

# Experiences of Nursing Home Residents During the Pandemic

What we learned from residents about life under Covid-19 restrictions and what we can do about it

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# **Executive Summary**

How have Covid-19 restrictions impacted the lives of nursing home residents, and how do these residents feel about those changes? Altarum's Program to Improve Eldercare sought to answer these questions by surveying the people who are directly affected by the restrictions—the nursing residents themselves, a population that is often frail and vulnerable and whose voices are rarely heard in the public debate over policies that directly and deeply affect their health, well-being, and quality of life.

To address this gap, Altarum funded and fielded an online survey, the first of its kind of nursing home residents since the start of the pandemic, from early July to August 2020. We asked residents key questions about their daily life before Covid-19 restrictions were imposed and afterward, including how often they had visitors, left their nursing home for routine activities, went outside to enjoy fresh air, where they ate their meals, and much more. The findings are stark, showing a drastic reduction in social activities and a steep increase in reported feelings of loneliness.

Below are key findings from the survey:

#### Social interactions outside the nursing home have dropped sharply

- Only 5 percent of respondents reported having visitors three or more times per week, compared to 56 percent before the outbreak.
- ▲ **93 percent** of respondents reported that they did not leave their nursing home in a given week for routine activities such as shopping and visiting family, compared to **42 percent** before the outbreak.
- ▲ Only **28 percent** reported they went outside to enjoy fresh air one or more times a week, compared to **83 percent** before the outbreak.

**76%**felt lonelier
than usual



64%
did not leave
their rooms
to socialize



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#### Social interactions and activities within the nursing home have also dropped sharply

- ▲ **54 percent** reported they are not participating in any in-home organized activities (such as exercise classes, art classes, resident meetings, and religious services), compared to **14 percent** before the outbreak.
- Only 13 percent reported eating their meals in the dining room, compared to 69 percent before the outbreak.

Additionally, **76 percent** of respondents reported that they felt lonelier under the restrictions, an unsurprising finding given that **64 percent** of respondents also indicated that they no longer even leave their rooms to socialize with other residents.

The broader evidence in the literature, as well as our survey findings detailed in this report, suggest that social isolation has produced a devastating emotional impact on many residents—and that this has also translated into accelerated physical and mental health decline.

We hope this report will help to make the case that even if Covid-19 continues to impact life in the U.S. for some time to come (as many healthcare experts believe is likely) that the concepts of "distance socializing" will be widely adopted and built on as a premise for ensuring that nursing home residents—who have for too long been assumed to be merely living out their last days and lacking full personhood—can, with compassionate work and commitment, be safely re-integrated into the larger life of their communities.

When implemented effectively, innovative distance socializing can be created in the context of social distancing to maintain—and even increase—socialization, with the help of friends, volunteers, and community organizations. The alternative to this scenario is both avoidable and grim.

# **Background**

It has now been well established that the Covid-19 pandemic is having an outsized impact on one of the most vulnerable segments of our population, frail elders living in nursing homes. Highly publicized reports emerged this summer documenting that 40% of deaths from the highly infectious virus were occurring among residents of nursing homes and assisted living facilities. This rate is highly disproportionate given that this population represents just 8% of total U.S. cases. As we move into fall, nursing home residents remain at risk.

Some nursing homes, such as those in the Green House Project, have reported lower death rates from Covid-19 among residents—likely due to good infection control and deployment of personal protective equipment (PPE). Still, the general record of nursing homes shows longstanding gaps in infection control procedures. In May, the <u>Government Accountability Office</u> released a report showing that prior to the pandemic, 82% of nursing homes were cited for infection control deficiencies. In addition, many nursing homes have reported significant difficulty obtaining sufficient PPE for all staff and for residents.



While many facilities are making significant progress, gains made during the pandemic have been hard won, and chronically short-staffed facilities have faced—and continue to face—tough challenges not only with obtaining adequate PPE, but also with gaining access to affordable, rapid testing for staff, who may unwittingly bring the virus into a nursing home from surrounding communities. Under these circumstances, trying to protect residents while retaining staff and maintaining their morale and safeguarding their health has not been easy.

But there is a second, silent crisis in many nursing homes today that is now gaining widespread public attention—the widespread social isolation and loneliness among residents. In March 2020 restrictions were placed on nursing homes prohibiting residents from seeing their loved ones, traveling freely outside the home, and in some extreme cases even leaving their rooms to socialize with other residents. The response from loved ones barred from visiting nursing homes has been mounting frustration and deepening concern. In mid-September, a federally appointed Coronavirus Commission for Safety and Quality in Nursing Homes issued a report with recommendations on infection control, safety and visitation. This was closely followed by a CMS memo on September 17th to the State Survey Agency Directors focused mainly on nursing home visitation. This guidance remains partly voluntary, with many decisions on the specifics of how visitation will be arranged left up to facilities. States have also been issuing varying reopening guidelines. However, the agency memo firmly notes that if "core principles" of good clinical care and safety are met-i.e., if the positivity rate of Covid-19 in the surrounding area is below 5% or between 5% and 10%, and there have been no new cases in the nursing home for two weeks-nursing homes "must facilitate inperson visitation." This begins to return to the norms that guarantee residents the right to receive visitors of their choosing (and to refuse visitors) that were clarified via regulation in 2016, unless a nursing home has "reasonable" clinical and safety reasons for restricting visitation.

# Survey Methods

We created a simple survey that was disseminated to residents nationally as an online, public link. Residents learned of the survey through organizations representing nursing homes, through ombudsman programs, activity professionals, nurses, administrators, family members and friends, and through other sources. The resulting convenience sample of 365 responses provides a glimpse of what residents are experiencing and how they are feeling, including in their own words. We asked a series of multiple-choice questions followed by an open text comment section, the latter of which provided a window into how residents have suffered during the lockdown.

Despite the difficulties inherent in surveying nursing home residents—which must exclude a large percentage of residents who have cognitive impairment, a lack of technology in many facilities, and the sheer difficulty in reaching residents during a time when they have been mostly closed off from the world—we received responses from 36 states.



# Resident Responses to Open-Ended Question

The following is a snapshot of resident responses to the open-ended question asking how their lives have changed since the cornavirus restrictions, summarized across five categories.

#### Failure to Thrive

Failure to thrive is a concept first used for children experiencing weight loss, poor nutrition, and inactivity due to a variety of psycho-social, emotional, or other hard to identify underlying causes. The term has more recently been applied to older adults who experience a generalized decline and have unexplained weight loss, poor appetite, and inactivity. Several residents wrote about this type of decline in their comments, including weight loss, feelings of hopelessness, and feelings of sadness or depression. These residents are concerned their isolation and inactivity is bringing on physical decline. Residents also clearly expressed their feelings of deep sadness and loneliness, and a persistent loneliness impacting them daily.

If the virus doesn't kill me the loneliness will.

I have depression—why keep living? It's not living and it's barely existing.

66

I became depressed, requiring medication approximately 6 weeks after restrictions were put into place.

I have increased confusion, weight loss, and sadness.

I feel worthless and most days I feel like giving up, and I'm usually an upbeat positive person. The facility needs to create a safe way for me to see my spouse and not keep me locked up in my tiny room. Hopefully I won't die from the way I'm now being treated.

I have become more anxious and depressed due to the separation from my loved ones. I have little appetite and am losing weight.

# Isolated Within the Nursing Home

Residents wrote about being restricted in their basic freedom of movement. They expressed their desire to go outdoors and felt nursing homes should do more to enable them to socialize. Some attributed the lack of outdoor access as an important change impacting their quality of life.

I am not able to get around in center, no group activities or able to socialize with friends. I miss visitors and volunteer that came very often and music groups.

I have been restricted to my room so long my life has gotten worse. No visitors, no going out, no nothing.

I do get lonely at times and I sometimes cry.



### Isolated from My Family

Isolation from family is a major hardship for many residents, who feel strongly that family visits should be a priority and that nursing homes need to be more creative about how to make these visits possible. Some residents spoke of being separated from their spouse, in one case even when both were residents of the same nursing home.



### Isolated from the Larger Community

Feelings of isolation from the surrounding community is another type of separation and restriction experienced by residents. Several said they feel like there are in prison and miss going into the surrounding community. While many acknowledged the need for isolation to prevent or slow the spread of Covid-19, some also pointed out that since families have not been able to visit for months, at this point it may be staff who are vectors of Covid-19 transmission. Some residents believe the total restrictions (staying in their rooms, no visitors, no communal dining, e.g.) are too confining. Residents felt they should be afforded the option to assume a higher risk from visiting with family and that a total "lock down" strategy is not workable.

I am unable to go out of the building to the programs around town.

I feel like I am in prison and need to get out and visit my kids and grandkids and be able to run around town with my daughter.

#### Bereavement

This comment shows a lack of attention to resident grief. Missed opportunities to be with loved ones who died and a lack of attention to the need to memorialize those who died, as well as anxiety about being separated from loved ones who are gravely ill, weigh on residents.

My husband passed away and due to [Covid-19] special circumstances we did not have the burial and now we need to before the weather changes, and I cannot get out long enough to get that done. I need to have closure with that. It has been 9 months.

