



Dementia Care Call


Moderated by Leah Nguyen
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Operator: At this time, I would like to welcome everyone to today's Medicare Learning Network® event. All lines will remain in a listen-only mode until the question-and-answer session. This call is being recorded and transcribed. If anyone has any objections, you may disconnect at this time. I would now like to turn the call over to Leah Nguyen. Thank you. You may begin.

Announcements & Introduction

Leah Nguyen: I am Leah Nguyen from the Provider Communications Group here at CMS, and I am your moderator today. I would like to welcome you to this Medicare Learning Network call on Dementia Care. During this call, learn about the unique challenges facing nursing home residents living with dementia during the COVID-19 pandemic and best practices to support them. A question-and-answer session follows the presentation.

Before we get started, you received a link to the presentation in your confirmation email. The presentation is available at the following URL – go.cms.gov/mln-events. Again, that URL is go.cms.gov/mln-events. Today's event is not intended for the press and the remarks are not considered on the record.

If you are a member of the press, you may listen in, but please refrain from asking questions during the question-and-answer session. If you have inquiries, contact press@cms.hhs.gov. At this time, I would like to turn the call over to Michele Laughman from the Division of Nursing Homes to introduce our speakers.

Presentation


Michele Laughman: Hi and welcome. Our first speakers, Cathleen Lawrence and Dara Graham, are both Nurse Consultants that work on policy and guidance within the Division of Nursing Homes here at CMS. And I am going to start by turning it over to Cathleen.

Dementia Care and COVID-19

Cathleen Lawrence: Hello, everyone. As you all know, caring for residents living with dementia has become more challenging during the COVID-19 public health emergency as nursing homes try to prevent the spread of COVID-19 among their residents and staff. Residents living with dementia may find new practices related to COVID-19 confusing or even frightening.

While infection control practices such as transmission-based precautions and cohorting may be distressing for residents, these practices are necessary to prevent transmission of this life-threatening virus. Facility staff can generally explain the new practices such as wearing masks or face coverings and social distancing to residents without cognitive impairment.

However, residents living with dementia may have difficulty understanding these changes. This means facilities need to explain the new practices to resident families and resident representatives, as well as take extra time to work with residents living with dementia. For this call, we wanted to highlight some of the long-term care facility requirements which are especially significant during this pandemic.



The regulations at 42 CFR 483.80 contain important requirements for infection control in nursing homes. Specifically, 483.80(a)(2)(iv) here on slide 6 states that facilities must determine when and how isolation should be used for residents including, but not limited to, the type and duration of the isolation depending upon the infectious agent or organism involved, and a requirement that the isolation should be the least restrictive possible for the resident under the circumstances.

The guidance at F880 provides additional information, resources, and examples. This guidance, as you can see on slide 7, also addresses the challenge of caring for residents living with dementia while adhering to infection control practices to prevent the transmission of diseases like COVID-19.

Guidance in F880 states, “Facility staff should take measures to reduce or minimize any potential psychosocial negative effects of isolation for whom transmission-based precautions are being used. Boredom, anger, withdrawal, or depression are just some of the mood changes that could occur. The facility must proactively ensure that individualized needs such as activities are met.”


When caring for residents with dementia while also addressing infection control issues like COVID-19, facilities should provide education to residents and their representatives on infection control practices such as hand hygiene, especially before eating and after using the restroom, cough etiquette, use of masks and physical distancing; provide education that is consistent with the resident’s capacity for understanding; monitor for resident-to-resident direct contact transmission which may occur in common areas of the facility such as the recreation room, rehabilitation area or dining room; and ensure appropriate use of transmission-based precautions so that these precautions are not considered involuntary seclusion.

Additionally, the regulations at 483.12 and guidance at F603 address involuntary seclusion. The guidance states that facilities need to ensure that isolation to prevent transmission of infection is not involuntary seclusion.

The guidance at F603 further states that a resident in a secured, locked area would not be considered to be involuntarily secluded – involuntarily secluded if all of the following are met: the facility has identified the clinical criteria for placing a resident in the secured area; placement in the area is not used for staff convenience or discipline; based on the resident’s diagnosis alone since the determination for placement in the area must be made on an individualized basis; and/or based on a request from the resident’s representative or family member without clinical justification.

Additionally, as seen on slide 9, F603 specifically addresses this transmission-based precautions and isolation. When used appropriately, transmission-based precautions such as isolation due to infection is not to be considered involuntary seclusion. Facility’s policies must identify the type and duration of the transmission-based precautions required, depending upon the infectious agent or organism involved, and the precautions should be the least restrictive possible for the resident based on his/her clinical situation.

Furthermore, the resident’s record must contain the rationale for the selected transmission-based precautions. However, once the resident is no longer a risk for transmitting the infection, the removal of transmission-based precautions is required in order to avoid unnecessary involuntary seclusion.



Facilities also need to continue to comply with the requirements related to physical and chemical restraints while adhering to infection control standards and practice. We recognize that adhering to infection control practices and current guidance during this public health emergency may cause feelings of anxiety, distress, isolation, and depression among residents.

When performing procedures which may cause indications of distress, ensure that staff are compliant with the resident's right to be free from physical and chemical restraints. For example, facilities should not initiate a chemical restraint to sedate the resident and keep him or her from walking into another resident's room or getting too close to other residents.

