

LONG TERM CARE in a PANDEMIC: Making Difficult Decisions

September 24, 2020

A Webinar for **ALOA**

Adult **L**utherans **O**rganized for **A**ction

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ALOA <https://aloaserves.org>

In memory of my mom

One of 1.2 million people
in an assisted living
in the
United States



In honor of my aunt. . .

One of 1.4 million people
in a nursing home today in
the United States



In memory of my friend

One of 80,000 people
in nursing homes and
assisted living facilities
who have died from
COVID -19
since March 2020



Background Info

Difference between NHs and ALFs

- NHs have nurses
RNs required 8 hours a day
- NHs are federally regulated with national regulations (rules), inspections (surveys), and sanctions
- NHs are funded in part by Medicare for rehab (short stay) and Medicaid (long stay) once a person has used their personal resources
- Assisted Living Facilities are not all required to have nurses (varies from state to state)
- ALFs are regulated by the states; some states have comprehensive rules; others have few; may vary depending on size of ALF
- ALFs are primarily private pay with some exceptions; fed govt has limited \$\$ for NH residents to return to community; some states have limited funding for people with low incomes

Background Info

- Independent Living Senior housing with limited or no services
- Retirement Community Senior housing with some services
- CCRC **C**ontinuing **C**are **R**etirement **C**ommunity Retirement community with all levels of care on one campus – independent, assisted living and nursing home care. Oftentimes run by non profit faith based organizations.
- HCBS **H**ome and **C**ommunity **B**ased **S**ervices Long term care services are provided in the person's home. Now funded in some states by Medicaid for NH residents who can live in the community.

Background Info. . .

CMS Centers for Medicare and Medicaid

- Very large federal agency overseeing health care
- Responsible for NH regulations, inspection (every 9 to 18 months), enforcement (penalties)
- Responsible for implementing Medicare and Medicaid including for NH residents

Long Term Care Ombudsman

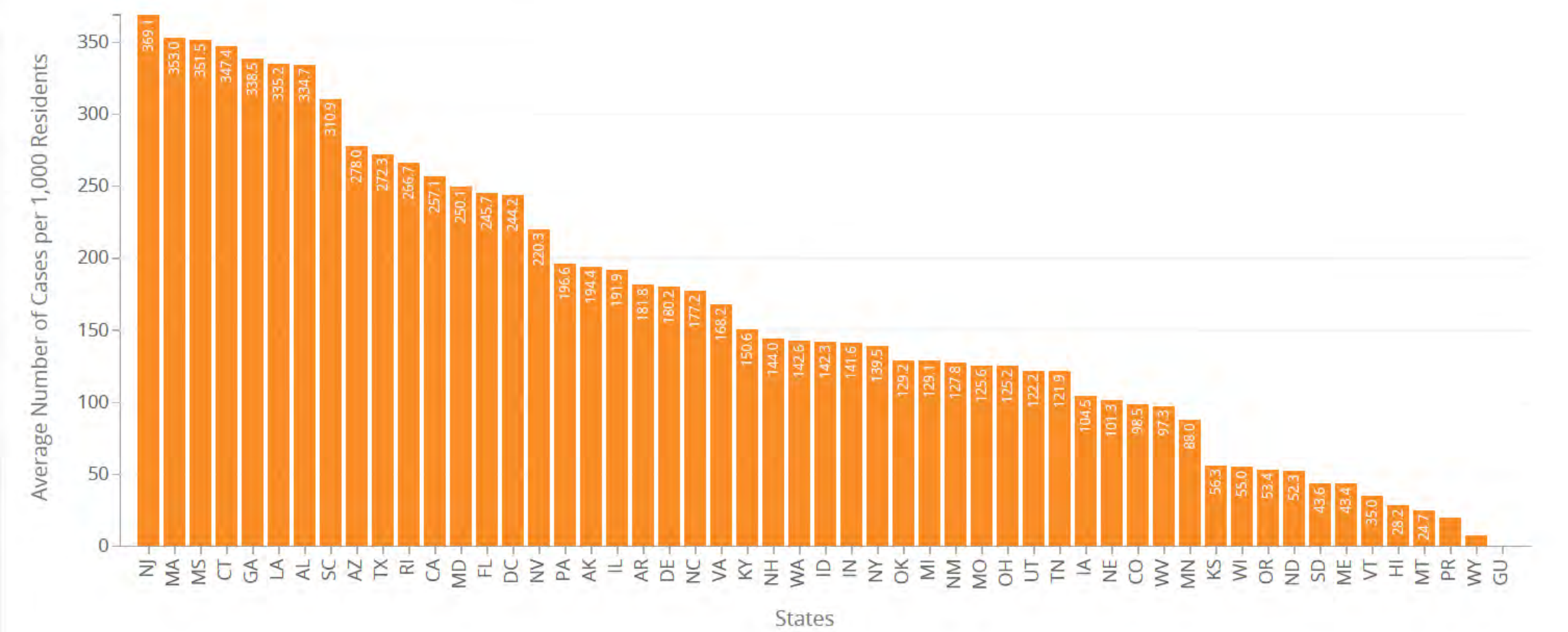
- An advocate for residents of ALFs and NHs
- Federal program gives ombudsman authority to protect rights of residents in each state
- Typically visits residents, helps them to address problems/complaints

