



Life During a Pandemic: FTD Facility Care Amidst COVID-19

Introduction

Across the U.S., long-term care facilities have emerged as hotspots for the spread of the novel coronavirus, significantly disrupting their usual routines. For people living with FTD who are in such facilities, measures taken to control the virus can be profoundly confusing, isolating, and anxiety-making, particularly as the circumstances around the pandemic change on a near-daily basis. Facility staff also must

contend with significant changes to the way they provide care, and family members who can no longer visit their loved ones in person also have to deal with increased anxiety and even feelings of guilt. This issue addresses the impact of the coronavirus outbreak on families affected by FTD and facility staff, and offers strategies for maximizing care for persons diagnosed in the face of new reality caused by the pandemic.



The Case of Julius S.

Julius S., age 45, was diagnosed with FTD eight years ago. His condition manifested itself in many ways, most prominently his compulsive need to collect bottle caps and empty bottles. He walked his neighborhood for hours at a time and became agitated when interrupted. A healthy man in his 40s, he was difficult to comfort when distressed. His wife, Phyllis, realized she could not ensure his safety or provide adequate care for him at home, and sought to place him in a long-term care facility. She quickly found, however, that finding the right facility is not an easy task. Over the course of two years, Julius was dismissed from several facilities for his behaviors; Phyllis believed that the lack of understanding about FTD among staff contributed to his dismissals.

After multiple placements, Phyllis finally found a facility equipped to care for Julius. He has been settled there for the last three years, during which time Phyllis has established positive relationships with staff and worked with them to understand Julius's symptoms, behaviors, and how to best manage his care. Although the facility is located three hours from his family's home, Phyllis visits him frequently and, as a treat, brings him to the local convenience store once a month to choose a snack—typically a candy bar or box of cereal. Julius is comfortable with select staff members who know his likes and dislikes, and who know how to redirect him when he becomes upset.

In late February 2020, the facility began taking steps, based on clinical and governmental recommendations, to curb the spread of COVID-19. Early media reports suggested that nursing homes could emerge as virus hotspots, and Phyllis considered bringing Julius home with her to keep him safe from the disease. But she ultimately decided he would be better served remaining in the facility. She worried that taking Julius out of the facility could jeopardize the relationships she has built with his care staff, or that he would be placed on a years-long waiting list before he was allowed re-entry. Because she knew how difficult it was to find a care facility for him, Phyllis decided bringing Julius home was not worth the risk of losing his current placement. Moreover, the public health mandates and closures put in place to combat the virus created increased responsibility for Phyllis at home, as her middle school-aged son now required daily supervision and homeschooling. Becoming a full-time FTD caregiver on top of that would leave her feeling even more overwhelmed.

COVID PREPAREDNESS AND FACILITY CARE

For families navigating an FTD diagnosis, the decision to move a loved one into a long-term care (LTC) facility can be made even more difficult by the COVID-19 pandemic, as recently addressed by Carmela Tartaglia, MD, FRCPC, of the University of Toronto, in a letter published on AFTD's website. In helping families prepare for long-term care, it is important to consider the safety and stability of the person diagnosed, and to be aware that restrictions set in place to contain the virus may present unique challenges for those with FTD.

LTC facilities have emerged as frequent locations for COVID-19-related infections and deaths, in part due to challenges surrounding social isolation in such environments. Residents are at a higher risk of infection because of their proximity to one another and the generally advanced age of residents; the risk of succumbing to the virus are additionally heightened because LTC facility residents are more likely to have comorbid conditions. Many facilities are also chronically understaffed—a shortage exacerbated by the pandemic—and the rotation of LTC staff around multiple facilities can also increase the spread of infection.

Restrictions imposed to prevent the spread of the virus can lead to increased feelings of distress for those facing FTD. Family members, friends, and caregivers have largely been prohibited from visiting during this time, and such restrictions can lead to heightened anxiety for both the person diagnosed and their family members. Indeed, family members are not guaranteed access to their loved one if they contract COVID-19, which can further add to the stress of the situation.

