

Family Councils and Advocacy 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 all the care and services residents need to reach their highest level of well-being. While family councils may need to change how they communicate and interact during this crisis, they still play an important role in fostering communication and supporting residents and staff, and can continue to be active. In this fact sheet, we describe family councils, family council advocacy, and how a family council can help make a difference for all residents in their area, state, and nationwide.

Family councils can be an effective way to advocate on behalf of all residents in a facility. While this fact sheet applies to nursing homes only, some assisted living facilities may also have family councils. To find out what the state law and regulations are where your loved one lives, contact the Long-Term Care Ombudsman Program. See below for information about this program. Family members interested in how to advocate for their own loved one should refer to the fact sheet, [Family Advocacy for Nursing Home Residents During COVID-19](#).

What a Family Council Is

A **self-led, self-determining** group of families and friends of nursing home residents that:

- Works to improve the quality of care and quality of life of the facility's residents; and
- Provides families with a voice in decision-making that affects them and their loved ones.

What Family Councils Do

- Act on concerns and complaints affecting nursing home residents.
- Advocate for positive change within the facility and the long-term care system.
- Communicate with the nursing home administrator and staff.
- Serve as a sounding board and advisory body on new ideas and improvements.
- Educate and inform families about issues relating to residents, the nursing home, and the long-term care system.
- Provide support to family members.

Family Council Rights

- A resident's family has the right to meet in the facility with the families of other residents in the facility.

- The facility must provide a family council, if one exists, with private space. Due to the COVID-19 crisis, a facility cannot provide indoor space, but it could arrange for the council to meet on the facility property, such as on a patio or in a courtyard. Alternatively, it could set up a ZOOM meeting for council members using the facility account.
- The facility is to take reasonable steps, with the approval of the council, to make family members aware of upcoming meetings in a timely manner.
- Staff or visitors may attend meetings only at the council's invitation.
- The facility must provide a designated staff person responsible for providing assistance and responding to written requests that result from council meetings.
 - The staff person must be approved by the family council and the facility.
- When a family council exists, the facility must listen to the views and act upon the grievances and recommendations of families concerning proposed policy and operational decisions affecting resident care and life in the facility.
 - The facility must be able to demonstrate its response and reason for such a response.
NOTE: This does not mean the facility must implement every request the family council recommends.

Family Councils During COVID-19

Starting a Family Council

If there is not currently a family council, consider starting one!

Possible ways to get started:

- Develop a flyer announcing the formation of a family council; put your name and contact information on it.
- Ask the administrator to send your flyer to family members.
- Ask for permission to post the flyer on the front door or near where families are visiting outdoors.
- Contact the Long-Term Care Ombudsman Program for assistance:
https://theconsumervoice.org/get_help. (See below for information about the program.)
- Create a Facebook group to attract family members; communicate directly with them about forming a family council.
- Be creative and innovative.
 - One family member handed out flyers with her name and contact information at the facility's laundry pick up/drop off area. She also asked for the names and contact information of interested family members.

Holding a Family Council Meeting

- **In-person.** Although it is not possible for most families to meet at the facility, there may be places in the community where family members can meet, such as a restaurant, a mall or an outdoor park. Also, as noted above, the council could coordinate with the facility to meet through Zoom or on the property, such as in a courtyard, on a patio, or even in the parking lot.

- **By phone or virtually.** A council could meet by phone using a conference service like freeconference.com. One virtual video platform that many are now using is Zoom. There is a free version of Zoom that allows users to hold an unlimited number of meetings with multiple participants. Meetings are capped at 40 minutes in length, so the council would have to work within that timeframe or reconvene.

Addressing Concerns

One of a council's most important functions is to bring concerns to the attention of the facility so they can be resolved. A family council can use the same strategies to address grievances during the pandemic as it would in non-pandemic times. There are a range of approaches, including communicating complaints and facility responses in writing, or meeting directly with the administrator or the grievance official for the nursing home.

Often issues can be resolved within the home itself. However, there may be times when this is not the case. If the facility is not responsive to council concerns:

- **Contact the Long-Term Care Ombudsman Program.** The Ombudsman program advocates for residents' rights and well-being. It also provides technical support to family councils and may be able to assist the council in working with the facility to resolve concerns. Locate the Ombudsman program in your state by going to: https://theconsumervoice.org/get_help.
- **File a complaint with the State Survey Agency (SSA).** This agency is responsible for regulating and overseeing all 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, the council should file a complaint anyway. The complaint also documents that the council identified a problem.
 - Each family member can file a complaint, or the council can file a complaint as a group. One unique approach is to organize your members to all file a complaint about the issue on the same day. In addition to filing a complaint about the specific problems, the council should file a complaint about the facility not responding to and addressing council concerns.
 - You can find information about where to file a complaint here: https://theconsumervoice.org/get_help (See Licensure and Certifications).

Communication with Administration and Staff

Another council role is to promote communication between families and the facility. During the COVID crisis, the council can urge administration and staff to provide families with regular updates on the status of COVID-19 and the conditions in the facility. Examples of questions the council could ask include:

- How many resident cases of COVID are there? How many staff cases?
- How many residents have died? How many staff?
- What are the staffing levels? Are agency staff providing care?
- Is there enough personal protective equipment (PPE)?

- What is happening with testing?
- What is being done to prevent the spread of the virus?

The council could also indicate that it wants to be supportive of staff and find out what it can do to show its appreciation and/or to help.

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

- **Share your stories.** By telling the stories of what council members and their loved ones 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. These stories 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, visit: <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-19 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;** each family member can sign up individually, the council can join as a group member, or you can do both. Join our [Action Network](#) too. 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. And 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>.