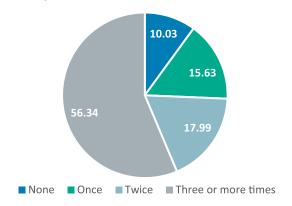


# Changes in Social Isolation Due to Covid-19: What Residents Reported About Their Experience

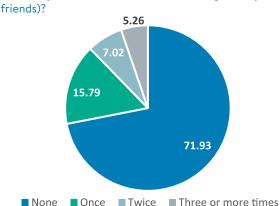
As the charts below show, our survey identified several types of isolation: isolation from family and friends; isolation from participating in the larger community; isolation within the facility; and isolation from the out-of-doors.

Prior to the Covid-19 outbreak, visits from friends and family were common—56% of residents responding had visitors three or more times a week and nearly 90% had a visitor at least once per week. After mid-March, 79% of respondents reported having no visitors at all.

BEFORE the Coronavirus restrictions, how many times during the week did you have outside visitors (e.g., family or friends)?

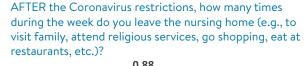


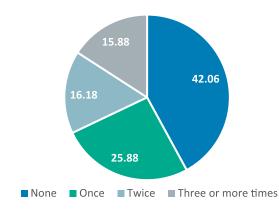
AFTER the Coronavirus restrictions, how many times a week do you now have outside visitors (e.g., family or friends)?

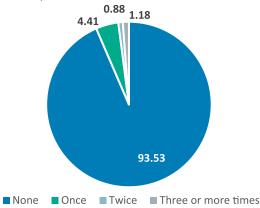


Before Covid-19, many residents responded that they went out to community events each week, with 58% reporting that they left the nursing home to go to church, to go shopping, and to eat out, among other possible activities. After the pandemic took hold, however, that dropped precipitously, to 6% now saying they had a chance to leave the nursing on a weekly basis.

BEFORE the Coronavirus restrictions, how many times during the week did you leave the nursing home (e.g., to visit family, attend religious services, go shopping, eat at restaurants, etc.)?



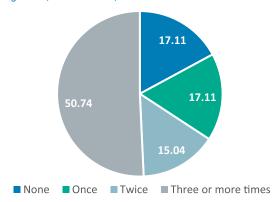




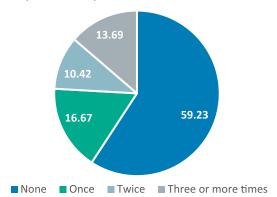


Prior to the pandemic, 83% of residents reported that they went outside to enjoy fresh air one or more times a week. After restrictions on physical movement were imposed, however, this fell to 28%.

BEFORE the Coronavirus restrictions, how many times during the week did you leave the nursing home to get some fresh air (e.g., take a walk around the building, enjoy the garden, sit out front, etc.)?



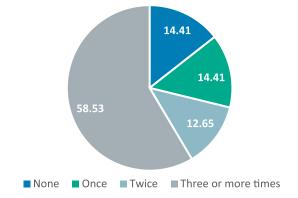
AFTER the Coronavirus restrictions, how many times during the week do you leave the building to get some fresh air (e.g., take a walk around the building, enjoy the garden, sit out front, etc.)?

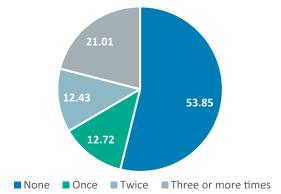


Even within the nursing home, residents reported that activities have been greatly reduced; prior to the pandemic, only 14% of residents responded that they never engaged in activities such as art class, exercise class and Resident Council meetings. During the pandemic, however, 54% of residents reported not participating in any in-home organized activities.

BEFORE the Coronavirus restrictions, how many times during the week did you participate in activities held within the nursing home (e.g., a Resident Council meeting, art class, exercise class, religious services, etc.)?



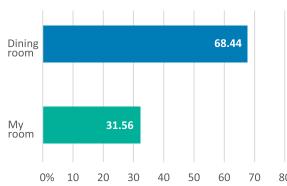




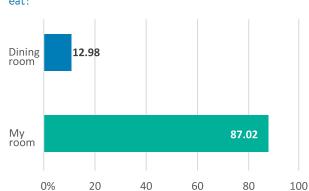


Dining, an activity that was once an opportunity for residents to socialize, has also changed dramatically. About 69% of respondents told us that they had eaten their meals in the dining room prior to the pandemic, but, after Covid-19 restrictions were imposed, this figure dropped to just 13%. The result is that 87% of these respondents now are confined to eating in their rooms, often alone.



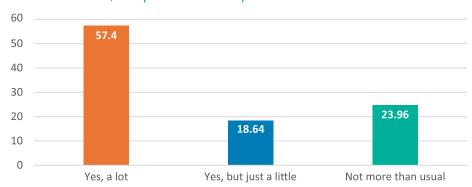


AFTER the Coronavirus restrictions, where do you usually eat?

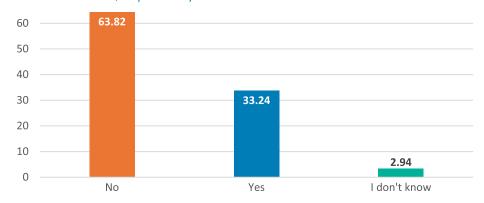


The survey found that throughout the day, residents spent most of their time room bound. Well over half (64%) of nursing home resident survey respondents indicated that they now did not leave their rooms to socialize with other residents at all. It is no surprise than that 75% of residents said they are lonely, with 57% reported being "a lot" lonelier than usual.

AFTER the Coronavirus restrictions, have you felt more lonely than usual?



AFTER the Coronavirus restrictions, do you leave your room to socialize with other residents?



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### What the Evidence Says

The results of our survey are consistent with the literature, which clearly shows that social isolation, defined as physical separation from other people—and loneliness, a subjective distressed feeling of being alone or separated—is a major scourge for older adults. Both are also common, with one study estimating that 50% of individuals over 60 are at risk of social isolation, while one-third will experience some degree of loneliness later in life. Among the risk factors are family dispersal, decreased mobility and income, loss of loved ones, and poor health. Some studies find that social isolation and loneliness are more pronounced in nursing homes, with the prevalence of severe loneliness among older people roughly double that of those living in the community: 22% to 42% for the resident population compared with 10% for the community population.

Regardless of setting, the effects of social isolation and loneliness are known to be very harmful to health: According to the Centers for Disease Control and Prevention (CDC), social isolation significantly increases the risk of premature death from all causes—a risk that is on par with smoking, obesity, and physical inactivity. Social isolation

If the virus doesn't kill me the loneliness will.

is also associated with a 50% percent increased risk of dementia. Both have been linked to increased risk of heart disease and stroke. In addition, social isolation and loneliness have been associated with an increased prevalence of vascular and neurological diseases and compounding the psychological burden of isolation, fewer opportunities for physical activity are also detrimental to health.

Social exclusion is significantly associated with higher risks of cognitive impairment, which, in turn, increases the risk of Alzheimer's disease and accelerates disease progression of existing conditions. Persons living with dementia may also be at higher risk of loneliness. A National Academy of Sciences, Engineering and Medicine consensus report study released in 2020 highlights a population-based study of 589 Swedish older adults, which found that loneliness was more prevalent in those with dementia (33 percent) than in those without dementia (22 percent). Verbal agitation (e.g., constant requests for attention, complaining, screaming) has been found to be more common in nursing home residents who are cognitively impaired and among those who are lonely.

More generally, emotional distress is another risk factor for premature death, since anxiety is known to predict all-cause death and is especially detrimental in persons aged 75 and older. Thus, when longterm care facilities prohibit visits from outside, including visits by family members, this is especially burdensome for residents with cognitive impairment and dementia.

Fortunately, there are clear counterpoints to social isolation and loneliness, both in the research literature and in recent work done by many thoughtful organizations and individuals who have published creative ideas—many of which are in the Recommendations and Resources Sections.

In the literature, rewarding social relationships have been identified as a key factor in psychological health, including happiness and subjective well-being. For example, family and friends, as well as larger groups (e.g., churches, clubs), are powerful sources of social support that variously offer tangible or instrumental support (e.g., physical assistance, financial assistance, information) and emotional support (e.g., affection, love, companionship). In addition to social support, research has found that social participation is a potent factor for physical and mental health in old age, in part because it underscores that older adults have the same rights to contribute and be included in society as younger individuals do, and because it improves overall quality of life. In nursing homes, social participation is particularly important because it prevents loneliness and other psychological problems, given that these elders are these elders are living apart from their families and former neighborhoods.

Research powerfully suggests that physically isolating residents in a manner that is known to be harmful to health as a preventive measure is tolerable only during acute emergencies and for <u>limited periods of time</u>, and should be carefully balanced against the interests of maintaining health-promoting activities. So, for example, although prohibiting all group activities may decrease the risk of spreading Covid-19 infection, it also significantly increases the isolation and resulting loneliness of residents. "<u>Lock down</u>" must be offset with safe, creative activities that keep residents' sense of self-worth and hope intact and with new modes of connecting with family and loved ones.