Activities within facilities, including social gatherings among residents and other physical activities, have also been restricted. Such changes in daily routine can be particularly difficult for those living with dementia. Also, a lack of exercise and/or cognitive stimulation can lead to sleep disturbance, anxiety, and depression. Changes in sleep are especially worrisome as they can result in delirium and agitation. Decreased socialization may worsen cognitive symptoms and contribute to neuropsychiatric symptoms such as agitation or depression. Social isolation can be especially difficult for people with FTD, as they may not fully understand what is happening and may feel abandoned, leading to sadness, loneliness, anger, and even suicidal thoughts.

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Facilities Take Strict Precautions

As the number of local COVID-19 cases rose nationally and locally, the facility began taking aggressive steps to control the virus. In early March, the facility went on lockdown, ceasing all in-person visitations from family members—excluding one-time family visits at end-of-life—and transitioned to digital communications. Phyllis has since scheduled weekly video calls with Julius using FaceTime, and in lieu of their monthly shopping trips, sends him a care package with his favorite snacks and letters from their children. Due to her close relationship with facility staff, she is able to call and check on Julius at any time, and trusts they will call her with updates or concerns if necessary.

The facility also implemented a series of infection-control protocols. While the measures are intended to ensure safety and prevent the spread of the virus, many residents—particularly those with FTD and other dementias—have struggled to adjust to the new normal. Due to cognitive and behavioral symptoms, Julius is inattentive to personal hygiene and becomes resistant to hand-washing, causing staff to consider alternative methods to effectively maintain hygiene. After a phone conversation with Phyllis, the facility assigned two staff members whom Julius likes to assist with a daily hygiene routine: They created cards with pictures depicting easy-to-follow steps of how to wash his hands and, in case Julius refuses, established a backup plan (specifically, the use of antibacterial hand wipes or hand sanitizer). They also scheduled regular FaceTime calls with Phyllis to help diffuse a situation in which Julius became resistant to care.

Since the outbreak, the facility has implemented a more individualized approach to care in an effort to enforce social distancing practices. Activities that were once done in large groups, such as painting and walking outside, became limited to a maximum of five residents at a time, with just one staff member. Social distancing is difficult for Julius due to his symptoms—inappropriately approaching or touching strangers is a common behavioral symptom of FTD—and he is unable to understand why these behaviors are more unacceptable now than ever due to the risk posed by COVID-19.

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While the ongoing situation presents unique challenges for families facing FTD, there are steps that can be taken to help lessen the burden imposed by COVID-19. Families should be encouraged to share their perspective with facility staff, and to seek information about rules surrounding visitation, communication, and voluntary facility discharge. It is also important that facility staff be made aware of the ways in which disease symptoms can interfere with safety protocols, including the potential challenges of social distancing and hygiene behaviors for persons with FTD.