Instead, look at ways the resident's need to walk around could be met while maintaining safe infection control practices, such as by having staff go for walks together with a resident with both the resident and staff member wearing a mask or face covering. And consider walking during less busy times of the evening or night or going outside, if possible. Next, my colleague Dara Graham will provide additional information on other federal requirements that are especially important during this time.

Dara Graham: Thank you, Cathleen. Moving to slide 11. Situations including public health emergencies can be extremely stressful for both residents and health care workers, leading to increased distress and the potential for unnecessary use of medications. Federal requirements at F757 and F758 specify that each resident's entire drug medication regimen is managed and monitored to promote or maintain the resident's highest practicable mental, physical, and psychosocial well-being.

The facility implements gradual dose reductions, also known as GDR, and non-pharmacological interventions unless contraindicated prior to initiating or instead of continuing psychotropic and P.R.N. order, or psychotropic medications are only used when a medication is necessary and P.R.N. use is limited.

We want to ensure that even during a time of crisis appropriate person-centered resident care continues for each resident and that the risk of adverse consequences related to medication use is minimized. Additionally, as part of all medication management, especially with the use of psychotropic medications, it is especially important for an interdisciplinary team to implement non-pharmacological approaches designed to meet the individual need of each resident.

Educating family or, rather, facility staff and providers about the importance of implementing individualized, non-pharmacological approaches to care prior to the use of medications may minimize the need for medications or reduce the dose and duration of these medications.

We would like to note that there may be isolated situations where a pharmacological intervention is required first. These situations do not negate the obligation the facility – of the facility to develop and implement non-pharmacological interventions unless contraindicated.

The indications for initiating, withdrawing, or withholding medication or medications, as well as the use of non-pharmacological approaches, are determined by assessing the resident's underlying condition, current signs and symptoms, expression, preferences, as well as goals of treatment. This includes, where possible, the identification of the underlying cause or causes since the diagnosis alone may not warrant treatment with medications.



For residents with dementia or another type of cognitive impairment, assessing an underlying condition may be especially difficult. Non-verbal behaviors, sometimes thought of as being challenging, are often attempts by the resident to communicate an unmet need. Unlocking the need that the resident has and the use of non-pharmacological approaches to care and support the resident may minimize the need for a pharmacological intervention.

We are now on slide 12. Under F725, facilities are required to have sufficient qualified nursing staff available at all times. This is especially critical during a situation of crisis or a pandemic and for residents living with dementia. Residents living with dementia may require more one-on-one support and services.

The challenges of a pandemic like COVID-19 could involve changes in routine, use of testing and PPE and other safety restrictions which could be confusing or upsetting to residents, especially those with dementia or other cognitive impairment. These changes can lead to distress and new or worsening behaviors.

Some concerns like falls, weight loss, dehydration, pressure ulcers, as well as incidents of elopement and resident altercations can offer insight into the sufficiency of the number of staff within a facility. A facility must ensure that there are sufficient number of skilled licensed nurses, nurse aides, and other nursing personnel to provide care and respond to each resident's need; must ensure licensed nurse coverage 24 hours a day, except when waived; and ensure a licensed nurse is designated to serve as a charge nurse on each core duty, except when waived.

Lastly, slide 13 details some additional CMS resources including Quality, Safety and Oversight, QSO, policy memorandums. On this particular link, you will find the most recent nursing home CMS memorandum released on September 17 that details new guidance regarding visitation during the public health emergency. We expect this guidance will help address the isolation and confusion residents have been feeling while visitation has been restricted to reduce the – to reduce the risk of COVID-19 transmission to nursing home residents.

In this guidance, CMS states there is no reason facilities should not conduct outdoor visitation except for concerns with weather, a resident's health status, or if the facility is currently expecting a COVID-19 outbreak. Facilities may also conduct indoor visitations as long as visitors are screened and adhere to core principles of COVID-19 infection prevention outlined in the guidance.

Facilities should also use their county positivity rate to determine the ability to conduct indoor visitation. The guidance also provides more information on compassionate care visits if a facility finds it must still limit indoor in-person visits due to an outbreak in the facility or a high county positive rate. The memo number is QSO 2039N, as in nursing, H, as in homes and can be found on the CMS QSO Policy Memorandum website listed on this slide, slide 13. I will now turn it back over to my colleague, Michele Laughman.

Michele Laughman: Thank you, Cathleen, and Dara, appreciate that. Our next speaker is Kara Jacobs Slifka, an Infectious Diseases Physician and Medical Epidemiologist with the Long-Term Care Team in the Division of Healthcare Quality Promotion at the Centers for Disease Control and Prevention. Kara, I turn it over to you.

Strategies for Combating COVID-19

Kara Jacobs Slifka: Thank you so much. So, I'm going to be talking with you today about some strategies for combating COVID-19 infection prevention challenges that we can face in nursing home settings, especially with residents with dementia and how to work with them as caregivers. And that's starting on slide 14.

Moving on to the next slide, I am first going to talk a little bit about some of the core activities of COVID-19 prevention and response in nursing homes. But, then, I'm going to talk a little bit more about some of those challenges with actually implementing the IPC practices and, then, discuss some considerations and strategies for trying to prevent the transmission of SARS-CoV-2, the virus that causes COVID-19.

