption to routine.
- Ask your pharmacist to prepare blister packs of your medication for the duration of the trip. The blister packs are sealed and identify the drug and the pharmacy who prepared it. This will aid in getting through security or customs.

Huntington
Society of Canada
151 Frederick St.,
Suite 400,
Kitchener ON
N2H 2M2
1-800-998-7398

info@huntingtonsociety.ca
www.huntingtonsociety.ca
Charitable Registration
Number
11896 5516 RR0001

Simplify (continued)

- Choose the trip and style of travel that will work best for you. Some families will want to experience an all-inclusive vacation to keep meal preparation and other tasks to a minimum. It will also allow for activities to be pre-planned.
- It is important to find out if the hotel/ship/resort is able to accommodate a special diet (e.g. puréed and/or soft foods).
- If flying to a destination, choose a direct flight if possible.
- If travelling by car, consider shortening each day of travel and extending the overall length of the trip to make it more enjoyable and less tiring. Taking frequent stretch breaks may be helpful.

Ask For Help

- Go with a travel buddy if possible. Choose someone who will be able to provide the level of support needed.
- If you booked your trip with a travel agent, ask him/her for advice and ideas for support and assistance.
- Inform the airline ahead of time that you are travelling with someone who has HD and ask for any accommodations needed including early boarding, a wheelchair, transportation upon arrival, help with carry-on baggage and boarding and getting off the plane.
- If flying, request extra leg room and a seat close to the washrooms.
- Ask for a contact at the hotel who can help if there are any issues or concerns throughout your stay.
- When travelling in unfamiliar places or foreign destinations with language barriers especially, carry a list of the name, address and phone number of the hotel or ask the hotel for its business card which has the address on it. If you get lost or lose your group, it will be possible to hire a cab or ask someone for directions.
- For individuals with HD, carry the "I have HD" wallet card (available through HSC), so it is easy to educate people about HD and for emergency personnel to contact loved ones if there is an emergency or sudden illness. In addition, a letter from your doctor that would describe any special characteristics of the disease would be particularly beneficial when going through security or customs.

HSC suggests that families register with a medical alert system like the "MedicAlert Safely Home" program to help provide identification for loved ones. The MedicAlert engraved identification bracelet enables police and emergency responders - internationally - to quickly identify a person who gets separated. Bracelets can include information about medical conditions to help first responders provide the best care possible. Information on "MedicAlert Safely Home" can be found at <https://www.medicalert.ca/safely-home>. For other medical alert options available, please connect with your local Family Services team member.

RESOURCES

The Huntington Society of Canada wishes to thank the Alzheimer Society of Canada for sharing their tips for travelling. The information has been modified with permission from the Alzheimer Society of Canada (www.alzheimer.ca).

[Understanding Behaviour in Huntington Disease: A Guide for Professionals \(Third Edition\)](#)

Fact sheets on a variety of other topics pertaining to HD are available at www.huntingtonsociety.ca/hd-fact-sheets.

Ongoing support, education and information is available from the Huntington Society of Canada (HSC). You can find a listing of our Family Services team members at www.huntingtonsociety.ca/family-services-team.