COVID and Long Term Care

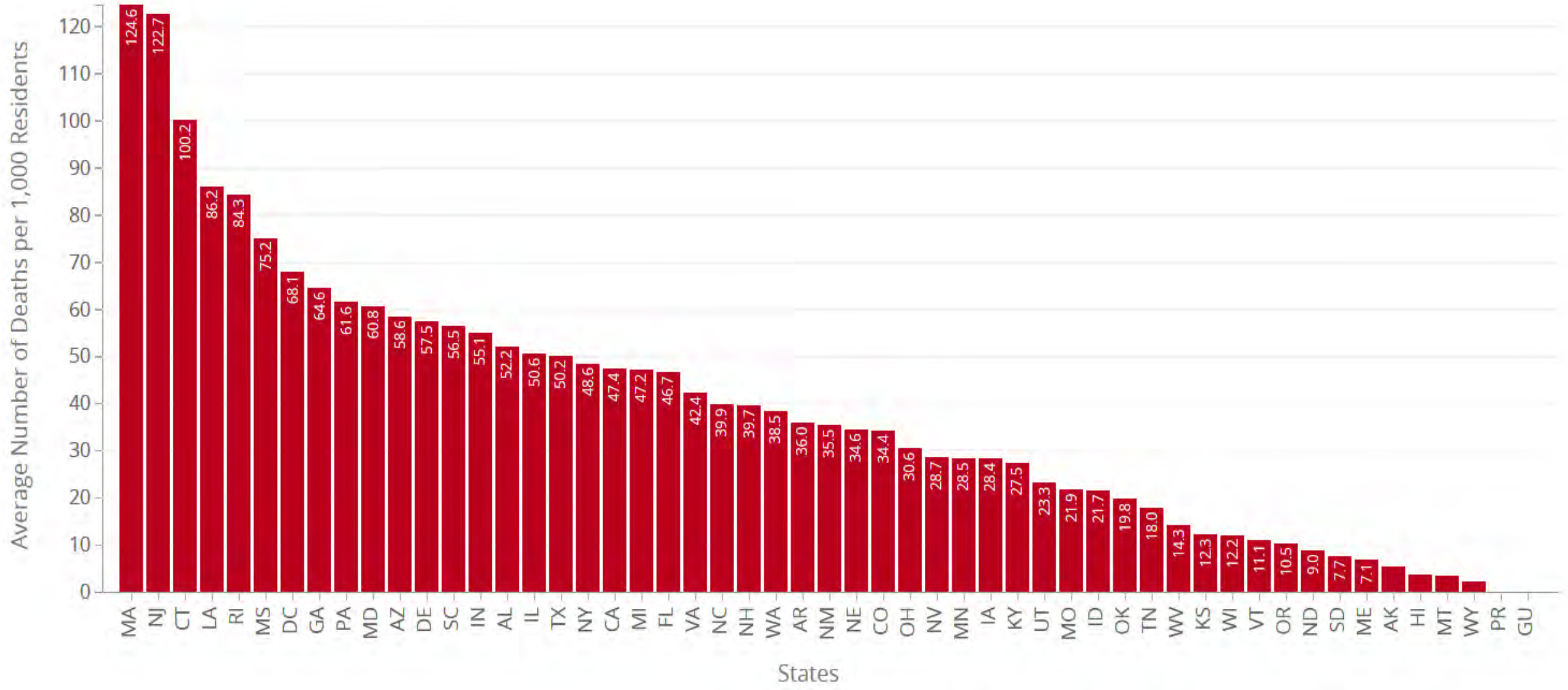
- COVID first occurred in Kirkland, Washington NH Feb 28, 2020
- LTC facilities have ~1% of population and 40+% of deaths
- 1 in 5 cases early May in US, 1 in 10 cases mid August
- Varies greatly between states – Some have “flattened the curve (CT, MA, NY); Others are showing an increase this summer (CA, FL, TX)
- Assisted Living COVID data is not required by CDC, a few states track and report