# What Our Survey Found About Connectivity, and Why it's Important

One way to mitigate isolation is to engage in the world of events and activities that are available online. The research literature suggests that older adults are already quite active online, although nursing homes may still lag in providing WiFi and hardware. Findings in the research literature support this, with studies showing that older users enjoy using the Internet as much as their younger counterparts.

I live a full life online, taking classes, visiting with friends, attending meetings. We have our programs on the TV now.

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A recent analysis, for example, indicates that 68% of U.S. Baby Boomers (ages 55 to 73) and 40% of the Silent Generation (74 to 91) own a smart phone. Despite the stereotypical view of older adults as resistant to new technologies, a growing number of online users are older adults. Yet while a Pew Internet and American Life Project report (Fox, 2004) and the U.S. Census Bureau (2001), report that Internet use roughly doubled to 47% between 2000 and 2004 for individuals 65 years and older, nursing homes do

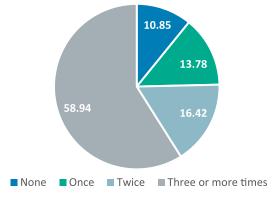
not yet appear to be on par. The use of computer and Internet may serve to <u>enhance recreational</u> <u>activities</u> and meet psychosocial needs of residents who experience excessive unoccupied time. Studies also have found <u>positive effects</u> of computer-assisted stimulating activities on psychosocial well-being among nursing home residents.

Providing residents who do not already have their own technology—such as a tablet—with equipment is likely a worthwhile investment for combating social isolation and loneliness, since the use of

technology can help reduce isolation and depression. One study in the Journal of Gerontology found that Internet use among retired older adults reduces the probability of depression by 33%, with the largest reduction in people who live alone. Internet use can also build social networks, enhance well-being, and feelings of self-empowerment, and promote deeper engagement in self-management of their health.

During the pandemic, nursing home residents have been isolated in their rooms—void of most human interaction. Providing alternative means to stay connected during such times can alleviate the effects of isolation. In

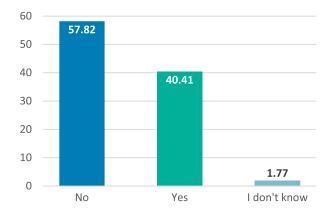
AFTER the Coronavirus restrictions, how many times during the week do you talk to someone using the telephone or video chat?



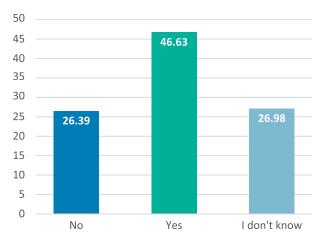


our survey, we found less than half (40%) own a device which allows them to interact readily with the web. Nursing homes are also not typically providing these devices, just 47% of respondents indicated that their nursing home has computers or tablets. And while 67% of respondents said they are aware that their nursing home offers free unlimited access to the Internet via WiFi, 45% indicated that the nursing home did not facilitate access to online activities such as live concerts, exercise, art and book clubs.

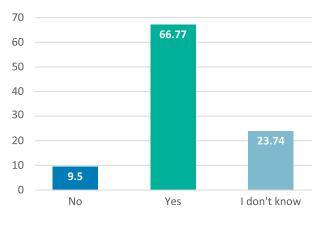
# Do you have your own smartphone, laptop, or tablet that you can use to access to the Internet?



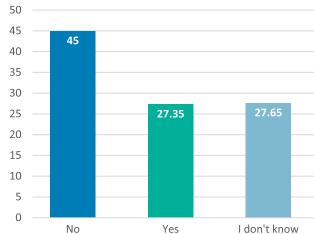
Are there computers or tablets available at the nursing home that you can use to access the Internet?



# Does the nursing home offer free WiFi that allows you unlimited access to the Internet?



Does your nursing home make online activities available for you to participate in (e.g., watching a live concert, exercise activities, art, book clubs, etc.)?



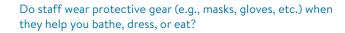


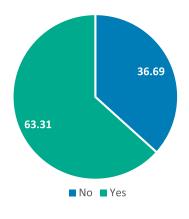


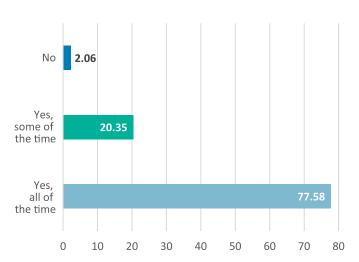
# How Safe Are Residents Feeling During Covid-19?

When asked about feelings of safety, most survey respondents-80%-affirmed that they felt the nursing home was doing their best to keep them safe from Covid-19. Nevertheless, 68% of residents also said they were very or somewhat concerned about becoming infected with the virus. And when asked whether staff talk directly to them about how they are keeping residents safe from Covid-19, most said yes (63%). Some lapses in infection control may be occurring, with nearly half (46%) of residents reporting that staff washed their hands only sometimes or not at all. On the other hand, more than three-quarters of responding residents (78%) reported that staff wore PPE when they helped residents bathe, dress and eat, Finally, with regard to testing, 61% of residents said that the home tested staff frequently for Covid-19; the remainder said they did not know.

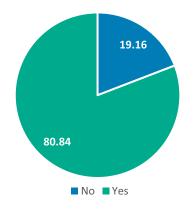
Do staff talk with you about what they are doing to keep you safe from the Coronavirus?



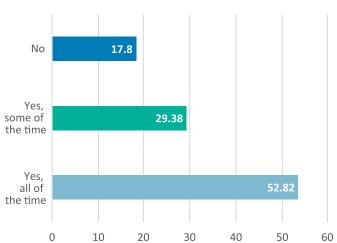




Do you feel you are adequately protected from exposure to Coronavirus?

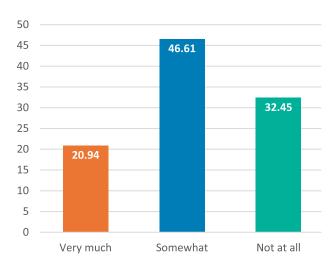


Have you noticed staff frequently washing their hands before and after providing care to you?

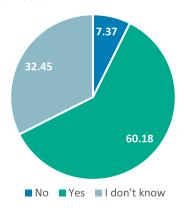








Does your nursing home test staff frequently for Coronavirus infection?



The Agency for Healthcare Research and Quality (AHRQ) defines safety as "a type of process or structure that reduces the probability of an adverse event." Adverse events generally refer to harm to a resident from care-related activities; resident-to-resident interactions; and medical management. The most commonly occurring adverse events include falls, pressure ulcers, infection (including Covid-19), and medication errors, adverse drug events and inappropriate use of medications. Nursing homes have been trying to balance the preferences of individual residents and what matters most to him or her, while simultaneously ensuring that they are safe from infection (and other adverse events), and that all have access to excellent <u>quality of care</u> and quality of life.

Measuring safety includes environmental factors and quality of care, based on the assumption that if a resident does not first feel safe, then he or she does not have optimal quality of life or good quality of care. A <u>recent study</u> showed that one of the things that mattered most to nursing home residents was that they felt safe in the facility. This has also been noted in the context of Covid-19, where many residents, including most of those in this survey, recognize that they

All the staff works very hard, we're proud of them. They all work hard to keep us safe.

feel safe from Covid-19 and well-cared for and protected in the care communities they are living in.

The ethical <u>principle of justice</u>—a moral obligation to act on the basis of fair adjudication between competing claims—requires staff to consider the safety of the larger community as well as assuring person-centered care. This is a substantial challenge in the Covid-19 era. While it is critical that there be some level of isolation to prevent and contain the spread of the virus in nursing homes, this survey demonstrates that long-term restrictions on visitation negatively impact residents' quality of life. To achieve a good quality of life in nursing homes that are heavily impacted by Covid-19, therefore, staff need to be flexible enough to make continual modifications to care protocols, staffing duties and workflows, and the physical environment, in order to help residents adjust to safety-focused restrictions, while not compromising their quality of life.



New ways of forming relationships with the larger community outside of the nursing home, and new avenues for gathering and participating in activities, e.g., attending online events, having video-conference interactions with family and friends, and reconfiguring more activities to be held outdoors whenever possible, are essential to both decrease the risk of exposure to Covid-19 (and other infections that may arise in the future) and not effectively confine residents in small spaces where their physical, mental and psychosocial health is imperiled.

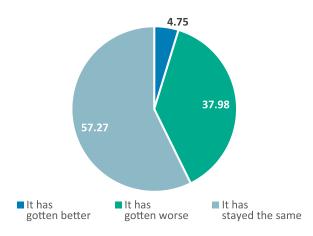
# What Has Changed in Basic Quality and Support?

In the survey, half of all respondents said that there are fewer staff today than there were before the pandemic—a worrying sign. A majority—57%—said that the quality of care was about the same, while 38% said it had gotten worse. Forty-one percent said they felt there were enough staff onsite to provide assistance with eating, while 31% said there were not. With regard to the quality of the food, 64% said it was unchanged, while 32% said it had gotten worse.