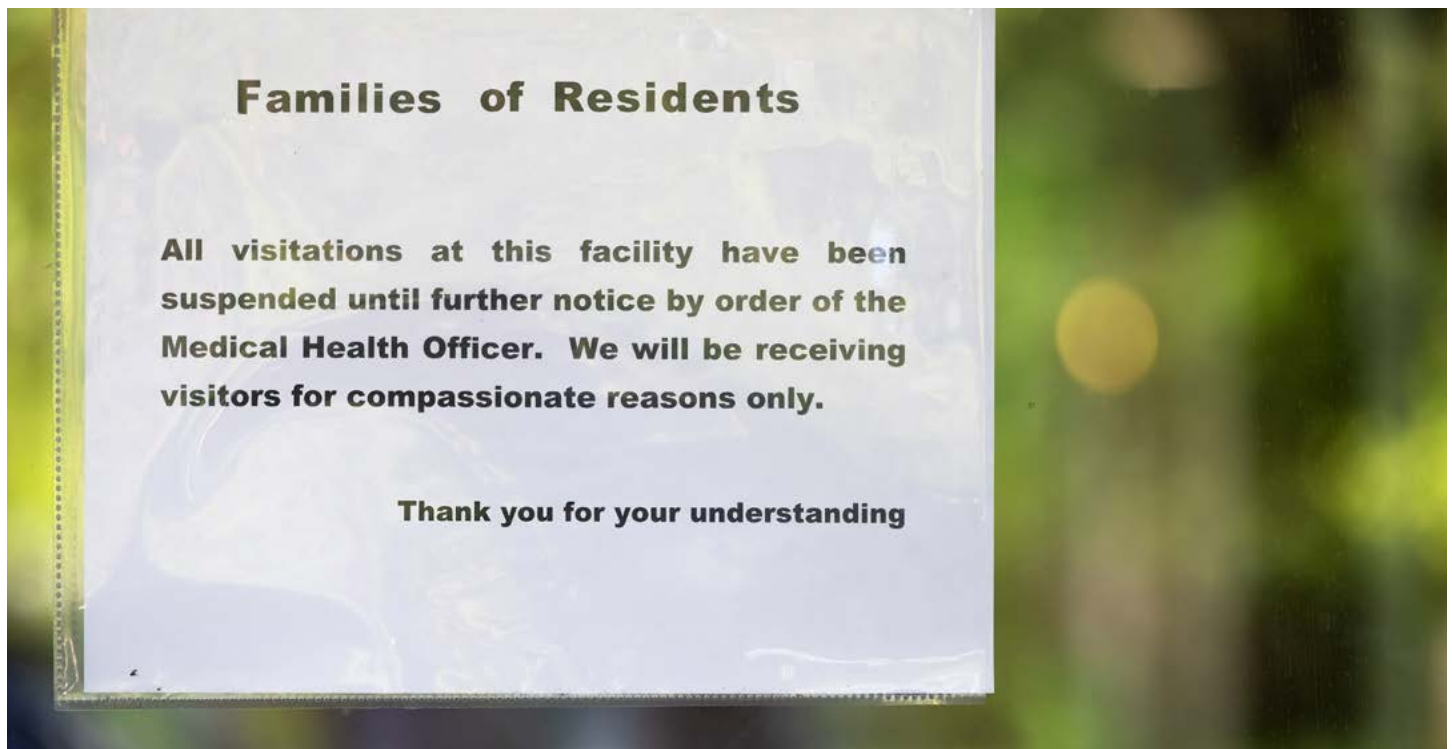
It is also important that family members and caregivers tend to themselves during this time, as they too are susceptible to the virus. In conversations with them, be sure to encourage family members to prioritize their own health and seek support as needed. ■

Changes Cause Anxiety and Depression

The rapidity and severity of the recent changes in the facility's routines have unsettled Julius. Within a few weeks of the lockdown, the resident whom Julius usually sits next to during daily activities presented COVID symptoms and was sent to the hospital for continued treatment. His friend's absence confused Julius; he would hover around his friend's door in a panicked state. Additionally, the decrease in group activities—particularly the cancellation of the facility's weekly movie night—leads to increased pacing, which staff previously had addressed by allowing him to sort bottles and cans in a designated area of the facility.

Despite efforts to keep him engaged and comfortable amid the rapid changes, Julius exhibits more depressive behaviors, such as a lack of appetite and a loss of interest in activities he once enjoyed. His care team responds by modifying his medication dosages and identifying ways to re-direct his restlessness. When he begins to withdraw from the few group activities still available, staff allow Julius to help them with small tasks in which he shows interest, such as ensuring that the chairs in the common area are spaced six feet apart. To re-direct his pacing, staff escort him outside to walk daily and encourage him to help tend to the facility's flower gardens. They take note of visual and physical cues that indicate he is anxious—most notably, he stands close to staff members, a cue that he needs to talk to Phyllis via FaceTime. Staff also refer to a list that Phyllis long ago taped to the inside of Julius's door, which includes preferred activities when he is upset, such as playing his favorite songs on their phones.