So, on slide 16, I just wanted to first start by saying a big thank you from all of us at CDC to all of you in the nursing home communities for your commitment to your residents and families. We definitely see you and appreciate the work that you are doing.

And on slide 17, I also want to acknowledge just how important the experiences are that you all have shared with us and with our deployers because they have directly contributed to the guidance that we have put together. And you can see a snapshot here of preparing for COVID-19 in nursing homes. This is our nursing home infection prevention guidance.


And we have recently created a new landing page because there is so much information that can be sometimes challenging to navigate to. But, if you are able to make it to the Nursing Home section or the Long-Term Care and Nursing Home section within the Infection Prevention area on our COVID webpage, you will see a new page that has links to our guidance, testing guidance. It has links to NHSN, to even some of the mentioned CMS memos that were described, as well as some additional resources and educational materials.

So, the COVID-19 pandemic has really highlighted the critical importance of strong infection prevention and control programs. And this includes the need for trained and dedicated staff in every facility who really have time to provide the education for everyone in the facility, from residents and families to all levels of health care personnel.

Facilities, we know, are doing surveillance for COVID signs and symptoms in residents and in health care personal and anyone who is entering the building. And this alone can be very time consuming. It can be a fulltime job, especially in addition to maintaining communication with state and local health partners and as well as weekly reporting into CDC's National Healthcare Safety Network, or NHSN, COVID-19 module.

And then, a lot of these different activities are changing over time. Some are staying the same. The recently mentioned new visitation guidance moving from complete restriction to allowing some of that visitation again, source control, screening health care personnel and residents – these are all things that have – that will – may and will continue to change over time as we go through.

But, I do think that some of the changes that we have seen and that we have made as a result of COVID-19, like implementing sick leave policies and benefits that allow staff to stay home when they are ill will have a positive impact on reducing even some of the other common outbreaks in nursing homes.



So, moving on to the next slide on slide 19. There is very little that is new on this slide when it comes to implementing infection prevention and control practices. These, again, are also practices that can really help prevent spread of infectious pathogens other than COVID-19 – so, COVID-19 and others – MDROs – excuse me – influenza and other pathogens.

So, probably the most common thing that we talk about when we are visiting providers are reasons why CDC has promoted the use of alcohol-based hand sanitizer for most clinical situations, except when hands are visibly soiled and while walking through clinical areas and residents' rooms, talking about strategic placement of dispensers and how this can really help staff build hand hygiene into their workflow.

We know overall with PPE and other supplies that there have been supply disruption and that all of you have been doing your best to manage inventory while trying to maintain safety for your staff and residents. And with this last point, implementing a respiratory protection program, this is relatively new for most of you. But we have heard several different ways that centers have been able to access and implement these programs for their staff as part of the use of N95 respirators.

So, now on slide 20. While I have shared some of the core infection prevention practices – at least run through quickly – one of our early observations during COVID-19 nursing home deployments was that implementing these practices on a large scale, especially with residents who have dementia and even more so in settings where there are multiple residents with dementia residing together, settings like memory care unit or a dementia unit, it can be quite challenging.

And, so, these observations and some of the lessons learned have prompted our development of a Considerations for Memory Care Unit in Long-Term Care Facilities guidance. And some of this guidance really can be applied to settings outside of memory care units as well.

So, on slide 21, almost half of nursing home residents have been diagnosed with Alzheimer's disease or other dementias. And with less than one out of every five nursing homes having a specific dementia or memory care unit, we fully recognize that these units are not the only places, not the only locations within nursing homes where implementing infection prevention practices can be challenging.

So, it's really important not just for staff providing care for residents, but also for us on the public health side and others involved in helping to make outbreak prevention and response decisions to first understand the needs of residents with dementia and of their caregivers.

And, so, each resident's needs may be unique. And things that we see, such as changes in behavior or worsening dementia, really should be investigated because while they may indicate increased stress or anxiety, they also have the potential to indicate a change such as infection.

And with this constantly new and changing period of time that we are all living in right now, it's hard for all of us. But even little changes or disruptions to resident routines or daily schedules can lead to fear and anxiety and potentially result in behavioral changes. So, especially during this outbreak when nursing homes can be at a change of – kind of a constant state of flux with movement of residents and cohorting, residents with dementia may be especially vulnerable.



Now, on slide 23. And what I wanted to share were some of the lessons that we have learned in nursing homes. And those include things like once we see a single confirmed case of COVID-19 in a nursing home setting, we often find that there are other residents and health care personnel who are infected.

SARS-CoV-2 most often appears to be introduced into nursing homes through health care personnel and can spread rapidly. And we have especially seen this in memory care units or dementia units. And many of our observations that specifically come in those dedicated units include that we actually have seen that in some settings where there is an outbreak going on within a nursing home, that if there is a locked memory care unit with dedicated staff, they actually sometimes have been initially protected because there is less overlap between the residents and health care personnel – less interactions with the rest of the facility. But we have also seen the reverse happen as well.

And, then, as I think has been mentioned, residents with dementia can have a difficult time following some of those recommended infection prevention practices, things like social distancing, washing their hands, avoiding touching their face, or even wearing a cloth face covering. And it may take some extra staff time and support to assist residents with performing some of these practices.