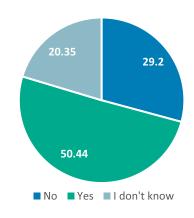
Concerns about the adequacy, or inadequacy, of staffing in nursing homes are longstanding. Under the Nursing Home Reform Act of 1987, providers are required to have "sufficient staff" to meet resident needs with at least one registered nurse on the day shift and one licensed vocational or practical nurse on the evening and night shifts. This is a soft and imprecise standard, and federal nursing home staffing requirements have not changed since then, although some experts and advocates support higher mandatory minimum staffing standards. A 2001 CMS study called for 4.1 nursing hours per resident per day to prevent harm or jeopardy to residents.

A <u>recent study</u> documented that half of nursing homes have low total nursing staffing (3.53 hours per resident day or less), and at least a quarter have very low staffing (3.18 hours per resident day or less). Conversely, higher nursing staffing (including RNs, LPNs, and CNAs) levels are generally associated with better nursing home quality, improved physical functioning, less weight loss and fewer pressure ulcers and catherizations. Examining RN staffing, one analysis concluded that required RN staffing levels are not being met by about half of all nursing homes, which may be a critical element in protecting the health and safety of residents during Covid-19. In addition, a recent survey of RNs in nursing homes found that 72% reported missing one or more necessary care tasks on their last shift

Has the quality of care in your home changed since the Coronavirus restrictions were put into place?



AFTER the Coronavirus restrictions, are there less staff available now to take care of you?



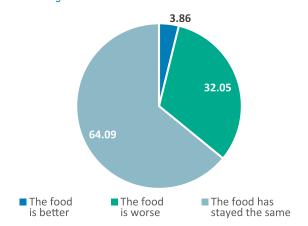


due to lack of time or resources. Finally, a California nursing home study concluded that those with lower RN staffing levels were more vulnerable to the Coronavirus, resulting in more than 28,000 U.S. nursing home resident and worker deaths by May 11, 2020.

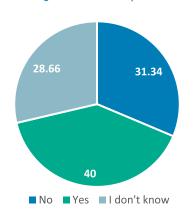
Chronic understaffing makes providing consistently good-quality care a challenge, especially during the pandemic, which requires close monitoring of residents for Covid-19 symptoms, and keeping them physically distant. Poorly compensated frontline staff, heavy workloads and little to no paid sick time are contributing factors to staffing shortages over many years. These conditions may be exacerbated by <u>fears among frontline</u> aides of getting the Covid-19 virus themselves, or transmitting it to their family and friends. Beyond this, it is believed that staff may be spreading the virus within nursing homes, 10 especially because many who are subject to low wages and a part-time employment culture work at multiple nursing homes.

Although the widely reported delays associated with getting PPE to nursing homes have partly been resolved, the failure at higher levels of government to prioritize this sector in planning has served to harm and marginalize nursing home professionals—at a time when they needed focused support and attention.

AFTER the Coronavirus restrictions, has the quality of the food changed?



AFTER the Coronavirus restrictions, if you need help to eat, are there enough staff to assist you?



### Advance Care Plans and Bereavement

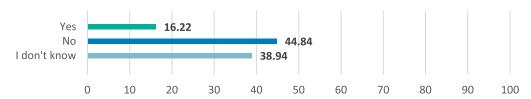
In general, residents in this survey have communicated their end-of-life preferences. Seventy-seven percent responded that they had an advance care plan (ACP), and 90% said they had designated an individual to speak for them and convey their wishes in the event that they become very ill. The <u>research literature</u> strongly supports the value of ACPs, while also calling for additional study of the experience of death and dying among individuals with and without ACPs.

But the survey also showed there is room for improvement on bereavement care, with 45% of residents saying that nursing home staff did not help them acknowledge the loss of a fellow resident with a memorial service or other form of recognition. Resources to help residents and families grieve are now widely available. For example, the University of Georgia has assembled training materials

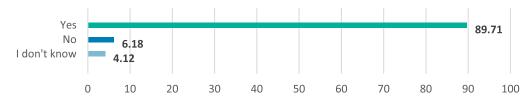


based on interviews with residents and staff featuring actionable, practical help: "If you are grieving, think about what might help you cope and discuss it with staff members," the <u>UGA booklet</u> states. "Consider talking to a therapist, social worker or chaplain if they are available. It may also be helpful to discuss your feelings with the administrator, admissions director, or a trusted friend." For staff, talking about and openly acknowledging grief should begin "long before a death occurs," the booklet advises, and encompass care of the resident's body in preparation for the family. Ceremonies (perhaps monthly) are suggested, and innovative ideas are mentioned and encouraged, including the possibility of residents throwing "farewell parties" for themselves.

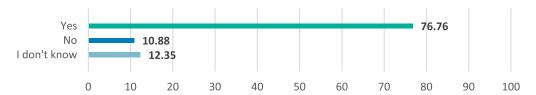
After the Cornoavirus restrictions, do staff help you acknowledge resident deaths with a memorial service or other recognition?



Have you chosen a person (e.g., spouse, friend, adult child, etc.) to convey what treatments you want and don't want in the event you become very ill?



Do you have a written advance care plan that says what treatments you want and don't want in the event you become very ill?





# Recommendations: Mitigating Social Isolation and Loneliness Among Nursing Home Residents

Each resident's autonomy, and their individual understanding of what makes their life worth living, are foundational elements in assuring their well-being. This has not changed during Covid-19. Residents' individual goals and preferences must be taken into account and documented in their personalized care plans. Loneliness and social isolation are not currently assessed—but the more restrictive circumstances of Covid-19 underscore that we must examine these issues more forthrightly.

Under current CMS guidance featured in the <u>State Operations Manual</u>, social isolation is identified as a possible risk for some residents in the context of falls, PTSD, urinary and fecal incontinence, mental disorders, placement of a feeding tube, side effects of certain medications (i.e. antipsychotics) and disturbances in the physical environment—as possible sequelae which, if it occurs, must then be mitigated. Social isolation is not, however, discussed as a possible cause of morbidity, and/or a contributing factor to premature mortality.

Loneliness is discussed as a factor to be addressed if noticed and documented as part of a pattern of citations of actual harm. It is also mentioned in the context of activities, where if loneliness is identified, it can be included in a person's care plan as part of their psychosocial needs, along with fear, anxiety and depression. If identified, interventions would then be included in the plan of care. However, care planning currently stops short of forthrightly requiring that the risk of loneliness must be assessed.

Following are recommendations to make improvements that can reduce social isolation and loneliness and increase distance socializing in the context of social distancing.

#### Nursing homes can:

- Assess each resident for social isolation and loneliness, and create practical, readily implementable approaches to mitigate these risks, documenting them in resident care plans. Social activity professionals could provide help with this part of care planning.
- Create a section for addressing isolation and loneliness within Facility Assessment Plans, and consider making these topics, along with tailored interventions that could work for most residents.
- Make isolation and loneliness a focus of QAPI Performance Improvement Projects.
- Create visiting plans for residents who want to see family and friends, and document this in resident care plans. Assign a specific staff member to be responsible for arrangements for visits that comport with CMS guidelines on visitation, most recently updated on September 17, 2020.
- Seek out ideas from staff and outside the nursing home for innovative planned online and inperson events (see examples in the "Reports & Resources" section).
- A Gather resident and family input on activities and ways to connect that are of interest to them and maintain a running list to implement. Use a continuous quality improvement approach to adapt and improve activities as they are repeated.



- ▲ Provide residents with reliable, regular access to communication technology, e.g. videoconferencing via tablets, smart phones, laptop computers or other devices, along with assistance to use whichever technology is available and works best for the resident.
- ▲ Encourage staff to focus on reintegrating residents back into the larger community using appropriate distance socializing protocols, to foster a sense of greater independence, activity and engagement among residents. Collect and share "best practices" with other nursing homes.
- Weather permitting, allow residents to leave their room every day and go outside if they wish.
- ▲ Ensure that residents nearing the end of life have opportunities to see their families before the last few hours of life. All residents should be afforded a dignified death, palliative care and the companionship of family.
- Make bereavement a part of care planning and provide support for residents who are grieving in the form of counseling and other support.
- Deploy leadership staff to prepare daily updates on Covid-19 for residents and staff. Distribute the updates by various means accessible to family and residents.
- Assign department heads and supervisors to be available to families by phone to answer questions or concerns about health, safety, loneliness and social isolation.

#### To better support frontline care staff, nursing homes can:

- Work with CMS to produce succinct training resources on:
  - o PPE;
  - o infection control and hand hygiene;
  - o physical distancing protocols;
  - o support for end-of-life care and bereavement; and
  - o ways of acknowledging and quickly addressing resident concerns and complaints about loneliness and social isolation.
- Work to promote staff stability, including:
  - o providing, if possible, housing on site or dedicated housing for those living in higher risk situations (e.g. multigenerational housing in communities where Covid-19 prevalence is high);
  - o providing daily meals and snacks to staff, rest breaks, and daily recognition of their hard work; and
  - o offering full-time employment, hazard pay, sick pay, staffing flexibility.
- ▲ Implement creative initiatives to expand the workforce, such as the possibility of using health sciences students and staff from other health facilities, e.g. hospitals.
- ▲ Encourage "daily huddles" for providing updates, addressing staff concerns and reviewing updates and evolving requirements and standards.