Resident Cases and Deaths per 1,000 Residents

Resident Average Cases per 1,000 Residents



Resident Average Deaths per 1,000 Residents



Why is this happening?

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WHY is COVID so prevalent in long term care?

- Vulnerable, medically fragile people; many with dementia in close proximity to one another
- PPE, testing, etc. not always available
- Poor infection control (NHs have history of infection control problems that have been identified but not sanctioned)
- Level of community COVID
- Racial disparities with higher rates in Black and Latinix Communities
- Staff provide personal care and assistance to multiple residents, going from one person to another in a short period of time
- Staff may not have sick leave, hazard pay, benefits
- Not enough staff to meet resident needs; no minimum staffing standard
- NHs with less RN coverage have more COVID
- Some staff work in multiple facilities so transmission is increased
- Initially people admitted to NHs without being tested
- NHs may not have been high on the emergency preparedness radar screen
- NHs faced staff shortages as staff got sick or did not return to work due to fear of virus, lack of PPE, etc.
- Other:

Wide disparity between facilities....

- Some have had no COVID cases in staff or residents
- Some have had a few cases and have been able to address
- Some have had lots of cases initially, and then flattened their curve
- Some have had on-going sporadic cases
- Some have had horrific numbers of cases and deaths in staff and residents (Some states make “strike teams” available to turn around care)

Personal Opinion: Don't judge a facility until you know specific details. There are factors within and beyond each facility's control. But we should expect that facilities, regulators, public health, and government at every level will implement concrete policies and strategies to stop the spread of the virus in facilities. Residents in long term care should be a local, state and national priority. If we don't stop the spread in LTC, the pandemic will continue.

Scenario: What are we going to do???

Mr. Hanson provided care to his wife in their home for 4 years. Her dementia has increased and she no longer always knows who he is. She needs to be fed and he can no longer assist her to the bathroom. Both are over 80; their children live in other states. One child wants mom to be in a nursing home, two want home care. Mr. H would like her to stay at home. The family is worried about exposure to COVID.

Family goal: Mom is in a safe place where care is lovingly provided

? Are there services available for Mrs. H to stay at home? Action Steps

- Contact Elder Care Locator, the local Area Agency on Aging, Alzheimer's Assoc.

- Identify financial resources – long term care insurance, savings, etc.

- Develop a plan utilizing neighbors, friends and family sharing responsibilities

- Identify changes needed to the house to accommodate care

- Consider Mrs. H's preferences for quality of life (enjoys being outside, active in church for many years, likes birds)

Resolution

Mrs. Hanson was able to stay at home with the following support:

- She had a long term care policy for home care which helped fund a Lutheran Social Service agency to provide home care 6 hours a day
- The family, in home workers, and all visitors practice social distancing, wear masks and wash hands frequently
- Her church's senior support team put in a ramp, improved access to the bathroom and built two bird feeders that Mrs. H could easily see
- Mr. H was able and enjoyed being with Mrs. H from 2 to 6 pm heating up dinner that the aide had prepared
- A neighbor is paid to come over after dinner helping Mrs. H get ready for bed
- The church's support team does "porch visits" weekly and calls daily singing her favorite hymns and providing Mr. H with support
- The children alternate long weekends with mom and dad, coming in Friday eve and returning home late Sunday
- A local hospital has a physician visiting program so Mr. and Mrs.H no longer have to go to the doctors office

Scenario: Mrs. H has fallen and is hospitalized

- Doctor explains that she has broken her hip
- Communication and decisions are made over the phone due to COVID
- It is recommended that Mrs. H go into a rehabilitation center so that she can regain ability to walk if possible
- Mr. H is tired and his health is declining

Family Goal: Find a nursing home with rehabilitation that has controlled COVID, has adequate staff to provide needed care, and has a plan for communicating with the family. Bring Mrs. H home if possible.

