TRAVELLING WITH HD



Travelling can be both enjoyable and challenging for a person living with Huntington disease (HD). Fortunately, with careful planning and packing, the experience can be both easier and more positive. This fact sheet can function like a travel checklist and may be a valuable resource for both carers and individuals with HD when preparing to travel.

Planning Your Trip

- If travelling is new, starting out with a shorter trip may be a good idea.
- Learning as much as possible about the destination location can help with anticipating the most likely needs.
- Considering how busy and crowded the destination may also be important.
- Ensure there is adequate accessibility for any physical needs (i.e. ramps, elevators, parking).
- Consider making a checklist of what to pack to be as prepared as possible.
- Try to arrange travel plans to maintain the regular schedule of eating, sleeping, exercise, rest and other routines as much as possible.
- Inquire if the destination can accommodate a special diet (e.g., puréed and/or soft foods) if required.
- If flying to a destination, choose a direct flight, if possible, as well as a seat with extra leg room that is close to the washroom.
- If travelling by car, frequent stretch breaks may be helpful.

Travelling With Medication

- Before the trip, consult with the health care team about the travel plans. Ask about contingency plans and strategies that could be helpful in an emergency.
- Ask the doctor for a letter explaining the impact of HD and any support that may be necessary, as well as a list of all medications required.
- Carry all medications in a carry-on bag either in original bottles with labels or in a blister pack prepared by the pharmacist.
- Travel with the pharmacist's contact information in case medications are lost or there is an emergency.
- Use a medication reminder system or set alarms on a phone to help remember to take medications, as there will be some inevitable disruption to routine.
- Consider wearing a medical alert bracelet. In an emergency, it can help first responders provide the best care possible.

TRAVELLING WITH HD



Ask For Help

- Go with a travel buddy if possible. Choose someone who will be able to provide the level of support needed.
- If the trip is booked through a travel agent, ask for advice and ideas for support and assistance.
- Inform the airline ahead of time about any accommodations needed, including early boarding, a wheelchair or ride to the gate, help with carry-on baggage, boarding and getting on and off the plane and transportation upon arrival.
- Ask for a contact at the hotel who can help if there are any issues or concerns throughout the stay.
- When travelling in an unfamiliar place with a language barrier, carry the name, address and phone number of the destination in case directions are required or if travelling by taxi.
- Carry the "I have HD" wallet card, available through HSC (ask your Resource Centre Director). This can be helpful as it includes emergency contact information.

RESOURCES

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).

If you are ready to receive individual or group support from the Huntington Society of Canada, you can self-refer here: https://contactme.cloud/form/huntingtonsociety

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at www.huntingtonsociety.ca/family-services-team-list/

Informational fact sheets for family and friends impacted by HD are available to view, print and download at www.hdfactsheets.ca

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at www.huntingtonsociety.ca/hd-booklets-and-publications/, on:

- A Physician's Guide to the Management of Huntington Disease
- Understanding Behaviour in Huntington Disease: A Guide for Professionals.
- A Carer's Guide for Huntington Disease

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