- ▲ Emphasize interdisciplinary teamwork and train staff for the role of universal worker.
- ▲ Train and reassign administrative staff to provide extra support for frontline care, as needed. These staff can, for example, make room visits at various times during the day for 10 to 15 minutes for conversation and helping residents to connect to preferred online activities; assisting with setting up meals, and helping residents make phone calls or participate in video chats.
- Offer bereavement training and counseling.
- ▲ Use messaging platforms (e.g., a WhatsApp group) to efficiently disseminate guidelines to managers and staff in a timely manner, and institute weekly "virtual rounds" that connect the medical director, infection control staff, medical providers, consultants and nursing home staff to review clinical care issues and updates.

#### Policymakers can:

- Direct CMS to require nursing homes to report resident social isolation and loneliness on a regular basis.
- Separately commission analyses of nursing home efforts to combat social isolation and loneliness to determine whether interventions are working well or not.
- ▲ Direct Long Term Care Ombudsmen to pay close attention to reports of social isolation and loneliness and prioritize these issues in their reporting and advocacy.
- ▲ Hold hearings and sponsor discussions for nursing home providers, public health officials, and the public about the dangers to elders of being socially isolated and how to remedy isolation.
- A Require CMS to establish a public registry of medical directors for nursing homes across the country. This will enable local and state public health officials and emergency management officials to coordinate with medical directors during public health emergencies. A registry of nursing home medical directors is also important to highlight the positive role that these physicians can play in advocating for improved quality of care, quality of life, and consistent, stable, well-trained staffing in nursing homes.
- ▲ Direct CMS to produce guidance for nursing homes on how to assess and respond to residents individual preferences around what level of risk they are comfortable with regarding group activities and Covid-19.



### Reports & Resources

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They've also set up a <a href="https://www.webpage">webpage</a> for you or your loved one to share experiences with your long-term care facility during this pandemic.



#### APPENDIX A

During our survey, residents were asked: "Is there anything else you would like to tell us about how your life has changed since the Coronavirus restrictions? Please write your answer here." Following are their responses.

"I want to go home; I am so lonesome I just want to see you. This is awful." This is a quote from my Mom about two weeks before she died at the beginning of July. There was no medical event -- there was just not life for her anymore. She died from loneliness, hopelessness and boredom.

The Activities Department should work with residents one on one, for example, to keep them exercising and to show an interest in their welfare.

All the staff work very hard and we're proud of them. They all work hard to keep us safe.

Although some activities are available now through Zoom and small safe distancing, life as I once knew it regarding activities is now quite different. I am no longer able to travel freely throughout the community, socialize with the various staff members and various departments, more confined to my immediate Pavilion area, limited in any outdoor activities and "ALWAYS" must remember to wear my mask in the proper manner while practicing "safe distancing." Being a person who thrives on socializing, this is all quite challenging and frustrating at times.

I have been restricted to room so long my life has gotten worse, no visitors, no going out, no nothing.

Covid-19 has limited my visits with my son; there is no hope.

I am completely isolated (my daughter is filling this out for me). I might as well be buried already.

I am completely isolated, lonely, depressed. I want to join my wife in heaven. Why can't family come inside if they wear their own personal "Haz Mat" suit, so we can hug and be in same room together? Especially if I am in hospice, and have chosen DNR and comfort care due to Parkinson's disease and CHF heat failure. It's been over five months since the facility has been in Covid-19 lockdown!

A resident [that a staffer is helping] stated that he wants to give a special thanks to his CNA on day shift -- Cindy R., nurse Robin S., and night shift nurse Chelsea B., who are the best nursing staff he has had. He also wants to give a special thanks to recreation staffers Sonya and Shannon for all they do!

I have depression—why keep living? It's not living and it's barely existing.

I don't get to exercise or do PT. I can't talk with staff or friends.

I don't like it. I don't know of any way of improving.

I eat less.

I eat more.



I feel as if I am in jail. I have to stay within the walls of this room. Family cannot come in and see me and I am not able to see the spring planting season, see the crops grow, attend family gatherings. Sad.

It has gotten much worse; inability to see grand and great-grandchildren.

HAIR! I need to get my hair done!

I AM NOT ALLOWED TO GO OUTSIDE. The Administration will not create an area that is safe for us to go out, or assign staff to go and watch us.

I miss visiting my friends and having group activities.

I am 42 years old. My mother took care of me for 42 plus hours a week after working her day job. To go from 6 hours a day, 7 days a week, to zero and not seeing her at all after her caring for me like this for 18 years is agony. I was clean, got fresh air, clean clothes, got my weekly shower, shaved every night, hair washed every night, sang with her, and got hugged, etc. Now, I have staff that never had a tube feed before, and I got a wound on the outside of my wrist that got infected -- but no one knows how I even got the wound—size of a dime. I was fighting a bedsore on my bottom, got a case of shingles, [an injury] on my ankle, conjunctivitis, and was sent to the hospital.

I am answering this from my brother's perspective. He is currently on hospice, goes out to dialysis three times a week, and takes little notice of the people around him. I believe that he is isolated from others as he has more exposure to possible outside infection which does not improve his mood.

I am lonely and feel like a prisoner.

I am not able to get around in the center, and there are no group activities or able to socialize with friends. I miss visitors and volunteer that came very often, and music groups.

I am obligated to stay in my room. In July I have only been out on the patio twice. There are no activities or exercise program and no in-house visits except the doctor. The food is far worse.

I am unable to go out of the building to the programs around town. However, I understand it cannot be changed at this time.

I became depressed requiring medication approximately 6 weeks after restrictions were put into place. I miss seeing my family and friends. I miss being able to leave the facility fora change of atmosphere.

I do fine and I talk to my family.

I do get lonely at times and I sometimes cry.

I don't feel the touch of my family and I need that. I feel like they don't love me anymore. I don't understand why I can't see other residents because we have all been tested. I really worry about the staff bringing Covid-19 into the facility. My days seem so long.

I don't like it.



I live a full life online, taking classes, visiting with friends, attending meetings. We have our programs on the TV now.

I don't understand why if the staff can leave and come back and put on masks why can't our family come inside and put on a mask? I hope I live to see my family again. If the virus doesn't kill me the loneliness will.

I feel it is more restrictive than necessary. I think we should still be allowed to choose what we want to eat. I think we should be allowed to go out for fresh air if we are able to socially distance ourselves.

I feel like I am in prison and need to get out and visit my kids and grandkids and be able to run around town with my daughter.

I feel like I am in prison. The prospect of weeks or months more of isolation make me feel like giving up on life. This is not living at all. Workers keep bringing the virus into the building, so tell me why my family can't visit me in my room?

I feel like I am stuck in my room.

I feel like I'm living in prison literally!

I had several family that visited weekly and I am not able to have my family come visit now at all. My husband passed away and due to special circumstances, we did not have the burial, and now we need to before the weather changes and I cannot get out long enough to get that done. I need to have closure with that. It has been 9 months. I don't understand why employees can live their life and wear a mask while working but my family cannot do that. They can just wear a mask when they come to visit.

I have a variety of ongoing and new health issues as a result of being very sick from the virus. I was hospitalized for 39 days, intubated for 12 days. Before, I would go to the hospital for outpatient care depending on the issue. Now, that is discouraged. This worries me, although I don't want to catch the virus again.

I have become more anxious and depressed due to the separation from my loved ones. I have little appetite and am losing weight.

I have changed about 95%. I used to take everything for granted and now I don't. Others do not understand what we are going through.

I have no cognitive impairments. However, there is the isolation and the loneliness, not seeing my spouse for over 100 days (my spouse was usually here 2 times/day) frequent change of rooms to allow for isolation room (my current room is so tiny, I can't maneuver my wheelchair), temporary staff. I feel more like an object than I did before Coronavirus. I'm very depressed and the nursing home has no mental wellness support other than medications. I feel worthless and most days I feel like giving up and I'm usually an up-beat positive person. The facility needs to create a safe way for me to see my spouse and not keep me locked up in my tiny room. Hopefully I won't die from the way I'm now being treated.



I have no feeling in my feet so I am in a chair. That upsets me but I am taken care of. I would like to go visit my home. I miss my family.

I have tried to reach out to several people including the Mayor and the Governor, because the nursing home staff won't allow me to walk around the outside of the building which restricts me from getting exercise. There is no one outside for me to come in contact with so I don't understand why they won't let me walk. I am lonely because they won't let anyone come in to visit. This is very difficult for the residents not to have visits with family or friends; it is depressing.

I haven't been able to see much needed specialty or primary doctors and the dentist. My former roommate had Covid-19 and I learned died. I later got Covid and had to go to the ER. I don't get help with meals and my clothes are missing. I was barricaded in my room.

I just miss my family.

