

Holiday Traveling with FTD

Warning signs to consider ahead of travel:

- Consistent disorientation and/or agitation in familiar settings
- Agitation when routine is changed
- Wanting to go home when away on short visits
- Delusional, paranoid, aggressive, or disinhibited behavior
- Problems managing continence
- Teary, anxious, or withdrawn in crowded, noisy settings
- Wandering behavior

Traveling by Air

- When navigating TSA security, provide medical documentation of the person's diagnosis (click here to learn more: www.tsa.gov/travel/special-procedures). Let the security officer know how best to approach your loved one. You may request a private screening area if necessary.
- Notify the airline that you are traveling with someone with FTD to allow for priority boarding, disembarking and any other necessary accommodations.
- Build in flexibility and stopovers to enable your loved one to adjust gradually to time differences.
- Investigate the best travel insurance policy for your situation well in advance, to allow for unexpected changes without extreme penalties.
- Inquire if the airline has a meet & greet program to escort you through security.
- If necessary, ask for assistance from cabin staff when the person needs to use the restroom. Request seating close to the restroom to avoid long walks.
- Consider that requesting an aisle seat may also be helpful.
- If possible, check your luggage all the way through to your final destination. Luggage with wheels is helpful for ease of mobility. Alternately, you can invest in a lightweight suitcase.

General Tips for Families & Care Partners

- A music player and noise-canceling headphones may be a good solution for tuning out extra noise. Pack snacks to provide a diversion if your loved one is prone to agitation. Consider their interests and plan for ways to engage them throughout the course of your travel.
- Keep a sense of humor and find ways to laugh at the funny things that happen along the way.
- Be prepared to do everything for two. This can be taxing, so try to get plenty of rest before the trip.
- You need to hold all important possessions such as passports, money, schedules and tickets. Make sure you have enough space to do so, and a way to keep all paperwork and information organized. Where possible, store this information digitally in your phone or other electronic device, to avoid the need to rifle through papers and documentation in stressful moments.
- Always be willing and ready to ask for assistance from staff or other travelers if necessary. People cannot help if they don't know there is a problem.
- Be aware that large public bathrooms often have more than one entry or exit point. Whenever possible, locate private restrooms reserved for families or those with disabilities, where you will have more space and be able to remain together.
- Pack as light as possible, but always keep a change of clothes easily accessible.
- If staying in a hotel and wandering is a problem, lock the door to the room with the safety latch. Consider purchasing a portable door alarm that will alert you if your loved one attempts to exit the room while you are sleeping or showering.
- Leave the bathroom light on overnight.
- Unfamiliar faucets and knobs can be very confusing for a person with dementia. Make sure that you turn the shower on and adjust the water temperature for your loved one.
- Allow plenty of extra time for all tasks, and be flexible when plans change.

Documents to Bring Along:

- 1) A letter from your loved one's neurologist or physician, stating what their diagnosis is and how it impacts normal travel requirements (i.e. – the person diagnosed is unable to speak or be separated from the caregiver). In addition, it may be helpful to complete and carry this TSA Disability Notification Card:

https://www.tsa.gov/sites/default/files/disability_notification_card_508.pdf

You can also print out information about your loved one's specific diagnosis from the AFTD website: www.theaftd.org

- 2) A “business card” that the caregiver can show to people that gives brief information about the situation and asks for patience. They can be used with security agents, when asking an airline transportation official to assist while you go through the screening, etc. Several versions are available through AFTD’s website for you to print at home.

<http://www.theaftd.org/life-with-ftd/resources/awareness-cards>

- 3) Encourage your loved one to wear an identification bracelet at all times. Also make sure that the following information is in their wallet or purse: their name, your name and cell phone number as an emergency contact, the address and phone number of your destination, as well as information about any layovers. Mark all clothing with their name as well.
- 4) Bring along a comprehensive list of important contacts, such as doctors, family, and anyone else who should be contacted in case of an emergency.
- 5) Also pack a current list of medications, along with enough medications to cover the period of travel, and a few extra days in case of delays. Make sure medications are clearly labeled and easily identifiable – in their original containers, if possible.

Additional Resources

The TSA website provides more information and resources for navigating security at airports when accompanied by a person with a disability:

<http://www.tsa.gov/traveler-information/travelers-disabilities-and-medical-conditions>