The National CONSUMER VOICE for Quality Long-Term Care formerly NCCNHR

Making the Case for Compassionate Care

Compassionate care visits are special visits in which a family member or other visitor provides comfort, support, and/or assistance to a resident whose well-being is suffering or at risk, or who is dying. The Centers for Medicare and Medicaid Services (CMS) has developed **guidance** that provides some examples of situations when compassionate care visits should be permitted. These include:

- A resident who is at the end of life.
- A resident, who was living with their family before recently being admitted to a nursing home, is struggling with the change in environment and lack of physical family support.
- A resident who is grieving after a friend or family member recently passed away.
- A resident who needs cueing and encouragement with eating or drinking, previously provided by family and/or caregiver(s), is experiencing weight loss or dehydration.
- A resident, who used to talk and interact with others, is experiencing emotional distress, seldom speaking, or crying more frequently (when the resident had rarely cried in the past).

However, these are just examples. Compassionate care visits are not limited only to these situations. There are many other circumstances that would also qualify. Facilities are directed to identify the need for such visits using a person-centered approach and by working with residents, families, resident representatives, and the Long-Term Care Ombudsman Program.

What makes a compassionate care visit special and different from other visits?

Compassionate care visits have heightened protections and should occur through a person-centered approach, meaning support is planned and provided based on the resident's individual needs.

The CMS guidance lays out important distinctions between compassionate care and other forms of visitation as shown in the following table:

Differences between Compassionate Care Visits and General Visits

	Compassionate Care Visits	General Visits
	Visits permitted regardless of county positivity rate.	Visits **not** permitted if county positivity rate is greater than 10%.
Resident has confirmed or suspected case of COVID	Visits permitted.	Visits **not** permitted.
Frequency and length of visits	Based on needs of resident (person-centered approach). Ex. If you have a loved one who has lost weight and needs assistance eating, then their needs may dictate that you visit every day to help during mealtimes. If your loved one is experiencing emotional distress because of	Based on facility's schedule and capacity.

	their isolation, then their needs likely dictate frequent visits for companionship.	
Personal contact	Permitted if facilities and visitors find ways to allow for personal contact that follows infection prevention guidelines… "for a limited amount of time." This means that you should be able to touch your loved one and assist with activities like eating and hygiene if necessary.	Not permitted. Social distancing of at least 6 feet between persons must be maintained.

When can a resident receive compassionate care visits?

CMS does not indicate exactly when a compassionate care visit can be conducted. The agency only states that end of life and the four examples listed above meet the intent of "compassionate care situations." This gives you a great deal of flexibility in making the case for why your loved one should receive these visits.

Facilities are required to provide each resident with the care and services he or she needs to reach or maintain his or her highest level of well-being.[1] This is individualized, person-centered care. The resident must not decline unless the decline is unavoidable. A decline is only considered to be unavoidable if it has occurred despite the facility having done all the following: properly assessed the resident, developed a person-centered care plan, carried out the care plan exactly as written, monitored the resident's status, and reviewed and revised the care plan if it is not working.[2]

In advocating for compassionate care visits, you should focus on two major areas: individualized, person-centered care and significant decline.

- **Individualized person-centered care**: Think about your loved one's unique characteristics, who they are as a person, what their needs are and what they are experiencing now. If they are not receiving the care required to meet their specific needs and are experiencing a decline, this is a strong argument for compassionate care visits.
- **Indicators of significant decline**: Below are some points to consider when requesting a compassionate care visit for a loved one.[3] It is important to note that just because the answer to one or more of the points below is yes, does not mean your loved one will automatically be eligible for a compassionate care visit. The reverse is also true – just because they may not have any of the possible indicators below, does not mean they will not be eligible.

PHYSICAL STATUS

Activities of Daily Living

- Has there been a decline in any activity of daily living where the resident now needs a lot of assistance or is totally dependent on staff? [Activities of daily living include eating and drinking, walking, dressing, bathing, moving to/from a bed or chair/wheelchair, using the toilet.]

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[1] 42 CFR §483.24 Quality of Life, https://www.law.cornell.edu/cfr/text/42/483.24

[2] 42 CFR §483.25 Quality of Care, State Operations Manual Appendix PP - Guidance to Surveyors for Long Term Care Facilities, Summary of Investigative Protocol, https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/som107ap_pp_guidelines_ltcf.pdf

[3] These indicators come from the State Operations Manual Appendix PP, Definition of Significant Change, §483.20(b)(2)ii), https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/som107ap_pp_guidelines_ltcf.pdf

Nutrition/Weight/Appetite

- Has the resident lost weight (unplanned weight loss)?

Skin

- Has the resident developed a new pressure ulcer (bed sore)?
- Has an existing pressure ulcer gotten worse?

Incontinence

- Has there been a change in the resident's incontinence pattern (e.g., from continent of bowel and/or bladder to incontinent)?

COGNITIVE/MENTAL/PSYCHOSOCIAL STATUS

Antipsychotic medication

- Has the resident been given an antipsychotic medication as a chemical restraint when no antipsychotics had been administered before?

Cognitive status

- Has the resident's decision-making ability changed?