And I am going to get into a little bit more detail about this. But a dedicated COVID care unit – one of the things that we have observed is that this may not always be the best place for some residents.

So, moving on to the next slide. Some of the approaches that we have seen – that we have seen you all doing that may be helpful are really trying to stick to routines and keep those residents' environments as consistent as possible. Some residents may need continued reminders and even assistance with performing hand hygiene and reminders to keep distance from others and to wear – to put on those cloth face coverings and try to keep them on. And even that may still be extremely challenging and, ultimately, not possible to do.

But, as much – I think we have also seen that as much as possible – and, again, we recognize this is not always possible, especially when there are staffing shortages – but, trying to dedicate staff and keep staff as consistent as possible. And we have seen this as sometimes, sometimes maybe more feasible when there is a specific dedicated unit.

But we have seen that not only is this helpful for residents, especially those residents with dementia, but also to decrease the number of potential exposures should either the resident or staff become infected. And I will share that we have heard a lot of really creative ways in which providers have been able to encourage activity and try to find safe ways for residents to have fun and to stay busy and even socialize.

I know I've shared this example before on other calls, but one example we had – that had been shared with us – was for residents who were able to remain distant trying to do kind of an in-room or doorway dance party where mobile and even residents who were seated participate from their rooms or their doorways.

And I also want to add that because mask use may be challenging, hand hygiene may be challenging, residents may touch their faces and mouths, frequent cleaning and disinfection of high-touch surfaces – things like chair rails, tabletops, doorknobs – this is really important and continue to be even more important.



Moving on to the next slide, slide 25. One area I wanted to specifically cover are PPE recommendations. And, so, CDC has actually made slightly different PPE recommendations specifically for memory care units.

And, so, we recommend for health care settings in general that when you are providing care to someone that is suspected or confirmed to have COVID-19 that you use an N95 respirator or face mask if respirators aren't available, eye protection that's covering the front and sides of your eyes such as a face shield or goggles, gown and gloves and that, in general, you should be using face masks universally for source control and in areas with moderate to substantial transmission – that you should be using eye protection.

But, because of some of the challenges that we have observed specifically in memory care or dementia units with restricting movements of residents and residents being able to understand and follow some of the recommended infection prevention practices, we have actually made the recommendation that universal – for universal use of eye protection and an N95 respirator or face mask if a respirator is not available for all personnel when they are on that unit to address the potential for encountering wandering residents who might have COVID-19. And, so, this is a little bit different than what we have recommended overall. And it is possible that this is something that could be applicable, depending on your population, in other areas of the building.

On the next slide, slide 26, I wanted to touch upon a comment that I made earlier about considering the risks and benefits of moving residents specifically out of memory care units to a designated COVID-19 care unit. And, again, this may apply to some other residents in other settings.

So, what I want you to think about is what CDC has typically recommended when you confirm that a resident has COVID-19. We recommend creating a dedicated unit with dedicated staffing to care only for residents with confirmed COVID-19. So, a resident would move to this unit or area of the building as soon as they are determined to be COVID-positive or have tested positive for SARS-CoV-2.

This might not be the best option for a resident with dementia, especially for a resident who may also have fall risk or who is normally at risk of wandering. So, the main reason we are moving those residents away from others and to the COVID care unit is to prevent additional exposures.

But you really have to weigh that potential benefit of moving a resident to the COVID unit with the potential negative impact that movement of a resident with dementia could have. You may see things like confusion, disorientation, anger, agitation, increased wandering, and risk of falls.

And our experience has shown that once an individual in a memory care unit has been identified with COVID-19, there are likely to be others, especially with challenges implementing those infection prevention precautions. So, transmission may have already happened, and providers may determine that it's safer to maintain care of residents with COVID-19 on that unit and with those dedicated personnel.

Moving on to slide 27. I think some of this was mentioned at the beginning of the call. But, just adding to this, if you do end up needing to move residents with cognitive impairment that have confirmed COVID-19, you really want to make sure that you are communicating and providing information to everyone involved.

And that may mean, in addition to the resident, to family, to staff within the building, both in the area where that resident has been residing as well as where they are moving to. Try to keep routines consistent, ideally, if



possible, moving some familiar objects such as favorite décor or pictures in order to make that person feel as comfortable as possible.

So, in summary – and I am on slide 28 – we definitely do not have all the answers. This is very, very challenging. It's challenging to implement these precautions. It requires patients' reminders, assistance and sometimes that may not be enough. But, trying to keep routines and staff consistent; providing encouragement and support for things like hand hygiene, social distancing, and face mask use; and watching for changes in behavior, as well as signs and symptoms concerning for COVID-19, are some of the strategies that we suggest.

I encourage you to consider the risks and benefits of moving certain residents, especially those with dementia, and to remember that when a resident specifically in a memory care unit – but this may apply to other residents – is suspected or confirmed to have COVID-19, our recommendations are that you consider wearing universal respirator or face mask and eye protection.

And with that, the last slide I have here on 29 are just some resources that may be helpful to you. And I thank you. I appreciate the ability to share with you today.

Michele Laughman: Thank you, Kara. I appreciate your comments and your presentation. Our final speaker is Douglas Pace, Director of Mission Partnerships at the Alzheimer's Association. Additionally, Doug is a licensed nursing home administrator. Doug, I turn it over to you.

