

## What to Do About... Managing Facility Care During COVID-19

The COVID-19 pandemic has upended everyone's normal routine. Among the places with the most drastic changes are long-term care facilities. For people with FTD and their families, the coronavirus outbreak has compounded an already stressful situation; meanwhile, healthcare professionals in facilities are also struggling with the pandemic while continuing to provide necessary care to persons with FTD and other dementias. Managing this situation will require significant strategic effort for all concerned.

### Strategies for FTD Family Caregivers during the COVID-19 Pandemic

- Follow information from your state and local health departments about the number of cases of coronavirus in your area.
- Ask about specific COVID-19 policies and practices at the residential care facility, especially those related to changes in visitation policy and communication with families about positive cases. If visitation is possible, find out what you can and cannot do, along with what protective equipment will be supplied to you, or what you may have to bring.
- Consider changes carefully. Changes in routine are often difficult for persons with FTD and at times even more so for the caregiver; care needs may shift based on routine disruptions.
- If you're considering bringing your loved one home during the pandemic, it is imperative to learn the facility's policies regarding a return.
- Share with facility staff information about the person's FTD diagnosis, specific needs, responses to change/stress, and effective interventions, and inform yourself of facility rules.
- Educate doctors and other care providers who are less familiar with FTD and its symptoms by sharing AFTD resources.
- Talk to the facility about any changes to their mail protocol. If they have suspended letters and packages during this time, ask if you can send email correspondence to be printed out and shared. If the facility is still receiving mail, consider sending "comfort items" that will help to soothe the person diagnosed when they feel anxious or upset, which will benefit both your loved one and overwhelmed facility staff.
- Set up regular calls with staff for updates on your loved one. Make your questions specific: How are they eating, any changes in behavior, are they doing activities, are they allowed out of their room to walk, etc. Remember to be kind and thank staff for their time.
- Advocate for medication adjustments, referral to palliative care, or hospice for additional support as needed.
- Foster communication. If possible, provide a means for your loved one to communicate with you, such as a phone or iPad. Coordinate with staff to facilitate communication as needed.
- When communicating with a loved one, try to keep conversations upbeat by talking about things your loved one enjoys or by sharing new and happy experiences.
- Always try to give a positive response: For example, you can say "I can't wait to see you again" instead of "We can't see you for a while." Do not focus or dwell on coronavirus-related restrictions, nor feelings of frustration, anger, or disappointment.
- Sustain what level of routine you can. Routine can be comforting to persons diagnosed with FTD, as well as helpful for the staff. For example, if your loved one is used to receiving a phone call from you after dinner, continue the nightly routine of phone calls while visiting is not possible.
- Monitor your own physical and mental health. This is a stressful time for all. You are not immune to the virus and so you must take care of yourself. The separation from a loved one and the anxiety about their health can take its toll.

- If hospitalization is necessary for your loved one, learn beforehand which local hospitals are admitting people; some areas have designated specific hospitals COVID-19 only.
- If you need to visit a hospital, prepare as much as possible. Have a plan in place before a crisis occurs to help moderate stress for the person diagnosed and care partner. Be ready to adopt COVID-related restrictions that have been put in place to combat the virus.
- Update advance care directives or Provider Orders for Life-Sustaining Treatment (POLST) as necessary to communicate the person's wishes about end-of-life care, especially in light of the potential for ventilator use in serious cases.
- With the caregiver, brainstorm ways to support staff and the person diagnosed, especially if their loved one is acting inappropriately or impulsively. For example, you can ask the caregiver to provide a "fact sheet" to be posted on the inside of their loved one's door listing their likes and dislikes and offering tips for successful interactions.
- Emphasize the value of non-pharmacological interventions first. Provide ongoing assistance and support to help families determine the most effective interventions and responses tailored to the individual with FTD.
- Identify a consistent staff member as a primary point of contact to ease communication challenges with families. The pandemic has exacerbated staff turnover at many facilities.

## Guidance for Medical Professionals

- Hold regular meetings with the caregiver, family and the health care team to maximize care efforts and keep everyone informed about emerging challenges. Review and adjust the care plan on an ongoing basis.
- Listen. Tune in to what the caregiver thinks and feels about the situation. Patience and time spent listening often facilitate an opportunity to educate and offer person-centered care strategies for the person diagnosed.
- Educate staff about FTD. Make sure staff are aware of the challenges that may arise in caring for someone with FTD during the COVID-19 pandemic. Share AFTD resources often.
- Help the caregiver and person diagnosed access and informal support resources that they may need during these unprecedented times; AFTD's HelpLine and support groups can be valuable resources.
- Encourage families to choose a family spokesperson and compassion-visit electee. Families, friends and caregivers have largely been prohibited from visiting facilities during the pandemic.
- Assist families in updating all important paperwork, like advance directives, to include language about ventilator use and other COVID-related matters.
- Facilitate discussions between family members and physicians or long-term care providers about supporting the family's care preferences.
- Reassure family care partners who decide that continued residential facility placement during the pandemic is necessary. Feeling judged and questioned complicates their already devastating loss.
- Reassure families and caregivers they are not alone in their journey!