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Additionally, the need for facility staff to wear personal protective equipment, including facemasks, gloves and gowns, has added to the confusion for Julius and other persons with dementia living in the facility. These protective measures also impede staff from nonverbally communicating emotions; because of social distancing, they are also unable provide reassuring touches and hugs. This loss of connection has exacerbated an already challenging environment, and proves especially difficult for Julius, who likes to have his back rubbed when upset. Staff have instead made a particular effort to use a soothing voice to help alleviate his distress and try to communicate feelings of empathy with their eyes.

Staff have made an effort to use a soothing voice to help alleviate Julius's distress amid the rapid changes caused by the pandemic.

Effects on Staff

As the facility contends with a rise in positive cases, staff shortages and burnout become issues. Every day, all staff must complete a screening protocol, which includes a temperature check, before entering the building. Staff whose temperature exceeds 100.4° are sent home to be monitored over the next 48 hours; if a staff member tests positive for COVID, they are directed to self-quarantine for at least two weeks. Staffing shortages are also driven by increased responsibility at home, as many staff are juggling their own families' needs and schedules. While many staff members are asked to work overtime to cover shortages, the facility is also forced to rotate employees from other locations to cover crucial shifts—a necessary step that nevertheless heightens the risk of introducing COVID to the facility. To combat feelings of helplessness among staff, the facility partnered with an outside organization providing therapy and mindfulness sessions for care providers facing mental health challenges during the pandemic.

Despite her strong relationships with staff, Phyllis soon finds herself unable to reach the nurses who have always provided her with updates on Julius' care. And as the pandemic worsens, staff become increasingly unable to set aside time to call her, and updates about the status of COVID cases in the facility become

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hard to come by. Her anxiety grows, along with feelings of guilt for wanting to contact an already overworked staff. These feelings often overcome Phyllis, leaving her to constantly worry about Julius's care and state of mind.

With so much drastic change in such a short amount of time, Phyllis focuses on what she still can control. For example, she updates Julius's advance directives to include information about ventilator usage in the event that he gets COVID. This small but important step partially alleviates the anxiety Phyllis feels about not being able to see her husband in person.

The absence of certain staff also adds to Julius's distress. One night, after the male staff member who usually bathes Julius was

sent home due to an elevated fever, a female staffer attempted to step in. Julius became upset and resisted a bath. Fortunately, an on-duty nurse—with whom Phyllis had shared AFTD resources in the past—was able to help calm Julius. The nurse agreed to remain “on call” in case a similar situation arises in the future, and suggested that staff unfamiliar with Julius's case refer to the list posted on the inside of his door with his likes and dislikes, as well as the AFTD care brochures contained within a pocket folder, attached to the outside of his door.

As the pandemic continues, Phyllis begins to second-guess her decision to leave Julius in the facility. While she trusts he is receiving the best care possible, she wonders if he is feeling

IT'S OK NOT TO BE OK: DEALING WITH GRIEF AND LOSS AMID FTD AND COVID

You have chosen an incredibly meaningful line of work, which not only supports persons diagnosed with FTD, but also their families. While it is truly an honor to be part of the care and treatment of the families you serve, it can also take an emotional, physical and spiritual toll, especially during this extremely demanding and difficult time. The COVID-19 pandemic has created even more challenges for families already facing the burden of an FTD diagnosis, which in turn can lead to an increased toll on healthcare providers. Studies have found a higher risk of burnout and Post Traumatic Stress Disorder (PTSD) among employees in the healthcare sector, and direct care workers, such as Certified Nursing Aides (CNAs) and Nurses are especially vulnerable in this time.