Transforming Quality Dementia Care

Douglas Pace: Thank you, Michele. And thank you so much for the opportunity to be with you today. So, I'm moving on to slide 31. I wanted to start today by sharing some information from our 2020 Facts and Figures Report. This report, which is available at [alz.org/facts](https://www.alz.org/facts), provides the latest information, as well as this year including a special report which is focused on primary care physicians and Alzheimer's in the U.S.

So, today, there's currently more than 5 million Americans 65 and older living with Alzheimer's, a number that's expected to triple by 2050. It's currently the sixth leading cause of death in the U.S. and the fifth leading cause of death for both those 65 or older or for women in any age.

And there is also gender and racial differences in Alzheimer's prevalence. Almost two-thirds of Americans with Alzheimer's are women, and older black African Americans and Hispanic Latinos are disproportionately more likely than older whites to have Alzheimer's or other dementias.

And while deaths from other major diseases have remained flat or decreased, from 2000 to 2018, Alzheimer's deaths have increased by an alarming 146%. And as stated in this special report, while 87% of primary care physicians expect to see an increase in the number of people living with dementia during the next 5 years, about 50% say the medical profession is not prepared to meet this demand.

And as shown on slide 32, the cost continues to rise for the cost of care. In 2020, the national cost of providing health care, long-term care, and hospice is projected to reach \$305 billion dollars. Now that's up from \$290



billion in 2019. And that doesn't include the more than 16 million Americans who provided an estimated 18.6 million hours of unpaid care valued at nearly \$244 billion dollars.

And just a moment to think about who those unpaid caregivers are. About two-thirds of the caregivers are women and about one in three are age 65 or older. And over half of primary caregivers take care of their parent and a quarter of dementia caregivers are sandwich-generation caregivers, meaning they are taking care of both an aging parent and a child.

And it's important to note that 41% of caregivers have a household income of \$50,000 or less. So, if you combine the \$305 billion dollars for paid care and the \$244 billion dollars for unpaid care, that means that for 2020, the total cost of both of those cares is over half a trillion dollars.

And then, as you can see on slide 33, about 68% of that \$305 billion in cost in paid care is through the Medicare and the Medicaid programs. And we know as the baby boom generation continues to age that those numbers will continue to increase.

Moving on to the next slide. Since the late '80s, the Alzheimer's Association has established quality care dementia care guidelines for long-term and community-based care providers. In March of 2018, we released through a special supplement of *The Gerontologist* our most current dementia care practice recommendations.


And those recommendations, co-led by myself and my colleague Dr. Sam Fazio in coordination with 27 expert researchers, are for all paid care professionals working across the continuum of long-term and community-based care. So, these recommendations are grounded in person-centered care and that they provide the foundation for how we believe quality dementia care should be delivered in long-term and community-based settings.

So, on slide 35, you will see that the topic areas, in addition to the focus on person-centered care, are detection and diagnosis; assessment and care planning; medical management; information, education, and support; dementia-related behaviors; activities of daily living; workforce; supportive and therapeutic environments; and transitions and coordination of services. And in addition to those, there's two additional things that cut across all of the areas, which are the importance of advanced directives and quality improvement initiatives to evaluate care practices regularly and make appropriate changes.

And while we don't have enough time to go into detail today, I did want to share with you a couple of other initiatives from the association. For the past 2 years, the Alzheimer's Association has conducted several Project Echo series for long-term care. Project Echo utilizes a videoconferencing platform and an all-teach, all-learn model, with a continuous knowledge loop between subject matter experts and providers.

In addition, the association has developed state and federal policy recommendations around testing, reporting, surge activation, and providing support to the long-term care community. And for more information on those areas, you can visit our website.

So, moving on to slide 37. For the rest of my time with you today, I wanted to focus on our emergency preparedness guidelines that we developed and that are supported by 36 national aging organizations and associations.



We know that emergency situations such as COVID-19 presents special circumstances and that a large percentage of all long-term and community-based care settings serve persons living with dementia, including 48% of nursing home residents, 42% of assisted living residents, and 32% of individuals utilizing home health services and 31% using adult day services.

So, during this time, we are seeing staff shortages, and staff that are usually not involved in the day-to-day support of persons with dementia are now being more involved in their care and support. And leadership in these settings are facing many challenges. And, so, we wanted to develop these guidelines to help everyone in residential and community-based settings to be able to provide the best care possible.

As it was stated earlier, we know that persons with dementia thrive best in an atmosphere that minimizes change in routine, and they are often less able to adapt to changes in their environment. So, as such, they may become more confused, frustrated, or have an – display an increase in dementia-related behaviors.

Also, persons living with dementia may have an impaired ability to follow or remember instructions and may need reminders for things like handwashing or staying in a particular area or social distancing or sharing items or really anything that would require memory and judgment.

So, for instance, we have learned through our Project Echo series that while communities seem to have good protocols around handwashing of staff, handwashing of residents is something that's frequently overlooked. And we heard from one community that really decided to tackle this issue by creating a handwashing schedule, making it an activity for the residents. And the residents have loved that, and it also helped with their infection control protocols.

Now on slide 41. As I mentioned earlier, person-centered care is the cornerstone of our dementia care practice recommendations. And they are central to the tips for supporting persons living with dementia in long-term and community-based care.