ACTION STEPS:

- 1- Talk with hospital social worker ASAP about how to find placement
- 2 – Identify nursing homes for rehab by calling ombudsman, talking to friends/pastor etc., looking at inspection report and COVID data
- 3 – Communicate with Mrs. H by as much as possible by face time
- 4 – Identify staff in hospital and rehab who will report on Mrs. H regularly; tell them about Mrs. H's preferences, habits, likes and dislikes
- 5 - Use the time in rehab to make future plans considering Mrs. H's preferences

“New Regulations on NHs”: Temporary, put in place by CMS in response to COVID (Updates on The Consumer Voice website)

- No visitors allowed including family and ombudsmen; repealed Sept 17th IF facility has 14 day period without COVID and in the community the positivity rate is less than 10%
 - Can limit number of visitors to a resident
 - Must establish a process for visitation; outdoors if possible
- Compassionate care visits – initially one per resident at end of life; effective Sept 17th – end of life or resident decline; clergy or lay person
- Facilities must inform family members of cases and deaths, of residents and staff; facilities must report cases and deaths to CDC
- Initially inspections halted, later health inspections by video

Impact on residents

- Loneliness
- Depression
- Social isolation
- Loss of will to live
- Difficulty understanding why family has forgotten them
- Increased confusion – masks, schedule changes, different staff
- Health decline (Not enough staff to meet needs)
- Fear of death

Sometimes there are no good solutions

Decisions need to be made with the best information available and with consideration of quality of care **and** quality of life. Sadly, with COVID-19, families need to now deal with the social isolation of no or limited visitation. Activities, dining and schedules will be different as facilities deal with coronavirus.







Finding a facility:

- Get recommendations from people you trust and call the ombudsman
- Even with COVID, consider location for when visitation is possible
- Look at the data to see the facility's history on infection control, RN coverage, rankings (1 to 5), and the extent of COVID in the facility

(Look at the # of COVID cases and deaths of staff and residents; AND at how the facility responded. i.e., Was there one or two outbreaks that were addressed or is there a pattern of cases each month.)

- Talk directly to the facility if possible and **be forthright:**

? How are you addressing COVID – separate wing? private rooms? Infection control? How much RN coverage? How many CNAs for each resident? Do CNAs have medical leave? Do they work other jobs? How much backup supply does the facility have of PPE, cleaning supplies, etc. How is testing conducted?

? How can I communicate with my loved on? Who will be my link to the facility? How do you notify family members about new COVID cases in staff and residents? What activities are available for my loved one?

If possible, take a video tour of the facility.

Getting info on COVID in long term care

- CDC has a list of all facilities in US – it is detailed, very difficult to use
- Each state reports differently. Be sure to figure out if the data is over the period of the pandemic (i.e., March to present) or for the last few weeks (i.e., Maryland reports for a multiple week period; CT reports over the entire pandemic)
- Look at the many resources at the National Consumer Voice for Long-term Care. They have a whole section of fact sheets and videos to support the residents and family members during COVID, as well as detailed info on nursing homes and assisted living.
- Look at “Find an Ombudsman” to discuss facilities in your area
- Look at AARP Resources with concrete tips and policy recommendations.

COVID-related deaths are defined as persons with suspected or laboratory positive COVID-19 who died.

