

Resources for Traveling with FTD

Help & Support



Traveling lets us create new memories, connect with loved ones, or, for families impacted by FTD, participate in research and consult with medical specialists. This resource offers support for persons affected by FTD who are preparing to travel.

Making the Decision to Travel

Being out of a one's environment and familiar routine can cause unexpected changes and stress. Before considering a trip, try speaking with the medical team of the person diagnosed about any symptoms or other medical conditions that can impact travel. If you are considering a longer trip, you can take a quick overnight stay close to home as a trial run. The questions below help identify areas where special planning may be needed.

- How does the person usually respond to changes in their routine and new places?
- Does the person display stress, disorientation, agitation, or resistance? How have you managed such symptoms in the past?
- Does the person ask to go home when on short visits or outings?
- How does the person or care partner manage continence, and how can this be dealt with away from home?
- How does the person tend to react in crowded, noisy settings?
- Does the person display roaming or wandering behavior?
- Does the person have a history of falls?

Planning Tips

- Consider ways to reduce stress during the trip – e.g. noise-canceling headphones, devices containing favorite music and/or entertainment options, preferred snacks, or even additional people to support you.
- Whenever possible, try to eat meals and sleep at the same times you would at home. Write a schedule to prepare for the day's activities.
- Don't be afraid to ask for assistance from airline staff, train staff, or fellow travelers. Many people are willing to help.
- Large public bathrooms often have more than one entry or exit point. When possible, use restrooms reserved for families or caregivers, where you will have more space and be able to stay together.
- Be intentional about creating moments of joy and making memories. Ask those around you to take pictures to document your trip.
- Pack as light as possible, but always keep a change of clothes, incontinence products, and medication easily accessible.

The Association for Frontotemporal Degeneration

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- If staying in a hotel, be sure to lock the door using the safety latch. Consider buying a portable door alarm to alert you if the person diagnosed tries to leave the room while you are sleeping or showering. Bring a nightlight to help them navigate the new environment. Unfamiliar environments can be disorienting and could cause roaming, even if the person has not previously displayed roaming tendencies.
- Learn about the [Hidden Disabilities Sunflower program](#), available at many airports and other locations, which supports persons with medical conditions and disabilities.¹

Resources to Bring Along

- A letter from the neurologist or physician of the person diagnosed, stating their diagnosis and how it may impact their travel behavior (for example, the person diagnosed is unable to speak or be separated from their caregiver).
- AFTD's [FTD Awareness Cards](#) to hand out to people you encounter to educate them about FTD and ask for their patience. The business-card sized cards can be printed from the AFTD website.²
- A [TSA Disability Notification Card](#) if you are traveling by plane.³
- An identification bracelet for the person diagnosed, and make sure they are carrying identification, their care partner's contact information, important addresses, and travel information. Consider GPS tracking options.
- An updated photo of the person with FTD on your phone in case of emergencies.
- A list of important contacts, such as doctors, family, and emergency contact.
- Travel documents and medical information that you can easily access. Use phone apps to organize tickets and store medical information if you need to seek professional care during the trip.
- A current list of medications and enough supply of medication for the entire trip plus a few extra days. Make sure medications are clearly labeled and easily identifiable – in their original containers, if possible.

Tips for Traveling by Airplane

- Visit TSA Cares (tsa.gov/travel/tsa-cares) to learn about special security procedures and support for those needing additional help at the airport. Request assistance with this form: tsa.gov/contact-center/form/cares
- If needed, tell airport security workers how best to approach the person with FTD.
- Call the airline to discuss potential accommodations, such as an escort and early boarding.
- Consider travel insurance in the event you need to change your travel plans.
- Consider the best seating arrangements for your needs, such as an aisle seat or being near the restroom.

¹ <https://www.theaftd.org/posts/help-and-hope/gf-hd-sunflower-ftd/>

² <https://www.theaftd.org/living-with-ftd/resources/awareness-cards/>

³ https://www.tsa.gov/sites/default/files/disability_notification_card_508.pdf