Of the 56 practice recommendations, the very first one is know the person. It's important to know the unique and complete person – their values, their beliefs, their interests, their abilities, their likes and their dislikes, both past and present. And this information should inform every interaction and experience.

It's also important to see the world from the perspective of the individual with dementia and to identify and support ongoing opportunities for meaningful engagement. Doing so builds and nurtures authentic relationships, and it also creates a community that values and respects not only the residents but the staff as well. And it can – also important to regularly evaluate those practices and models to share the findings and make changes to interactions and programs and practices as needed.

And if there are new staff or staff that are reassigned from different areas, one way that a community can help with providing person-centered care is by developing a personal information form for each resident that's readily accessible to all staff who interact with the resident.

And the form can include information such as their preferred name, the names of family and friends, what their hobbies are, what is their normal structure or routine, what upsets the person or calms them down, or the remaining abilities or motor skills or verbal processing and communication abilities and methods.



Now, on slide 43. One thing that we know that is of vital importance is the need to help residents stay connected with family and friends. And, also, remember that each family is unique and sometimes it's friends that are the most connected to the residents.

Communities must have open lines of communication that allows family and friends to be able to always be up to date on what's going on in the community and that providers may want to hold town hall meetings where they can provide daily or regular updates or use other communication channels to provide updates.

Another useful form is the What You Need To Know Fact Sheet that's shared with staff and family that provides contact information that goes both ways – that provides information to the nursing home from families and friends and provides information from the nursing home on how families can best receive updates. This is also a good place to list all of the adaptive devices such as dentures or glasses or hearing aids so in the event of an emergency or transition those items follow the person.

But this is also a good reminder for the nursing home to make sure that every resident's advance care planning documents are in the resident's records and they are up to date. And this is to – this is so important to ensure that the resident's wishes are honored at all times.

So, there's many great examples of ways that families and friends can stay connected. Here's a few examples from our Project Echo initiative. But, in addition, the CDC has a great flyer on their website with several suggestions on ways to support communications between families and residents including technology.

We know that the use of technology has been one of the few bright spots during this unprecedented crisis and residents sometimes with help from staff are using video chats and iPads and text messages to stay more connected.

And if residents or family members are not always available, recorded phone and video messages from both the residents to family and friends and from family and friends to the residents that can be shared at times that's best for the resident has shown to be a great way to stay connected. Also, care packages that could be mailed or dropped off at the nursing home to include such items as photographs or snacks, letters or books or puzzles can also really brighten a resident's day.

On slide 45, one thing that we have learned so far with the pandemic is that residents with dementia's food intake has been declining, which has resulted in weight loss and dehydration. And it's important to remember that persons with dementia may not be able to recognize hunger or thirst, and they may need to be prompted to eat or drink.

It's important for staff to know the person's eating and drinking patterns and ability. And especially for persons with dementia, the loss of communal dining has been drastic. So, many providers are dedicating staff at mealtime to sit with the resident instead of just delivering a meal. And we've seen that really helps with food intake.

On slide 46, we discuss the importance of mobility and walking and exercise during this time that residents are spending almost all of their day in their rooms. It's important to remember that walking is a purposeful motor activity and builds strength. So, it's important that every resident has an opportunity for some form of exercise



every day, that they have ability to go outdoors when weather permits and that they are provided a safe environment to walk about.

One of the most important aspects of providing quality dementia care is the ability to observe and respond to dementia-related behaviors. As has been discussed earlier, dementia-related behaviors are often a response to convey a feeling or an unmet need or an intention. And they may include striking out, screaming, or becoming very agitated or emotional. And the care provider's role is to observe and to attempt to understand what the person with dementia is trying to communicate.

Now, on slide 48, when there are dementia-related behaviors, it's important to identify the root cause of the behavior. Does the person with dementia have difficulty expressing thoughts or feelings or difficulty in understanding the environment? One thing that's been brought on by COVID-19 is residents' reaction to staff wearing PPE and not being able to see the person's face. But, again, providers have been creative such as pinning pictures of themselves on their gown, which really helps with that recognition.

But, even before the pandemic, we know that nursing homes were trying to solve for loneliness, helplessness, and boredom. And now with the residents mostly confined to their rooms, those issues have really been magnified. And, again, we continue to hear from our Project Echo series how long-term care communities are being innovative.


They are embracing the use of huddles and shift change to share information. They are being creative in activities while still social distancing. And some communities are hiring extra staff that are focused on providing support for their residents' emotional well-being. Not only is that beneficial to the well-being of the resident, but many of these new hires have never worked in this setting before and they are finding that there may be new career opportunities for them with long-term care.

And on slide 50, there's strategies around observing and responding to these behaviors. Of course, the first thing to rule out is pain, thirst, hunger, or the need to use the bathroom. And remember to speak in a calm voice to try to reduce excess stimulation.

But additional strategies include offering the person a favorite food or just listening to music. Many times, the solution is easy if you know the person. And as outlined in our dementia care practice recommendations, we know that there's many now evidence-based therapies such as aromatherapy, bright light therapy, validation, and reminiscence therapy. And, of course, as we have all discussed earlier, connecting families and friends as much as possible can make a tremendous difference in their quality of life.