Table 1: COVID-19 Resident Impact in CT Nursing Homes

Town	Nursing Home	Current Census	Cumulative Data reported to CT DPH through July 21, 2020		Cumulative NHSN Data from July 22, 2020-September 15, 2020		NHSN Data for September 9, 2020-September 15, 2020	
			Cumulative # residents with confirmed COVID-19 ¹	Cumulative # COVID-related deaths among residents ²	# residents with confirmed COVID-19	# COVID-related deaths among residents	# residents with confirmed COVID-19	# COVID-related deaths among residents
Avon	Apple Rehab Avon	33	34	15	0	0	0	0
Avon	Avon Health Center	97	51	10	0	0	0	0
Berlin	Ledgecrest Health Care Center	39	32	6	0	0	0	0
Bethel	Bethel Health Care Center	113	60	17	0	0	0	0
Bloomfield	Bloomfield Health Care Center	101	47	23	1	0	0	0
Bloomfield	Caleb Hitchcock Health Center	49	4	2	0	0	0	0
Bloomfield	Seabury Health Center	48	34	12	1	0	1	0
Bloomfield	Touchpoints at Bloomfield	119	71	22	0	0	0	0
Branford	Branford Hills Health Care Center	126	103	25	0	1	0	0
Bridgeport	Jewish Senior Services	257	88	26	1	0	0	0
Bridgeport	Northbridge Health Care	69	36	16	1	0	0	0
Bridgeport	The Springs at Watermark 3030 Park	11	11	3	0	0	0	0

Maryland COVID-19 in Congregate Facility Settings: Week of September 16, 2020

Confirmed Staff Cases

2,824

Confirmed Staff Deaths

12

Confirmed Resident Cases

4,126

Confirmed Resident Deaths

860

Affected Facilities

Week of September 16, 2020

Carroll Lutheran Village

Staff Cases: 18
 Staff Deaths: 0
 Resident Cases: 44
 Resident Deaths: 12

Charlestown Senior Living Community

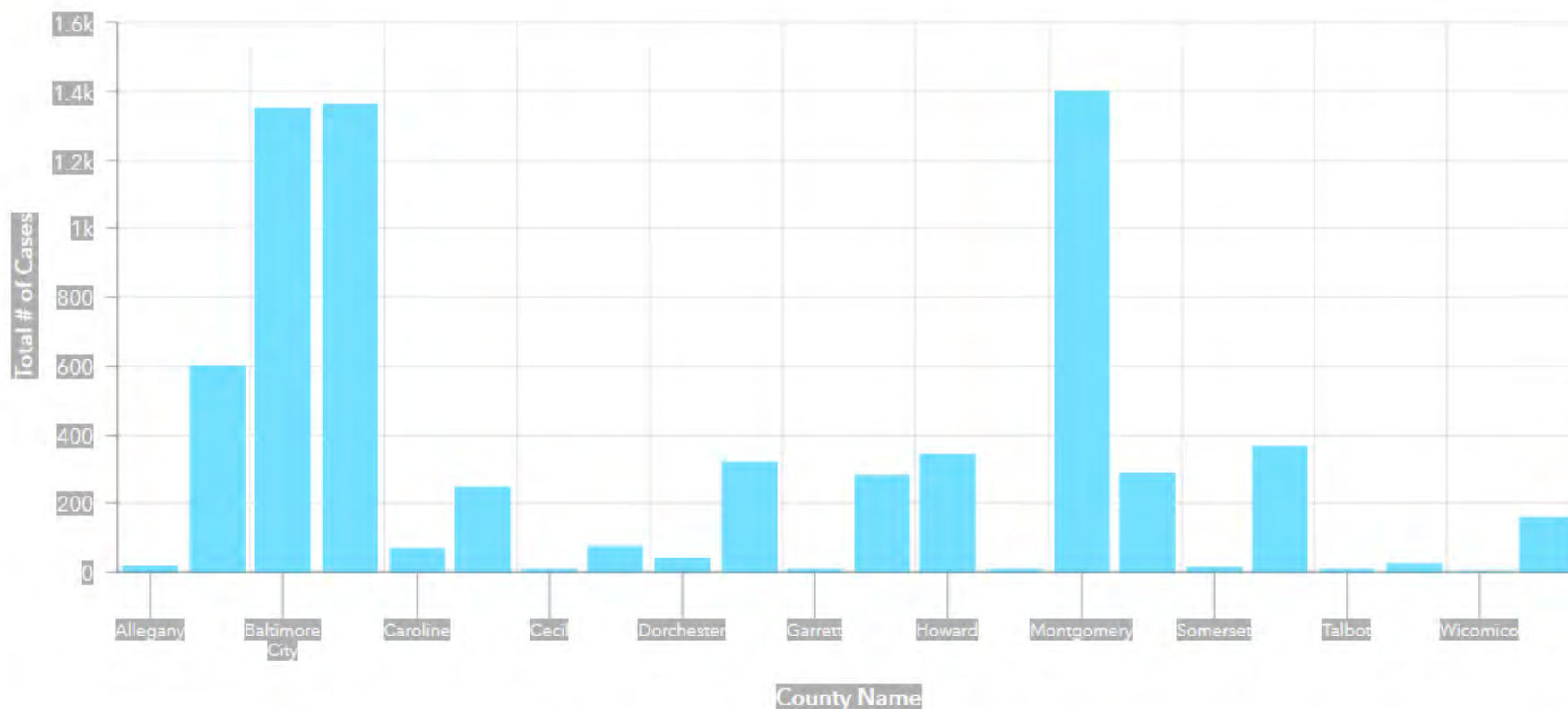
Staff Cases: 51
 Staff Deaths: 0
 Resident Cases: 37
 Resident Deaths: 11