Emotional status

- Are any of the following symptoms present when they were not present previously and/or has there been an increase in the frequency of the symptoms?
    - Little interest or pleasure in doing things.
    - Feeling depressed, hopeless.
    - Having little energy.
    - Feeling life is not worth living.

Dementia

- Are there signs that the resident's dementia has progressed?

PHYSICAL APPEARANCE

- Have you observed that the resident is not clean and/or well-groomed (face dirty, not bathed, hair not clean/combed, clothing dirty, nails not trimmed)?
- Have the resident's teeth not been brushed? Dentures not cleaned?

What can you do if the facility denies you compassionate care visits?

If the facility tells you that you cannot have compassionate care visits, there are a number of steps you can take.

- Ask for the reason. CMS guidance states that facilities may not restrict visitation without a reasonable clinical or safety cause. Check any visitation guidance/directives about compassionate care visits that your state has issued.
- Request a care planning meeting and emphasize your loved one's need for these visits.
- Involve your long-term care ombudsman. The Ombudsman program advocates for residents and can help resolve concerns. Not only can your ombudsman help you and your loved one advocate for their rights, but they can help you work with your facility to identify the need for compassionate care.

- File a complaint with your state survey agency. This agency is responsible for regulating and overseeing nursing homes in your state. One of its duties is to investigate complaints.

You can find contact information for both the Ombudsman program and the State Survey Agency at https://theconsumervoice.org/get_help.

What are some common issues you may face?

Shutdowns for community spread or new cases in the facility

CMS specifically states in its guidance that compassionate care visits are still allowed even when your COVID-19 county positivity rate is high. This shows how important CMS considers these visits.

Further, CMS does not indicate that compassionate care visitation can be discontinued when there is an outbreak of one or more cases of COVID-19 within the facility. In fact, CMS guidance states that residents who have a confirmed or suspected case of COVID-19 (referred to as "being on transmission-based precautions") should still receive in-person compassionate care.

Limitations on visits

The CMS guidance emphasizes that compassionate care visitation needs to be person-centered. This means that the number and length of the visits should be determined by each unique situation and in a way that meets each resident's needs. Because compassionate care visits occur when someone has experienced a decline or is experiencing distress, limiting the frequency and duration of visits usually will not offer the support the resident needs. As noted in the table above, the restrictions about number/length of visits do not apply to compassionate care visits.

If the facility is attempting to cut your visit short or only offering one or two visits, and it is clear your loved one could benefit from longer or more frequent visits, schedule a meeting or a care plan conference with facility staff. Discuss your loved one's condition, how current visitation is not meeting their needs, and ask how you can all work together to make compassionate care visitation more person-centered.

Once again, involve your ombudsman if you need help and file a complaint with your state survey agency.

Enforcement of social distancing

Compassionate care, unlike general visitation, is not subject to strict social distancing. The guidance states that personal contact is allowed for compassionate care -- if appropriate infection prevention guidelines are followed, and it is for a limited amount of time. Below are examples of situations in which personal contact for the limited amount of time is allowed.

- If you are visiting because your loved one has lost weight and needs encouragement eating, you should be able to assist with eating and drinking.
- If your loved one is experiencing emotional distress, you should be able to give them a hug to comfort them.
- If your loved one needs help with hygiene while you are in the room, you should be able to help wash them.

Refusal of Essential Caregivers

Some states or facilities have designated essential caregivers. The CMS guidance does not distinguish these visitors from others but notes that a person-centered approach should allow for all types of visitors, "including those who

have been categorized as essential caregivers." If your facility has already written your role as an essential caregiver into your loved one's care plan, the CMS guidance permits you to continue.

If you are considered an essential caregiver in your state, and your loved one is experiencing distress or a decline, then you should advocate that your essential caregiver visits fall under compassionate care. This should ensure you have the contact necessary to assist and comfort your loved one even when general visitation is shut down.

Visitation Beyond Compassionate Care

Federal disability rights laws require that persons with disabilities have equal access to care. This means that a person, such as a family member, must be permitted to enter the nursing home to help a resident access care if 1) the resident requires assistance; 2) assistance must be given in-person; and 3) no one in the facility is able to provide that assistance.

For instance, a resident with dementia needs help communicating their needs to staff who do not understand what the resident is trying to convey. However, as a family member, you know what the resident is communicating and can "translate" his or her needs to staff. In this circumstance you should advocate to be allowed into the facility to assist with communication under the federal disability rights laws. Although facilities can still impose legitimate safety measures, such as requiring you to comply with COVID-19 infection prevention measures, like wearing appropriate PPE, you must be permitted access. In addition, CMS guidance states that facilities must continue to comply with federal disability rights law even when general visitation shuts down.

For more information, visit the Center for Public Representation site at: https://www.centerforpublicrep.org/covid-19-medical-rationing/

General Visitation

An important reminder: Facilities may not restrict general visitation without a "reasonable clinical or safety cause," according to CMS guidance. If your county positivity rate is low or medium and your loved one's facility has not had cases of COVID-19 over the past fourteen days, then the facility must allow in-person visitation in addition to compassionate care visitation. If they do not allow visitation and do not have an adequate reason for doing so, they could be subject to citation and enforcement actions.