But, sometimes, it might just be as simple as moving the person to a quiet area or having a staff person that is special to the resident just spend some time with them. And as also was mentioned earlier, we know that non-pharmacological approaches are the best and the first approach to responding to dementia-related behaviors.

But we also recognize that there may be instances where medication may be appropriate. But it's important to remember the need for pharmacological treatment should be reassessed as required by the medication regimen or upon a change in the person's condition.



So, to close with slide 54, it's important to remember to provide a consistent routine, use person-centered care approaches, share information across teams, and to always put the person before the task. So, thank you for the opportunity to be with you today.

My final slide shares our 24/7 hotline number with you. That's 1-800-272-3900. And the help line is open to the public, as well as professionals, and its staffed by master's-level clinicians ready to answer your call anytime. Thank you again. And Michele, I will turn it back over to you.

Michele Laughman: Okay. Leah and Blair, I guess we can go into the question-and-answer session.

Question & Answer Session

Leah Nguyen: Thank you, Michele. We will now take your questions. As a reminder, this event is being recorded and transcribed. In an effort to get to as many questions as possible, each caller is limited to one question. To allow more participants the opportunity to ask questions, please send questions specific to your organization to the resource mailbox on slide 57 so our staff can do more research. Preference will be given to general questions applicable to the larger audience, and we will be mindful of the time spent on each question. All right, Blair, we are ready for our first caller.

Operator: To ask a question, press "star" followed by the number "1" on your touchtone phone. To remove yourself from the queue, press the "pound" key. Remember to pick up your handset before asking your question to ensure clarity. Once your line is open, state your name and organization.


Please note your line will remain open during the time you are asking your question, so anything you say or any background noise will be heard in the conference. If you have more than one question, press "star," "1" to get back into the queue, and we will address additional questions as time permits. Please hold while we compile the Q&A roster. Please hold while we compile the Q&A roster.

Again, to ask a question, press "star" followed by the number "1" on your touchtone phone. To remove yourself from the queue, press the "pound" key. Remember to pick up your handset before asking your question to ensure clarity. Once your line is open, state your name and organization.

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And we do have a question from a participant whose information was not recorded. Please state your name and organization and then pose your question.

Judy: This is Judy from Covenant Health. I am wondering – I am looking at the QSO and there doesn't seem to be a date on there – an effective date of when it is anticipated that all the requirements are met for inside visitation. Can you give me a date that that would be effective?



Leah Nguyen: Michele, do you want to answer that?

Michele Laughman: I don't know if Evan Shulman is still on the line with us. I'm going to ...

Cathleen Lawrence: I could try to answer, Michele.

Michele Laughman: Yes, Cathleen, if you want to.

Cathleen Lawrence: Yes, well, the guidance was effective immediately on the release of the memo, which was September 17.

Judy: But how long do they have to come into compliance with that?

Cathleen Lawrence: I believe that was just the next survey. I don't think we gave a date, as you know, we didn't give a date in the memo. We just said it was effective immediately. So ...

Dara Graham: This is Dara Graham. If you could send that question to our resource mailbox and we can do a little bit more research on that and get back to you ...

Judy: Okay.

Dara Graham: ... that would be great.

Judy: Thank you.


Dara Graham: Thank you.

Operator: Again, to ask a question, press "star" followed by the number "1" on your touchtone phone. To remove yourself from the queue, press the "pound" key. Remember to pick up your handset before asking your question to ensure clarity. Please hold while we compile the Q&A roster. Please hold while we compile the Q&A roster. The next question will come from the line of Kim Warchol.

Kim Warchol: Yes. Hi. I am Kim Warchol with Dementia Care Specialists. Obviously, these are unprecedented, challenging times, and we have so much empathy for everybody involved mostly for the residents and families. We provide training and consultation to the senior living industry, and we've seen our clients really struggle and the need to just really step back and pause a lot of the programming services. I have heard even we've got all our resources put on – allocated to putting out the fire. There is really not a lot of resources available to plant a pretty garden. I kind of get where they are coming from.

So, with all that in mind, I'm wondering right now what do you see ahead in terms of state surveys and that whole process? Because I think we have what we want to occur at the nursing homes during this time and I think this is a great presentation to remind us of all of that.

And then, there are the hard, cold realities of really very low staffing in some of these communities etcetera. We could go on. So, I'm just wondering what is the position the state surveyors will be taking when they go out



and they look for – are the standards of care being delivered? And are the surveys occurring right now? I'm just wondering your thoughts on that.

Dara Graham: Hi. This Dara Graham. That's a great question and thank you for that. And, so, we take the stand in terms of surveying and making sure that there is an effort that's put into – if their staffing that's short to make sure that there is – there is adequate staffing or adequate – rather adequate effort made to obtain more staff. We are making sure there is adequate efforts made towards obtaining, for example, PPE.

But we can bring – we are more than happy to bring that question back to our survey team within our division, and we can get a little bit more information for you if that will be helpful. And, so, just like the other caller, you could send your information into the resource mailbox and we can get you as much information as we can as it relates to that question because it is a good question.

Kim Warchol: Okay. Thank you so much.

Dara Graham: Of course.

Kara Jacobs Slifka: And this is Kara. This is not specifically in response to the last question. But, just because there was mention about some of the resources that have been paused and some of the activities that may normally be happening if we weren't in the middle of this pandemic, I would – I just would like to say that for those of you who have seen some of the creative ways that people are trying to do different types of activities as safely as possible or different ways to keep residents active, we would love for you to continue to share that with us.