I look like a cave man. No one will help shave me or cut my hair. They can't even cut my nails or toenails. I have lost weight and I stay hungry. I miss my family. I especially miss my wife. She really took care of me. I want to go home. I hate it here. I am lonely and bored and feeling very very sad and depressed.

I made the transition to my nursing home being my home during the restriction period. I don't yearn for home anymore.

I miss hugs and touch, especially from my family members! My wife used to be with me every day of the week. Now I only see her on the tablet they bring in to me three times a week. She comes to my window once a week and we talk using a phone the staff brings me. I miss my family!

I miss my family.

I miss my family and I'm very lonely and depressed.

I miss my family. I have not seen them in almost six months. My wife took care of my special help, she does not come anymore. I miss her and my daughters -- they took good care of [my needs for] special help. I forget things sometimes. I hope they come visit me soon. I want to go home.

I miss my husband. I used to see him every day.

I miss my son.

I miss seeing my husband. The virus is affecting him too.

I miss the daily visitation and stimulation given by loving daughters.

Many of the residents eat and stay in their room leaving little time to socialize.

I need my family.

I spend a lot more time alone in my room. It's self protection. I'm isolated. I do have books to read and a balcony. But when I mix with people I am more alive and more myself.



I stay in and don't see family and friends.

I stay in at all times.

I understand all the restrictions are for my benefit, but sometimes I get annoyed with the policies and procedures.

I want my daughter. She takes care of me. I saw her every day and now she can't come. I am scared.

I want to go home, I need my family.

I want visitors to be able to come inside to see me. I don't want to be restricted to my room all day and night. I want decent food and to have access to it. I want to be able to walk outside of my room and to see my friends and family that I would usually see daily. I want to regain my strength, better quality of life and independence. I want to be informed regularly about what the facility is doing and what is going to happen. I want to have my rights restored. I want to have the freedom to come and go like everyone else. I want to be treated with dignity and respect.

I was moved to a different place and my family has never seen my room. I do not have things hung on the wall to make it like home. I want my family to visit and think it can be done safely.

I wish that I could get out and go get my glasses, I must have my glasses to read books.

I would choose seeing my daughter and risk getting the virus instead of not seeing her for four months!

I would like my family to be able to visit me inside the facility at least once or twice a week. I miss them a lot.

I would like to have more visitors and more interactions with people and pets.

I'm going crazy just sitting here in my bed or in my wheelchair all day long.

If I didn't have my son to stand up for me and my needs, I don't think I would have anyone to help me.

I do not like it. I feel demeaned. I feel I am definitely being punished and am no longer in control of my life. I am in assisted living paying four figures rent to be treated like I am in jail. I am no safer inside this petri dish, than I would be if I put my mask on and took my chances like the rest of "normal" society. I want to be with my family. I want my children to be able to take me to the doctor, but instead the "powers that be" who run this place decide what is essential or not. When I came to assisted living, I thought I would be safe. I would rather be homeless under the bridge! Nothing to do.

In April, due to excessive weight loss of our mother during the late March/early April timeframe, we took her out of the facility. It was the best decision our family made. She did not understand why we were looking at her through a window and she needed to be fed and was not. That is why she lost 8 pounds in a three-week period. We were told to call and get updates at the beginning of the pandemic, but it was obvious the staff was irritated when we called to ask how she was doing. Sometimes in the evening they would hang up on my sister.



It breaks my heart I can't touch my child.

It is like being in jail; something needs to change. I cannot participate in any of my family events cannot ever leave building or have visitors.

It is very difficult not being able to see my daughter. She used to come every day and now I just get to see her once a week for an outside visit. It makes me very sad.

It sucks to be locked down.

It was terrible before virus and will be terrible after.

It's against my human rights to lock me up in my room for 5 months and say I'll likely be here for another year. I can't even visit my elderly mother or my kids. It's ridiculous. My staff travels and then comes in. If anything, they'll give it to me.

It's mainly the lack of socialization with family and friends. That has been horrible.

It's so depressing here. I feel like giving up. Can't they do something? Bingo in the hallway seated in the doorway of my room does little to help. Too many new staff who treat me like an object rather than a person with feelings—physical and emotional. That happened a bit before but it's worse now. I feel like they don't want me to die from Coronavirus but they don't care if I die from not getting good care and from deep depression. No emotional support nor mental health support is available to me.

It's ridiculous. Open us up, we are like prisoners; yet prisoners are released because of Covid-19.

It's frustrating to see staff who can't help me because they are on the quarantine unit and can't leave it to help me.

I'm more to myself.

I JUST WANT THIS COVID TO BE GONE AND GET BACK TO NORMAL. I AM TIRED OF BEING LOCKED UP.

Just ready for it to go away, I miss going to Walmart.

Just the isolation.

LIFE SUCKS.

Life has DRAMATICALLY changed since the Coronavirus restrictions. My family couldn't visit inside for four long months. Before, they visited me every day, especially during mealtimes. I get scared, lonely, and sad without my family. They looked out for me. They are my heart and soul. I don't understand why they couldn't come to visit me. The staff helps me to call them late at night...2:00 in the morning, 6:00 in the morning so I can talk with them. I wanted them to take me home, but I was told they can't come in. It's been so hard not to see my kids, and to be with them. I missed them!



Life is much more restrictive and personal interaction is down to a minimum. My outside activity is restricted to dialysis. That's it.

I am lonely and uncertain about the future. Staff can sometimes be rude when they take us outside for family visits.

I am lonely, so lonely. Not enough activity. I feel like a prisoner.

I am lonely.

Lost hope for a future.

This survey was completed by family member; the resident is isolated with no understanding of isolation, and no ability to advocate or care for self.

I miss doing errands in town, driving my car, getting out.

I miss going out with my family.

There is much less stimulation, and much less going outdoors for fresh air.

My Mom sleeps more since the dining room activities are non-existent. She misses her table buddies and just seeing other people. She keeps saying, I just want to come your house, so she can get out and see something different.

My daughter passed away and I was not able to see her or my surviving daughter in person for a month.

My home is the best.

My husband and I are being involuntarily discharged due to him breaking a Covid-19 rule when he was in the fenced back yard of our facility and our son was outside the fence. We had to hire an attorney and now we have to move. The facility has not helped us at all.

My life has changed dramatically since March 11th. I miss my wife terribly. She is in this same facility and we are not allowed to see each other. It's like living in prison.

My life has changed. I don't think we'll ever get back to how it was before. It is completely devastating. This makes me very sad, mostly for my kids.

My life has gotten worse. They do not like to help me when I need it.

My mother believes she has Covid-19 and does not. She has had delusions, both visual and auditory. I know they are trying very hard to help her. This has been such a difficult time. After one nurse is on shift, my mom calls me very agitated. All the others are amazing. This is such a hard time.



My mother has lost 20 lbs. she has also lost her ability to speak. She must eat puréed food now and thickened liquids. She has tested negative five times now for Covid-19. She is constantly being moved from room to room. The home has lost her one hearing aid. We are not allowed compassionate visits. We cannot do outside visits because she has not had Covid and recovered. She barely reacts to FaceTime and window visits. She is slowly dying from lack of visitation and stimulation with activities. It is criminal!

My weekends are really boring now because I can't have visitors anymore.

Next to God my family is the most important thing to me. I want to hug them. Please let my daughter come in to visit me.

No Beauty Shop Visits and porch-sitting with Nephew Jack.

No hugs, no one to talk with, limited time with my family, and the food is beyond gross. I have lost 40 lbs.

No organized activities.

Not allowing visits with my family for five months is inhumane. They need to allow more interaction among residents also (communal dining, activities etc).

Our facility has internet but the signal is terrible.

Our facility has maintained very strict quarantine policies, for which I'm grateful, but it is very lonely and boring at times. We can schedule window visits which help somewhat, but is not the same as having someone come in your room to visit face to face.

Phone, video, and window visits all must be booked ahead. Life seems very restricted. Lack of human contact (e.g. no visitors) is very hard. Human beings are not wired for isolation. Individuals who are tech savvy/or own devices have an advantage. The inability of family members to be more present is frustrating. There is far less sense of how my loved one is doing with such a long separation. I recognize facility staff for their service and fortitude in a difficult situation.

It's like prison. Caregivers come and go. Why can't my one family member come and go? I am 100 years old, dying and will never see my family again. This is INHUMANE!

This resident stated he wants to give a special thanks to his CNA Cindy R, Barbara, and the night shift nurse Chelsea for all they do during this time.

I feel safe! Most of the staff treats me like family.

Since I become Covid-positive I feel rejected by the facility. I do not have the freedom of doing what I used to do, even after being Covid-19 free. I got some pressure sores and spend most of the time in bed, and as I result a have panic attacks, due to the isolation.



Since the restrictions my father has begun pacing, walking the halls trying to "escape" and has become agitated and aggressive at times. We were just given 30-day notice to move him although I am not allowed in to visit, and he has declined so that we cannot have a conversation that he can comprehend. I am not sure how I am expected to find a place (because I cannot go in and tour facilities), go through his belongings and pack anything and move him when I am not allowed in the building.