Charlotte Hall Veterans Home

Staff Cases: 97
 Staff Deaths: 1
 Resident Cases: 212
 Resident Deaths: 61

Chesapeake Shores

Staff Cases: 7



Select a bar in the graph to filter the list of facilities and the number totals by county
 Click in empty space in the graph to reset to the statewide totals



























Facilities: Nursing, Assisted Living, Group Homes

Facilities: State and Local

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H

C
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P
A
R
E

Viewing 1 - 20 of 21 results

Nursing home information	Overall Rating	Health inspections	Staffing	Quality measures	Distance
  	  	  	  	  	  
SIGNATURE HEALTHCARE OF CHAPEL HILL 1602 E FRANKLIN STREET CHAPEL HILL, NC 27514 (919) 967-1418 <input type="button" value="Add to compare"/> Add to My Favorites	 Much Below Average	 Much Below Average	 Much Below Average	 Average	4.1 Miles
PARKVIEW HEALTH & REHAB CENTER 1716 LEGION ROAD CHAPEL HILL, NC 27517 (984) 234-3600 <input type="button" value="Add to compare"/>	 Much Above Average	 Above Average	 Below Average	 Much Above Average	5.2 Miles

27514

Within 5 Miles

State

Select a State

County (Optional)

Select a County

Nursing home name

Full or partial name

Filter by:

[Clear all filters](#)

Overall rating

[Learn more about these ratings](#)