We are really interested in hearing, knowing that this is so challenging for everyone but hearing how people are doing their best to make this work. Thank you.

Operator: The next question will come from the line of Jackie Clisso.

Jackie Clisso: Hello. Hi, Ashley Medical Center here. Under additional strategies and interventions, I noticed that you had listed some things like music. But the one I am concerned about now is the bright light. What do you mean by that? What kind of light (Inaudible)?

Douglas Pace: Yes. Sure. And thank you for that question. So, basically, if you refer back to our dementia care practice recommendations, it will give you more information around the evidence around bright light therapy. But I think what we are really speaking to is the ability for persons to have an opportunity to go outside and to get some fresh air and sunshine.

But, also, there is evidence now that – more around therapeutic treatment around bright light therapy can really be helpful around dementia-related behaviors and those recommendations can take you to the source of that evidence-based information.

Leah Nguyen: Thank you.



Operator: And, again, to ask a question, press “star” followed by the number “1” on your touchtone phone. To remove yourself from the queue, press the “pound” key. Remember to pick up your handset before asking your question to ensure clarity. Please hold while we compile the Q&A roster. Please hold while we compile the Q&A roster. Our next question will come from the line of Pam Doyle.

Pam Doyle: Hi. Good afternoon. I am a caretaker and I have a mother that’s home. And my question as far as trying to offer some resource or suggestions would be – and I’m not sure what the finances are like at different organizations.

But, I find – my mom is confined and we have a computer or a laptop or a cell phone and Zoom seems to work very well when family members or different friends can call in and see her and she sees them and have a conversation with them. I think it’s very helpful. So, I don’t know if that’s something that can be implemented in some of the facilities or not. I just wanted to make that recommendation.

Dara Graham: We thank you so much for that recommendation. And, so, that technology-based recommendation has been made and it has been successful within a lot of nursing homes that we’ve heard feedback from. And, so, like the other platforms as well that they use, whether it’d be FaceTime or WebEx. But Zoom is another option as well. So, thank you for that feedback, and we really appreciate that.

Operator: Again, to ask a question, press “star” followed by the number “1” on your touchtone phone. To remove yourself from the queue, press the “pound” key. Remember to pick up your handset before asking your question to ensure clarity. Please hold while we compile the Q&A roster. Please hold while we compile the Q&A roster. We do have a follow-up question from the line of Jackie Clisso. Jackie, your line is open.

Jackie Clisso: Ashely Medical Center calling. Charlie here. During this time of COVID, is it okay – I mean you were talking – they have listed on here pets. Can they – is that allowable in the nursing home?

Michele Laughman: I think – this is Michele Laughman. I didn’t quite hear your question. What is allowable in the nursing home?


Jackie Clisso: Pets. Animals.

Leah Nguyen: Pets, Michele.

Jackie Clisso: It’s listed here. There was a pet therapy you listed as the intervention. Is that allowed in nursing homes during COVID-19 time?

Kara Jacobs Slifka: So, this is – this is Kara. I think from the – from the CDC perspective in terms of just I think infection or just in terms of sharing a little bit of information, not necessarily allowable versus not, which maybe others – feel free to comment or add to this response.

But, I just – I will share that we have – we have seen – there are some early data and data that’s being collected by some of the folks at CDC that specifically work with animals and are following some of the information because there has been – there has been some – it has been noted that there are some animals that may possibly be able to test positive for – with COVID-19 – for SARS-CoV-2, the virus causing COVID.



I think we are still at a point of trying to understand exactly what that means. But, at least with some of our initial recommendations early on in the pandemic, we had – we had kind of considered them – considered animals, considered therapy animals or pets – really try to put them into the category of folks who may – we may not want to be regularly visiting.

But, as things are changing throughout this pandemic, I think that's something that we will probably need to evaluate somewhat individually. I think some places have pets that are residing within their facility. It may be best to continue to promote social distancing, to try to keep – try to restrict movement of pets so they are not just wandering throughout, going in to, for example, a dedicated COVID area and then to another area.

We definitely have said – CDC has come out and said that if you do, for some reason, notice that there is an animal that is acting off or you have any concern they are sick, you definitely want to make sure you seek care for them and let the health department and even the CDC know about that.

I think what I would – what I would say is that in general and thinking about this, if you are in a situation where you are in the middle of an outbreak in a facility, it may not be the best time to be bringing others into the facility. And that could include therapy animals. It could include the individuals who are working with those animals, therapists, etcetera. But that's something that you may need – you may be able to reevaluate or think different about if you are in a different setting and you don't have widespread transmission of COVID in your building.

Operator: And with that, we are showing no further audio questions. I will now hand the conference back to Leah Nguyen.

Additional Information

Leah Nguyen: Thank you. We hope you will take a few moments to evaluate your experience. See slide 57 for more information. An audio recording and transcript will be – will be available in about 2 weeks at go.cms.gov/mln-events.

Again, my name is Leah Nguyen. I would like to thank our presenters and also thank you for participating in today's Medicare Learning Network event on Dementia Care. Have a great day, everyone.

Operator: Thank you for participating in today's conference call. You may now disconnect. Presenters, please hold the line.