For as many challenges as there are with FTD in normal times, the relationships you develop with the diagnosed person and their family can be extremely meaningful and unique during this period of increased isolation. Since individuals with FTD are often younger, your relationships with them, their young spouses, and even young children, can hold a different depth of compassion and connection. In this pandemic, you have likely been a supportive, familiar, and caring surrogate for family members who have been unable to visit or stay connected otherwise.

The losses due to COVID-19 can feel overwhelming, and those feelings can be further compounded by increased anxiety and uncertainty. You are not alone in feeling the pain, fear, worry, stress and unimaginable sadness of this time. Having the opportunity to share, process your feelings, acknowledge your grief, and plan for how to best care for yourself is an essential part of your wellbeing, and your ability to provide compassionate care for those with FTD.

Grief is a natural response to loss. It can present with emotional, as well as physical symptoms. When we allow ourselves to name, acknowledge, and feel the waves of grief, we can better understand our experience and ultimately, better care for ourselves. There is nothing wrong with how you feel right now, yet it can be harmful to pretend otherwise. Efforts to avoid the reality of loss can have physical effects, such as fatigue, and even a weakened immune system.

Two innovative examples of health care systems responding to the losses that providers face include the Christina Care Network in Delaware and Rutgers Health/RWJ Barnabas Health in New Jersey. The Christina Care Network's Center for Wellbeing provides group support and daily inspirational texts. In addition to peer counselors, there are designated “oasis” rooms where workers can take a break during their shift. Rutgers Health/RWJ Barnabas Health, just adopted a “Check You, Check Two” initiative, encouraging staff to attend to their own needs and also check in with two colleagues daily.

Resources are also available for persons diagnosed with FTD and their loved ones and caregivers, including AFTD's newest publication, *Walking with Grief*, a guide to grief in FTD, available on the AFTD website.

You are making a difference in the lives of those living with FTD. It is important to know that you are not alone, and support is available. If you are concerned about yourself or a colleague, consult your health care professional or ask your employer how to access mental health resources in your workplace.

If you find yourself in a crisis, the National Crisis Text Line is available by texting HOME to 741741, or you can call the Suicide Prevention Helpline at (800) 273-8255. ■

EMPLOYEE BURNOUT AND THE VALUE OF A STAFF/CAREGIVER PARTNERSHIP

For health care professionals providing FTD care during this time, it is important to recognize the difficulties COVID-19 poses for persons diagnosed and their families. Practicing open and honest communication is crucial, as fostering a sense of trust will help to ensure all parties feel informed, supported, and heard, and can lead to conversations that improve care for the person diagnosed.

More so, health care workers and the families they serve may have to be more creative and/or flexible in the way they provide support to one another during this time. To help improve care for the person diagnosed, it may be beneficial for loved ones to ask health care professionals what they can do to support facility and care staff during this time. In choosing to work as a team, medical professionals and family members can ensure the highest quality of care possible, which will help both overwhelmed facility staff and loved ones who may be experiencing increased stress under the current circumstances.

To combat feelings of physical and emotional fatigue, it is important that health care workers acknowledge burnout and its effects on both self- and patient care. While resources are available to help medical professionals address this widespread stress, including free therapy sessions, healthcare workers should be encouraged to check in with themselves daily and find ways to de-stress when possible. ■

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FROM A CAREGIVER'S PERSPECTIVE: THE DELICATE BALANCE by Rachael Martinez

During the last few months, the world has largely stopped. Stores, churches, courtrooms, beaches, businesses and more all shut down to “flatten the curve” of the novel coronavirus. Both individuals and families sheltered in place, being told it was safer at home—but what about the people for whom it wasn't? Members of the geriatric population—one of the groups most susceptible to COVID-19—who fill the rooms of nursing homes and assisted living facilities are living through the pandemic amongst each other, but apart from their loved ones. My dad, who will soon turn 64, is one of those people. He has lived in his long-term care facility for over two years and is now on hospice and completely dependent on their support due to FTD. His facility went under “lockdown” the week before statewide orders were issued, leaving me an unfilled opportunity to say good-bye.

