

# Navigating the Transition to Facility Care and Working with the Care Team



## Help & Support

For families facing FTD, the transition into a residential care facility is often a challenging one, fraught with complicated emotions. Since FTD is not as well known or common as other dementias, and is often diagnosed at a relatively young age, families must often strongly advocate for the person diagnosed, actively working to adapt existing services and programs for the person's specific needs. Families can often find success with facilities that understand the importance of person-centered care and are willing to work closely with the family to achieve it. ([Click here](#) to download a list of questions AFTD has prepared to help guide your search for a care facility that's right for your loved one.)

This resource offers guidance for what comes after you find a facility: specifically, navigating the initial transition and building a relationship with the care facility to provide the best care for the person with FTD.

### Acknowledging the Emotional Impact

The transition to a facility can be emotionally difficult for all involved. For example, care partners experience a sudden and drastic role change, which can stir up a range of emotions. Some care partners also find themselves processing the time leading up to the placement and looking for new resources for support. To help process these emotions and gain additional support in navigating this transition, care partners can reach out to **FTD support groups** to share their experiences with others who are on the same journey, or even seek individual counseling.

The transition can be particularly challenging for persons diagnosed as well. Families should prepare for an adjustment period, which may include new symptoms and other changes as they adjust to a new environment and new people. Some persons diagnosed may experience significant stress during the transition period that can be described as relocation stress syndrome. ([Click here](#) to learn more.)

Work closely with the facility to create a plan to support the person diagnosed during this time. It is also important that staff spends time introducing themselves and getting to know the person and their specific needs. Use AFTD's **Daily Care Snapshot** to easily communicate to staff the person's history, needs, routine, and preferences. If the person had a professional caregiver at home prior to admission, it can help to continue their services during the initial adjustment to the facility to provide additional support. To make the person diagnosed feel more comfortable, set up their room with familiar items, making sure you honor their preferences, and allow them to make their own choices about their daily routine whenever possible. Highlight things the person diagnosed is proud of that can be used as a conversation starter with staff that focuses on the person's interests and strengths to assist with adjustment and relationship building.

The **Summer 2022 issue of AFTD's Partners in FTD Care** focuses on the transition to facility care, including guidance for care staff to ensure everything goes as smoothly as possible: **Tips for Residential Care Staff to Create a Smooth Transition**

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### Advocating for Your Loved One's Needs

During the transition, focus on building positive relationships with the facility's staff. Become familiar with the executive director or administrator, other directors (nursing, social services, activities), nurses, and direct care workers. Forging these relationships lets staff feel more comfortable approaching you with questions, and allows you the connections to discuss any concerns. If multiple family members are involved in the your loved one's care, choose one person to be the primary point person (usually the health care proxy) for facility communications and phone calls. Remember that you know your loved one best, and staff appreciate your support: you are an essential member of the care team.

For more information, watch these two sessions from AFTD's 2021 Education Conference -- [Advocating for Care: What I Wish I Knew](#), and [Advocating for Comprehensive FTD Supports](#).

### Making the Most of Care Plan Meetings

It is important to be involved in the person's care plan meetings, whether in person, virtually, or by phone. Staff should offer these meetings whenever the care plan of the person diagnosed is updated, but they can take place when requested by a responsible party. The meetings should include members of the interdisciplinary team, including the nursing, social work, dietary, activities, and (if relevant) rehabilitation departments.

Care plan meetings are your opportunity to learn more about how the person with FTD is being cared for, and to bring up any observations or concerns you may have about their care. Ideally, these discussions should anticipate and proactively address the person's needs.

AFTD has resources to help health professionals to learn more about FTD, its symptoms, and care approaches. Families can share these resources with facility staff, both so they can learn about person-centered approaches to FTD care and to make them aware of AFTD as a source of reliable FTD information. The article below from *Partners in FTD Care* focuses on developing a person-centered plan of care: [Developing a Person-Centered Care Team and Plan of Care](#)

AFTD resources include:

- [Partners in FTD Care](#)
- [AFTD Webinars](#)
- [AFTD HelpLine](#)
- [Other AFTD Publications](#)

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### Addressing Care Concerns

Issues and concerns may arise even in the best of facilities. When they do, try first to resolve the issue by speaking with the appropriate staff member or supervisor. Document your concerns, along with the names of staff you have spoken with. Depending on the issue, you may want to ask another family member, friend or a care manager to accompany you to the discussion to provide support. Approach issues with the mindset of problem solving and partnership. Facility staff can be more open if they feel you are working with them instead of against them.

If you are not satisfied with how the facility has addressed your concern, you have several options. You can bring your concern to a higher-level manager, such as the director of nursing or the facility administrator. Some facilities have a formal grievance process you can use as well.

Another option is to reach out to your state's Long-Term Care Ombudsman Program. Ombudsman programs work to advocate for facility residents and to positively resolve issues between residents, families, and facilities. Visit the [National Long-Term Care Ombudsman Resource Center](#) to learn more.

If your concerns have not been adequately addressed by the facility or an ombudsman, your State Survey Agency may provide assistance. Care facilities are required to post their contact information somewhere that residents and visitors can readily access it. The State Survey Agency will assess whether to investigate the issue, and, if necessary, will hold the facility accountable.

### Considering a Move to a Different Facility

Sometimes, moving to a different facility may become necessary. This may happen because the care needs of the person diagnosed have evolved, the family's decision or if the facility recommends a transfer or presents a discharge notice. These situations can be complicated, but the AFTD HelpLine is available to provide additional guidance. Call 866.507.7222 or email [info@theaftd.org](mailto:info@theaftd.org) to access the HelpLine.

### Considering a Move to a Different Facility

- [Family Caregiver Alliance: Caregiving Doesn't End When Your Loved One Moves](#)
- [Aging Life Care Association](#)
- [National Elder Law Foundation](#)
- [National Academy of Elder Law Attorneys](#)
- [National Long-Term Care Ombudsman Resource Center](#)

**The Association for Frontotemporal Degeneration**

[theaftd.org](http://theaftd.org) | HelpLine: 1.866.507.7222 | [info@theaftd.org](mailto:info@theaftd.org)

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