We used to be tested frequently for Covid-19. Now that the residents have tested negative, we are no longer tested. However, we've had several staff members out with Covid-19 or legitimate close exposure to the virus. Apparently, no residents are "symptomatic," so we are not tested anymore. It is a well known fact that Covid-19 can be asymptomatic or have very vague symptoms. Another thing that concerns me is that everyone in my facility, both staff AND residents, are supposed to wear masks. If a resident chooses to come out of their room, they are supposed to wear a mask. This is not enforced. I'm aware there are some diagnoses that prevent a mask.

My nursing home has done a great job despite limited access to testing. We did not get any testing until May! But our doctor has seen to it that our immune systems are in good shape and therefore we have had zero residents and only one staff infected. Thank you for asking.

Sometimes Mom goes hours before being changed and waits for people to answer her call light up to an hour. CNAs don't always wear masks.

I spent most of the time in a quarantine room following surgery and in an isolation room following Covid-19 that was brought into the facility by staff. I had to be hospitalized for care for Covid-19 and recovery.

I am terribly lonely. Too sedentary.

The home has taken extra steps to protect us from the virus.

The level of care has gone down. Families are not allowed in so there is no accountability on the part of the staff. There is SO MUCH turnover and people are worked to death so many times we wait and wait for assistance.

The nursing home has a strict "no visitor" policy that has prevented my life partner from coming into my building since March 2020. It is now August 2020. This has been devastating to both of us and our loving relationship. The policy even prevents us from being together out of doors, 6 feet apart and with masks on.

The restrictions are as bad as the virus.

The rigid rules on visitors, half-hour only, and the lack of availability of slots to accommodate visitors is ridiculous and cruel to residents as there are no openings to see family member who don't even have Covid-19. These places are not being creative, focusing on socialization, interaction, and emotional support needed or quality of life.

The staff gets nasty with you if you ask them a question. I don't know why my family can't bring me personal items from the store. I feel like I am in prison.



The visits with my family are hard. The first visit it was over 100° outside but I wanted to see them. The second visit was during typhoon Faye but I wanted to see them. The podiatrist used to come but not now.

There are two main issues: 1) lack of socialization with other residents (no communal meals, few activities); 2) not seeing my family. I miss them tremendously.

There are window visits with family which are nice but not the same as real visits.

There needs to be more emphasis on social engagement and living life. Also care partners need to be part of the care team; why can they not take a course in IPC and use the procedures that staff do? Red Cross or St. John training could be made available and if they could help during Covid-19.

They did not tell my family what was going on—they still don't, and it's been five months. My daughter helped me with this note.

This facility has become paranoid and acted with overkill. This overall project of the grand sanitizing of the rooms has gone too far. I was not allowed to participate and some of my possessions are now deemed "contaminated." This is unsatisfactory especially when other options are available.

My nursing home uses Covid-19 as an excuse to keep us in the dark. Since our family, friends and others don't check on us the supervisory staff has become rude and verbally abusive toward us residents. All excuses on why we can't visit our family, even with social distancing. Everything is scheduled and there is a waiting list. Our meeting time is very short and if we ask for more time we are denied visitations in the future.

I am very lonely. I'm an invalid so I am in bed most of the day. Sometimes I sit in my wheelchair. Not allowed to leave my room. Feel like I'm in prison. I miss my daughter seeing me almost every day. Now she window visits about 3 times a week. We have to talk on the phone because I can't hear through the closed window. I can't hold the phone a long time; only have use of my left hand. And windows are not allowed to be opened, since they don't want outside air in. But a person can sit outside in the garden by themselves for a few minutes. Isn't it the same air? I'm 97 and very good with my mind. I miss my daughter so very much. At my age I doubt I will be around much longer. My golden years are in jail. I need my hair done.

I am very lonely. I miss socializing with other residents. I miss getting out into the community and having visitors.

I was in emergency room two times within a week then admitted and was brought back to isolation, with very little care. They forgot to give me blood pressure medications for two weeks. The home is severely understaffed and always taking in new residents.

A resident said that he misses his wife and not getting to see her is very hard during this time. He also stated that he doesn't like that he is not asked daily like before about his meal preferences. He feels the food he gets is worse than before but that call lights are answered in timely manner.



The resident wants to give special thanks to CNA Shannon and therapist Shannon for all their hard work.

We are bored. I miss my daughter very much.

We are in prison. We are in a 12×12 room and told not to leave. This is no way to live.

We are no longer allowed in certain parts of the center, the dining room and lobby.

We have fewer workers than before virus. New ones are not being trained to handle us well. I have gone for days and have not showered and changed clothing. Staff forgot to get my new bottle of glaucoma drops when my bottle ran out, and I went for several weeks with no drops for open angle glaucoma. As a result, my glaucoma worsened, and my specialist had to add a new drop to my two kinds of drop regiment.

We need a hairdresser!

I would like visits allowed even if its outside. We don't even get that.

Yes, my facility will not let anyone go outside unless we are supervised and it's only for 20 minutes. I am a highly functioning quadriplegic. I go to the home doctor's appointments and all that by myself, so I don't understand why we are confined to our rooms after six months. My facility wants us to eat in our rooms and I don't agree with that.

Yes! I see nothing wrong with people coming in our facility to visit when our facility staff go out to be around their families and other people on the outside of the facility. I stand just as much chance getting the virus from them returning to work as my own family.

I can't go anywhere.

My wife and I came to this facility since the personal care home didn't work out. We had remained roommates 3.5 months into the Covid-19 problem and then they decided to separate us. We fought it by gathering relevant information by calling the state and our staff ombudsman. Because we did this and were gathering information related to other issues we had had here, the social worker employed bully tactics in an attempt to get me to leave the facility without a lawful course of action. Now, I am labeled a "troublemaker" with "behavioral issues." I just wanted my wife back in our room with me.

Everyone has been great. It has been a strain on all involved but staff really have stepped up. The Activity Department has gone above and beyond to help us residents stay connected with our families by phone facetime and booth visits. We receive activity packets and attend social distancing activities.

IT HAS BEEN VERY CHALLENGING NOT TO VISIT WITH MY WIFE.



My daughter can no longer come inside to give me care so I am often left without enough support and sit in my pull-ups for too long. I'm often confused and feel like I've done something wrong. My daughter would protect me from a lot of the things happening, or not happening, right now if only she were here. Our conversations in chat are always monitored and I do not feel safe telling her what's going on.

I would like some outdoor sitting without being supervised.

Since our church is closed, we watch it virtually. My friends and I used to play golf, but that has changed, but not because of the virus.

I'm very lonely......I'm no longer able to exercise and therefore am having trouble walking...... I sure do miss activities.

We can't even come out of our rooms for activities or meals. This is awful.





### APPENDIX B - All data relating to our survey.

# COVID-19: CHANGES IN SOCIAL ISOLATION AMONG NURSING HOME RESIDENTS

BEFORE the Coronavirus restrictions, how many times during the week did you have outside visitors (e.g., family or friends)?					
BVISI Frequency Percent Cumulative Cumulative Percent					
None	34	10.03	34	10.03	
Once	53	15.63	87	25.66	
Twice	61	17.99	148	43.66	
Three or more times	191	<mark>56.34</mark>	339	100.00	
Frequency Missing = 25					

AFTER the Coronavirus restrictions, how many times a week do you now have outside visitors (e.g., family or friends)?					
AVISI Frequency Percent Cumulative Cumulative Percent					
None	246	71.93	246	71.93	
Once	54	15.79	300	87.72	
Twice	24	7.02	324	94.74	
Three or more times	18	5.26	342	100.00	
Frequency Missing = 22					

**BEFORE** the Coronavirus restrictions, how many times during the week did you leave the nursing home (e.g., to visit family, attend religious services, go shopping, eat at restaurants, etc.)?

3.07					
BLEAV	Frequency	Percent	Cumulative Frequency	Cumulative Percent	
None	143	<mark>42.06</mark>	143	42.06	
Once	88	<mark>25.88</mark>	231	67.94	
Twice	55	<mark>16.18</mark>	286	84.12	
Three or more times	54	<mark>15.88</mark>	340	100.00	
Frequency Missing = 24					



AFTER the Coronavirus restrictions, how many times during the week do you leave the nursing home (e.g., to visit family, attend religious services, go shopping, eat at restaurants, etc.)?

ALEAV	Frequency	Percent	Cumulative Frequency	Cumulative Percent
None	318	93.53	318	93.53
Once	15	4.41	333	97.94
Twice	3	0.88	336	98.82
Three or more times	4	1.18	340	100.00

Frequency Missing = 24

BEFORE the Coronavirus restrictions, how many times during the week did you leave the nursing home to get some fresh air (e.g., take a walk around the building, enjoy the garden, sit out front, etc.)?

• •				
BLEBU	Frequency	Percent	Cumulative Frequency	Cumulative Percent
None	58	17.11	58	17.11
Once	58	17.11	116	34.22
Twice	51	15.04	167	49.26
Three or more times	172	<del>50.74</del>	339	100.00

Frequency Missing = 25

**AFTER** the Coronavirus restrictions, how many times during the week do you leave the building to get some fresh air (e.g., take a walk around the building, enjoy the garden, sit out front, etc.)?

