

# Family Advocacy for Nursing Home Residents During COVID-19

Although many aspects of nursing home life have changed since the COVID-19 crisis began, the right to expect quality individualized care has not. Facilities are still required to provide the care and services your loved one needs to reach his or her highest level of well-being. Additionally, you can continue to advocate for and be an active partner in ensuring quality care for your family member. In this fact sheet, we describe what you can do to advocate for your loved one and for all residents in your area, your state, and nationwide.

## Individual Advocacy

### In General

- **Monitor your loved one's condition and status.**
  - Try to arrange opportunities to see your loved one physically, either in-person indoors or outdoors, through video conferencing with FaceTime or Skype, or through a window visit. If that is not possible, ask facility staff to take a picture of your loved one and send it to you. These approaches will give you some idea of how your loved one is doing. For instance, has he/she lost weight? Does he/she appear dehydrated? Is he/she well groomed? Dressed in clean clothes?
  - Ask your loved one how he/she is doing. Some specific questions could include:
    - ◆ How do you spend your day?
    - ◆ Are there enough staff to help you when you need it?
    - ◆ How have your meals been? What did you eat for your most recent meal?
    - ◆ What time are you getting up/going to bed?
    - ◆ Are staff giving you baths or showers when they usually do? Changing your clothes daily? Brushing or helping you to brush your teeth?
    - ◆ Have you taken part in any activities you've enjoyed today?
  - Ask the facility to provide you with at least weekly updates about your loved one.
- **Monitor facility conditions.**
  - Track suspected and confirmed COVID-19 cases. Nursing home regulations require the facility to provide you with this information by 5p the day after the occurrence of a confirmed case or when three or more residents or staff show respiratory symptoms within 72 hours of each other.

- o Ask the facility for the number of COVID-related deaths, and total number of deaths of residents and staff. Although facilities are not required to provide you with this information, there is little point in them not disclosing it since facilities must report the data to the federal government where it is posted publicly. If the facility will not provide you with this data, you can access the information online: <https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg>.
- o Ask what the facility is doing to prevent the spread of COVID-19. Facilities are required to inform residents, their representatives, and families about the steps they are taking to contain the virus.
- o Talk regularly with staff and administration. Ask whether they have enough staff working and an adequate supply of personal protective equipment and tests. Again, this data is public since facilities must report it at least weekly to the federal government.

## If you have concerns about any aspect of care or treatment

It's important to speak up and take action. Here's how:

- **Discuss the problem with nursing home staff and administration.** Start with the staff member directly involved. If that is not successful, work your way up the nursing home "chain of command:" staff supervisor, department head, administrator, facility owner/board of directors.
- **Raise your concerns at the next care plan conference or request a special care plan conference.** The care plan meeting is an opportunity to share your concerns with staff, talk about what can be done, and develop a solution. Make sure to identify the staff person to go to if problems continue.
- **Use the facility grievance process.** Ask for a copy of the facility's grievance policy and follow the facility process to file a complaint/concern. The facility must work to resolve the problem promptly. You must receive a written response telling you what was done to investigate the complaint, the findings, whether the complaint was confirmed, and any action the facility has taken or actions they will take to correct the problem.
- **Raise your concern at the family council.** Family councils can be effective and powerful tools for maintaining a consumer voice in the facility and for addressing facility-wide concerns with administrators. If your facility has a family council, consider joining it. If your facility does not have one, consider starting one. See [Family Councils and Advocacy During COVID-19](#) for more information about councils during the pandemic. To learn about family councils in general, go to our [Family Council Center](#).
- **Contact the Long-Term Care Ombudsman Program.** The Ombudsman program advocates for residents and can help resolve concerns. If you have any questions or concerns about your family member's facility or the way they are being treated, contact the ombudsman program in your state: [https://theconsumervoice.org/get\\_help](https://theconsumervoice.org/get_help).

- **File a complaint with the State Survey Agency (SSA).** This agency is responsible for regulating and overseeing nursing homes in your state. One of its duties is to investigate complaints. However, at this point during the COVID-19 crisis, the federal government has told states not to investigate complaints categorized as “low priority.” But because you never know how a complaint will be classified, you should file a complaint anyway. Your complaint also documents that one or more problems have been identified in the facility. You can find information about where to file a complaint here: [https://theconsumervoice.org/get\\_help](https://theconsumervoice.org/get_help) (See Licensure and Certifications).

## Advocacy to make a difference for residents at the local, state, and national levels

- **Share your story.** By telling the story of what you and your loved one are experiencing during the pandemic, you help decision-makers and the public better understand the problems faced by nursing home residents and family members at this time. Your story can make the issues real and concrete, instead of abstract. It can motivate both decision-makers and members of the public to take action to make a change for the better.
  - You can send your stories to your local officials, state legislators, members of Congress, the Governor, and the media. Additionally, Consumer Voice invites you to share your story with us at <https://theconsumervoice.org/issues/other-issues-and-resources/covid-19/residents-families/share-your-story>.
- **Contact your elected officials.** Elected officials need to hear directly from families about what is happening in facilities during the COVID-19 crisis. By connecting with these decision-makers, you alert them to problems they may otherwise not hear about. You can also ask state and federal legislators to initiate or support legislation that could address the problem or improve the care and lives of nursing home residents. To learn who your elected officials are, click here: <https://www.usa.gov/elected-officials>.
- **Reach out to the media.** The media can be an important way to inform and educate the public and legislators about how residents are being impacted by COVID in nursing homes and to create pressure for change. There are a range of methods to involve the media, such as directly reaching out to reporters and letters to the editor.
- **Sign up as a Consumer Voice member** and with our [Action Network](#). We will give you the tools you need to take action regarding national and state policy developments, like the ability to contact your members of Congress (and other elected officials) directly through our website or issue a letter to the editor. Check out the Consumer Voice webpage on COVID to find out about our advocacy related to the pandemic: <https://theconsumervoice.org/issues/other-issues-and-resources/covid-19>.

The National Consumer Voice for Quality Long-Term Care

202.332.2275; [info@theconsumervoice.org](mailto:info@theconsumervoice.org)

[www.theconsumervoice.org](http://www.theconsumervoice.org)