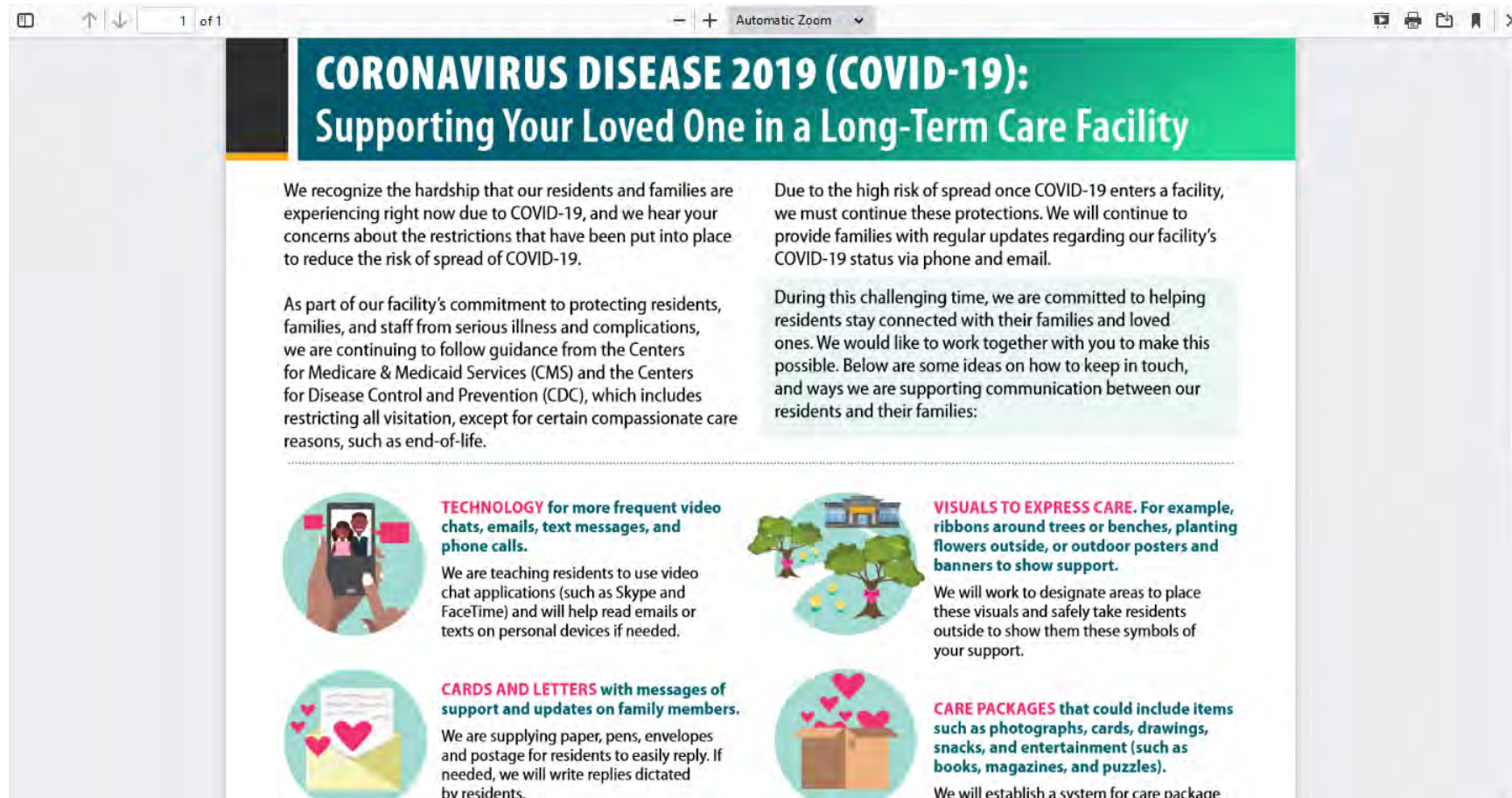
 (6)
Much above average

 (4)
Above average

Scenario Outcomes:

- Mr. H and his children were very upset at not being able to see their loved one in the hospital and with the doctors' failure to keep them informed. Eventually, a nurse was identified that briefed them daily and made sure each day they could video chat with Mrs. H.
- Mr. H made a cassette of Mrs. H's favorite music including hymns and the social worker makes sure the staff turned it on. Mr. H watches church services on line and appreciates the congregation praying for him and his wife. The "porch visits" continue for Mr. H.
- Mrs. H's children divided the responsibilities. One found the facility and handled the admissions process. One focused on talking with the hospital and doctors. One focuses on Mr. H, helping him with finances, household issues, and providing encouragement.
- Once in rehab, the son brought Mrs. H's favorite clothes, pictures, blanket, and her Bible to the rehab center.
- One daughter was the family liaison for Mrs. H and she shared with staff key information about mom – when she liked to get up, what she likes to eat, etc.
- The family looks forward to visitation deciding Mr. H will be the first person to visit. They participate in care planning by phone, support each other as much as possible, and enjoy car parades and other facility activities.

Connect with resident, advocate, and care for yourself.....



**CORONAVIRUS DISEASE 2019 (COVID-19):
Supporting Your Loved One in a Long-Term Care Facility**

We recognize the hardship that our residents and families are experiencing right now due to COVID-19, and we hear your concerns about the restrictions that have been put into place to reduce the risk of spread of COVID-19.

As part of our facility's commitment to protecting residents, families, and staff from serious illness and complications, we are continuing to follow guidance from the Centers for Medicare & Medicaid Services (CMS) and the Centers for Disease Control and Prevention (CDC), which includes restricting all visitation, except for certain compassionate care reasons, such as end-of-life.

Due to the high risk of spread once COVID-19 enters a facility, we must continue these protections. We will continue to provide families with regular updates regarding our facility's COVID-19 status via phone and email.