ALEBU	Frequency	Percent	Cumulative Frequency	Cumulative Percent
None	199	59.23	199	59.23
Once	56	16.67	255	75.89
Twice	35	10.42	290	86.31
Three or more times	46	13.69	336	100.00

Frequency Missing = 28



BEFORE the Coronavirus restrictions, how many times during the week did you participate in activities held within the nursing home (e.g., a Resident Council meeting, art class, exercise class, religious services, etc.)?

BPART	Frequency	Percent	Cumulative Frequency	Cumulative Percent
None	49	<mark>14.41</mark>	49	14.41
Once	49	14.41	98	28.82
Twice	43	12.65	141	41.47
Three or more times	199	<mark>58.53</mark>	340	100.00

Frequency Missing = 24

AFTER the Coronavirus restrictions, how many times during the week do you participate in activities held within the nursing home (e.g., a Resident Council meeting, art class, exercise class, religious services, etc.)?

APART	Frequency	Percent	Cumulative Frequency	Cumulative Percent
None	182	53.85	182	53.85
Once	43	12.72	225	66.57
Twice	42	12.43	267	78.99
Three or more times	71	21.01	338	100.00

Frequency Missing = 26

<b>BEFORE</b> the Coronavirus restrictions, where did you usually eat?					
BMEAL Frequency Percent Cumulative Percent					
My room	107	31.56	107	31.56	
The dining room	232	<mark>68.44</mark>	339	100.00	
Frequency Missing = 25					



<b>AFTER</b> the Coronavirus restrictions, where do you usually eat?					
AMEAL	AMEAL Frequency Percent Cumulative Percent				
My room	295	87.02	295	87.02	
The dining room	44	12.98	339	100.00	
Frequency Missing = 25					

AFTER the Coronavirus restrictions, have you felt more lonely than usual?				
ALONE	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Yes, a lot	194	57.40	194	57.40
Yes, but just a little	63	18.64	257	76.04
Not more than usual	81	23.96	338	100.00
Frequency Missing = 26				

AFTER the Coronavirus restrictions, do you leave your room to socialize with other residents?				
ASOCI	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No	217	63.82	217	63.82
Yes	113	33.24	330	97.06
I don't know	10	2.94	340	100.00
Frequency Missing = 24				

### **COVID -19: CONNECTIVITY**

Do you have your own smartphone, laptop, or tablet that you can use to access to the internet?				
CDEVI	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No	196	57.82	196	57.82
Yes	137	40.41	333	98.23
I don't know	6	1.77	339	100.00
Frequency Missing = 25				



Are there computers or tablets available at the nursing home that you can use to access the
internet?

CCOMP	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No	90	26.39	90	26.39
Yes	159	46.63	249	73.02
I don't know	92	26.98	341	100.00

Frequency Missing = 23

#### Does the nursing home offer free WiFi that allows you unlimited access to the internet?

CWIFI	Frequency	Percent	Cumulative Frequency	Cumulative Percent	
No	32	9.50	32	9.50	
Yes	225	66.77	257	76.26	
I don't know	80	23.74	337	100.00	
Frequency Missing = 27					

# Does your nursing home make online activities available for you to participate in (e.g., watching a live concert, exercise activities, art, book clubs, etc.)?

CONLI	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No	153	45.00	153	45.00
Yes	93	27.35	246	72.35
l don't know	94	27.65	340	100.00

Frequency Missing = 24

# AFTER the Coronavirus restrictions, how many times during the week do you talk to someone using the telephone or video chat?

·						
ATALK	Frequency	Percent	Cumulative Frequency	Cumulative Percent		
None	37	10.85	37	10.85		
Once	47	13.78	84	24.63		
Twice	56	16.42	140	41.06		
Three or more times	201	58.94	341	100.00		

Frequency Missing = 23



#### [Yes, Telephone] Would you be interested in learning about additional telephone or internetbased programs? (Please select all that apply)

CLEAR_1	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Not selected	282	77.47	282	77.47
Yes	82	22.53	364	100.00

# [Yes, Internet] Would you be interested in learning about additional telephone or internet-based programs? (Please select all that apply)

CLEAR_2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Not selected	273	75.00	273	75.00
Yes	91	25.00	364	100.00

# [No] Would you be interested in learning about additional telephone or internet-based programs? (Please select all that apply)

programs: (Flease select all that apply)						
CLEAR_3	Frequency	Percent	Cumulative Frequency	Cumulative Percent		
Not selected	151	41.48	151	41.48		
Yes	213	58.52	364	100.00		

### **COVID-19: FEELINGS OF SAFETY**

# Do staff wear protective gear (e.g., masks, gloves, etc.) when they help you bathe, dress, or eat?

SSPPE	Frequency	Percent	Cumulative Frequency	Cumulative Percent		
Yes, all of the time	263	<mark>77.58</mark>	263	77.58		
Yes, some of the time	69	20.35	332	97.94		
No	7	2.06	339	100.00		
	Frequency Missing = 25					



Have you noticed staff frequently washing their hands before and after providing care to you?						
SWASH	Frequency	Percent	Cumulative Frequency	Cumulative Percent		
Yes, all of the time	178	<del>52.82</del>	178	52.82		
Yes, some of the time	99	29.38	277	82.20		
No	60	17.80	337	100.00		
Frequency Missing = 27						

Do staff talk	Do staff talk with you about what they are doing to keep you safe from the Coronavirus?					
SSAFE	Frequency	Percent	Cumulative Frequency	Cumulative Percent		
No	124	<mark>36.69</mark>	124	36.69		
Yes	214	<mark>63.31</mark>	338	100.00		
	Frequency Missing = 26					

Do you feel you are adequately protected from exposure to Coronavirus?						
SPROT Frequency Percent Cumulative Frequency Percent						
No	64	19.16	64	19.16		
Yes	270	80.84	334	100.00		
Frequency Missing = 30						

How concerned are you about contracting Coronavirus?						
SFRIG Frequency Percent Cumulative Percent Prequency Percent						
Very much	71	20.94	71	20.94		
Somewhat	158	46.61	229	67.55		
Not at all	110	32.45	339	100.00		
Frequency Missing = 25						



Does your nursing home test staff frequently for Coronavirus infection?							
STEST Frequency Percent Cumulative Frequency Percent							
No	25	7.37	25	7.37			
Yes	204	60.18	229	67.55			
<b>I don't know</b> 110 <b>32.45</b> 339 100.00							
	Frequency Missing = 25						

# COVID-19: BASIC QUALITY AND SUPPORT

Has the quality of care in your home changed since the Coronavirus restrictions were put into place?							
AQUCA Frequency Percent Cumulative Cumulative Percent							
It has gotten better	16	4.75	16	4.75			
It has gotten worse	128	37.98	144	42.73			
It has stayed the same         193         57.27         337         100.00							
Frequency Missing = 27							

AFTER the Coronavirus restrictions, are there less staff available now to take care of you?						
AAVAI	Frequency	Percent	Cumulative Frequency	Cumulative Percent		
No	99	29.20	99	29.20		
Yes	171	50.44	270	79.65		
I don't know	69	20.35	339	100.00		
Frequency Missing = 25						



AFTER the Coronavirus restrictions, has the quality of the food changed?						
AQUAL Frequency Percent Cumulative Frequency Percent						
The food is better	13	3.86	13	3.86		
The food is worse	108	32.05	121	35.91		
<b>The food has stayed the same</b> 216 <b>64.09</b> 337 100.00						
Frequency Missing = 27						

AFTER the Coronavirus restrictions, if you need help to eat, are there enough staff to assist you?								
AHEEA	Frequency	Percent	Cumulative Frequency	Cumulative Percent				
No	105	31.34	105	31.34				
Yes	134	40.00	239	71.34				
I don't know         96         28.66         335         100.00								
Frequency Missing = 29								

### **COVID-19: ADVANCE CARE PLANS AND BEREAVEMENT**

Do you have a written advance care plan that says what treatments you want and don't want in the event you become very ill?							
SADVA	Frequency	Percent	Cumulative Frequency	Cumulative Percent			
No	37	10.88	37	10.88			
Yes	261	76.76	298	87.65			
I don't know         42         12.35         340         100.00							
Frequency Missing = 24							



Have you chosen a person (e.g., spouse, friend, adult child, etc.) to convey what treatments you want and don't want in the event you become very ill?						
SEOLP	Frequency	Percent	Cumulative Frequency	Cumulative Percent		
No	21	6.18	21	6.18		
Yes	305	89.71	326	95.88		
I don't know	14	4.12	340	100.00		

Frequency Missing = 24

After the Cornoavirus restrictions, do staff help you acknowledge resident deaths with a memorial service or other recognition?							
AMEMO	AMEMO Frequency Percent Cumulative Cumulative Percent						
No	152	44.84	152	44.84			
Yes	55	16.22	207	61.06			
I don't know	I don't know         132         38.94         339         100.00						
Frequency Missing = 25							