Residents Share Their Experiences Living in a Nursing Home During COVID-19

Recently, Consumer Voice asked residents what is happening in nursing homes regarding visitation and other activities. We asked: Is your nursing home opened for visitation? Are they allowing you to have indoor and outdoor visitation? Can you have communal dining or take part in group activities? Is your resident council meeting?

The results told us that as of June 2021:

- 85% are able to have indoor visits with their friends and family, however, the majority of those visits are limited in length and frequency.
- Only 55% stated their facility had explained their visitation policies to them, meaning many residents may be unaware of the rules surrounding visitation. It can be frustrating not knowing when, where, how, and for what amount of time you will be visited by your loved ones.
- 72% reported their visits were limited in length, while 50% reported the frequency of visits is limited.
- Only 43% said they were able to have all meals in the dining room.
• 33% said they have no group activities. This means that many residents are still not able to spend large amounts of time with others beyond their caregivers in their facility.

• 68% reported that they are not able to go outside as often as they like.

• 32% report they are not allowed to visit with their friends in the facility.

Sadly, 60% report they are not receiving the care that they need when they need it.

Several residents mentioned the inability to see their loved ones and their lack of interactions with others because of dining and group activity restrictions.

• One resident commented that, “Monday – Friday only. Scheduled time. 3pm is the latest time during the day. If visitors work, they can’t make it.”

• Many residents also said that they “Don’t understand why [visits are] limited to 30 minutes when we are all vaccinated...”

• Another resident said, “I have to eat in my room, and they always run out of food and bring me things I didn’t select that taste bad.”

• Several residents said the problem was lack of staff. There wasn't enough staff to allow them to participate in activities, see their friends, or go outside. For example, a resident commented, “They have doorway activities, but I can’t participate because I am in a wheelchair. You can’t see the other residents.”

• The lack of quality care provided during the pandemic has taken a toll on the residents. Many residents mentioned they weren't receiving the care they needed. One resident said, “Not enough baths. Have to ask for bed linen to be changed,” another stated, "they don't have time for me."

Some residents suggested that having more options for their family members to visit them and being able to get fresh air regularly would help improve their quality of life. They also said that being able to return to some form of “normalcy” within the facility through group activities and not eating alone would make a huge difference in their day-to-day lives.

We appreciate everyone who participated in this survey.
If you would like your voice to be heard there are many opportunities to work with Consumer Voice.

We have a Consumer Advisory Council made up of residents like you and opportunities for residents to participate in dialogues and listening sessions.

Please email info@theconsumervoice.org to get involved!
Compassionate Care Visits - Must Be Individualized and Person-Centered

Compassionate care visits are individualized special visits for residents during COVID-19, that support your well-being. The Centers for Medicare and Medicaid Services (CMS) gives examples of scenarios when compassionate care visits should be permitted, such as: if you are a new resident, if you are struggling with a recent loss, if it is easier for you to eat and drink with the help of family and you have lost weight, or if you are experiencing emotional distress. These are just a few examples, be sure to speak up if you have a different need. Compassionate care is allowed even if there is an outbreak, or if the resident has tested positive for COVID-19.

Facilities are required to provide care to help you reach your highest level of well-being. When advocating for compassionate care visits, you should take note of how you feel, what your needs are, and if your needs are being met in a way that is individualized or person-centered. If a facility denies you a compassionate care visit, ask for a reason the request was denied, request a care planning meeting, or contact your long-term care Ombudsman who can help raise your voice. Advocating as a resident or on behalf of a resident can seem daunting, but knowing your rights is essential.

For more information on how to make the case for Compassionate Care, find our fact sheet here: https://theconsumervoice.org/uploads/files/issues/making-the-case-for-compassionate-care.pdf

The Fight Against Chemical Restraints

Too frequently instead of ensuring residents receive the quality care they need, antipsychotic drugs are prescribed to control behavior or for the convenience of staff. When used like this, these drugs are a form of chemical restraint. Antipsychotic drugs are meant to treat patients with specific mental disorder diagnoses such as Schizophrenia. These drugs are not appropriate treatment for dementia. Residents are entitled to individualized care, not sedation.
Actions such as frustration, anger, pacing, swearing, or hitting are often signals that something is wrong. It's how the person is trying to communicate. These signs of distress could be caused by fear, pain, hunger, or something else. Masking the symptoms do not resolve the underlying problem.

Federal law gives residents the right to expect individualized care that meets their needs, and to be free from chemical restraints.

Questions you can ask if you are feeling uneasy about your treatment or notice a new medication in your daily schedule should be: Why was the drug ordered? What prompted it? Does the drug come with a black box warning? What possible interactions will it have with other medications?

Every person deserves individualized care and should be able to retain their dignity and autonomy while under the care of others.

- Know what’s in your care plan and ask questions about the usage and safety of your medications. You have the right to refuse treatment, including medications.
- Take control of your safety by staying up to date on which drugs you are taking and knowing about their risks and side effects.
- Keep an open line of communication with your caregiver and ask about any medications you are unsure about.

For more information, visit theconsumervoice.org/stop-chemical-restraints.

October is Residents’ Rights Month!

Reclaiming My Rights, My Home, My Life

The 2021 Residents’ Rights Month theme, Reclaiming My Rights, My Home, My Life highlights the need for residents’ rights to be recognized, recovered, and reasserted.

It emphasizes the recognition of the long-term care facility as the residents’ home, and the importance of residents reclaiming their own lives.

Visit www.theconsumervoice.org/events/2021-residents-rights-month for more information and resources.

Artwork by residents at Waterview Hills in Purdys, NY.

For more information and resources on COVID-19 and how to advocate for yourself, visit https://theconsumervoice.org/issues/other-issues-and-resources/covid-19.