Having my dad under the care of professionals, medical staff, and weekly visits from hospice relieves a portion of the anxiety and guilt I feel surrounding our distressing circumstances. I know he is still receiving excellent care, I know he is safe, and as of now, showing no signs or symptoms of COVID-19, but I do not know when I will get to lay eyes on him again. I have no idea if I will ever be able to hug him or tell him a funny story about raising two boys again. I have no idea if he's scared (or lucid enough to understand what is happening) or curious as to why we can only see each other via an iPad. The unknown keeps me awake at night and the worry about his health and mental well-being is overwhelming enough to be tangible.

As the global pandemic continues, so does the uncertainty. Through this unfamiliar landscape of distance and isolation, I have come to see a group of people show up and care for my dad with me, when I can't physically be near. They provide a human touch, a moment or two in the sun, or a favorite song played during dinner. The staff at my dad's facility has lovingly partaken in the delicate balance of humanity and the clinical care he so desperately needs. Amidst the chaos there are good people out there, striving to help others and I feel so grateful to watch that from afar. I know my dad would want me to accept the good; always, always accept the good wherever, however, and with whomever you can find it. ■

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scared due to his inability to understand the situation. To help ease her worries, she asks staff if they can arrange a “window visit” with Julius, in which they can see each other through a window facing the outside courtyard while talking over the phone. During the visit, Julius became confused and was unable to understand why he could see his wife through the window, but could not physically be in the same room as her. He became upset, and staff had to intervene quickly and redirect him. Phyllis stopped the visits immediately and instead increased their FaceTime calls from once to twice a week.

Throughout the pandemic, Phyllis has increasingly used AFTD’s closed Facebook group for peer support: Hearing from others who understand the FTD journey helps to calm her anxiety. Overall, she feels comforted by the idea that, while there are many things that she cannot control about the current and rapidly evolving situation, she can still be in frequent contact with Julius, and she remains confident in the facility’s ability to care for him during the pandemic.

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Discussion Questions

1. What does the staff do to maintain person-centered care amid the infection-control measures implemented in the wake of the COVID-19 pandemic?

Facility staff work with Phyllis to schedule regular FaceTime calls with Julius. They attempt to compensate for the loss of physical contact with Julius by using soothing voices and empathetic eye contact. Staff who are unfamiliar with Julius and FTD are encouraged to refer to the AFTD materials posted on the outside of his door and the list his likes and dislikes posted on the inside.

2. How does staff respond to Julius’s increasing anxiety and depression over the rapidly changing situation?

Julius’s care team modifies his medication dosages and identifies ways to channel his feelings of unease. They allow Julius to help them with small tasks in which he shows interest, such as ensuring that the chairs in the common area are spaced six feet apart. To re-direct some of his behaviors, such as his pacing inside the facility, staff escort him outside to walk daily and encourage him to help tend to the facility’s flower gardens.

3. How does Phyllis deal with her own increasing anxiety?

With so much drastic change in such a short amount of time, Phyllis focuses on what she still can control. She updates Julius’s advance directives to include information about ventilator usage in the event that he gets COVID. She also reached out for peer support via AFTD’s closed Facebook group. These small but important steps partially calm the anxiety Phyllis feels about not being able to see her husband in person.

Partners in FTD Care Advisors

The Partners in FTD Care initiative is the result of collaboration among AFTD, content experts and family caregivers. Advisors include:

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AFTD extends special thanks to all of this issue’s guest contributors, including AFTD Ambassador **Deb Scharper**, FTD care partner **Rachael Martinez**, and **Tim Lindsey**, a regional director of operations at Avenir Senior Living.

To join the Partners in FTD Care mailing list, or for permission to reprint this material in whole or in part, contact partnersinftdcare@theaftd.org.

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!