During this challenging time, we are committed to helping residents stay connected with their families and loved ones. We would like to work together with you to make this possible. Below are some ideas on how to keep in touch, and ways we are supporting communication between our residents and their families:

TECHNOLOGY for more frequent video chats, emails, text messages, and phone calls.
We are teaching residents to use video chat applications (such as Skype and FaceTime) and will help read emails or texts on personal devices if needed.

CARDS AND LETTERS with messages of support and updates on family members.
We are supplying paper, pens, envelopes and postage for residents to easily reply. If needed, we will write replies dictated by residents.

VISUALS TO EXPRESS CARE. For example, ribbons around trees or benches, planting flowers outside, or outdoor posters and banners to show support.
We will work to designate areas to place these visuals and safely take residents outside to show them these symbols of your support.

CARE PACKAGES that could include items such as photographs, cards, drawings, snacks, and entertainment (such as books, magazines, and puzzles).
We will establish a system for care package

RESOURCES: ALOA Website and National Consumer Voice Website

Should I Take My Loved One Home

COVID-19 What Families Need to Know

Summary of CMS Waivers for Nursing Homes

Creative Ideas to Stay Connected

Supporting Your Loved Ones in an Assisted Living or Nursing Home During COVID (CMS)

COVID-19 and Nursing Homes: What Consumers Need to Know

Six Questions You Need to Ask if Your Loved One is in a NH (AARP)

Taking Care of You: Tips for Residents

Taking Care of You: Tips for Families



[Understanding Trauma and Ensuring Person-Centered Care During the Pandemic: Training for family members, facility administrators and direct care staff. Free videos, released Sept 22nd, addresses compassion fatigue, anxiety and grief.](#)

End of Life. . . .

Compassion Visits

Hospice

Other

A faith filled response to COVID:

- Provide support to elders in their homes and facilities **and** their families
- Provide appreciation and support to those who work in facilities
- Identify ways to provide spiritual support including devotions, phone calls, prayer partners, and music, music, music.
- Identify a nearby facility and discuss with administrator and/or social worker how congregation can provide support.
- Offer conference call worship opportunities as well as on-line
- Develop relationships with residents. Remember, before COVID 40% of all residents had no regular visits from family and friends.

Long term care is a public policy issue.

Politicians in both parties, at every level – local, state and national – need to hear that long term care residents and their care givers need to be a priority.

A Pandemic Prayer.....

God who is always present, we pray for the 3 million people living in nursing homes and assisted living facilities, that they may feel Your presence in the absence of visits from family and friends.

We pray for our country and state decision makers, that they may be moved to ensure that each center serving older and disabled adults receives the masks, protective gear, tests and adequate staffing needed for the well being and survival of the residents.

We pray for those direct care workers who compassionately provide daily care to the residents of care facilities and to those living in their homes, that the workers may be kept safe from illness and harm.

We pray for the families separated by distance and too often not knowing the status of their loved ones, that fear is lessened and that communication with loved ones is facilitated.

We pray for ourselves, that we remain faithful in remembering and supporting older and disabled persons as unique children of God with our phone calls, cards, advocacy and prayers.

Lord in your mercy. Hear our prayer.

Amen

Resources

National Consumer Voice for Quality Long Term Care Fact Sheets for residents and families on all aspects of care including how to promote quality of care and address problems, links to regulations, documents related to quality care and life, opportunities for national advocacy on long term care. 202-332-2275

<https://theconsumervoice.org/issues/recipients/nursing-home-residents/fact-sheets>

Find Your Ombudsman, Regulatory Agency, etc. National Ombudsman Resource Center lists all Long Term Care Ombudsman Programs in the United States. Contact local ombudsman for information about facilities, information about long term care and assistance with problems in a facility. Also lists each state's licensing (regulatory) agency, Medicaid agency, etc.

https://theconsumervoice.org/get_help 202-332-2275

Nursing Home Compare Detailed information on all nursing homes, location, 5 star ranking system, inspection reports, sanctions, quality measures, etc.

<https://www.medicare.gov/nursinghomecompare/search.html>

Pioneer Network National organization promoting aging that is life-affirming, satisfying, humane and meaningful. <https://www.pionernetwork.net/>

Eldercare Locator A national program identifying resources for older adults throughout the United States. <https://eldercare.acl.gov/Public/Index.aspx> 1-800-677-1116