COVID Challenges in Special Populations of LTC

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DEFINING SPECIAL POPULATIONS
OBJECTIVES

• Understand the medical, emotional/behavioral, and activity challenges of special populations, including those with dementia, intellectual and developmental disabilities (IDD), and mental illness,

• Learn how to recognize possible COVID infection and how it may manifest differently in someone with dementia or Down’s syndrome,

• Learn coping strategies for these residents and ways to “touch without touching,”

• Get the newest updates from CMS and DHSS.
## Case Fatality Trends of COVID-19 in Adults with IDD

<table>
<thead>
<tr>
<th>Age Group</th>
<th>IDD Fatality (%)</th>
<th>Without IDD Fatality (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall case-fatality</td>
<td>reopening</td>
<td>5.1%</td>
</tr>
<tr>
<td>Patients aged &gt;75 y/o</td>
<td>reopening</td>
<td>21.2%</td>
</tr>
<tr>
<td>Patients aged 18-74 y/o</td>
<td>reopening</td>
<td>4.5%</td>
</tr>
<tr>
<td>Patients aged 0-17 y/o</td>
<td>reopening</td>
<td>1.6%</td>
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Among the patients with a diagnosis of developmental disability, 33% had an intellectual disability, 56% had a pervasive and specific developmental disorder, 18% had cerebral palsy, and 21% had a chromosomal abnormality, including 5% with Down syndrome.

• People with an intellectual disability have premature mortality in comparison to the general population. They also have high rates of emergency room visits and hospitalizations.

• In the years 2018-2019, 41% of those who died, died due to a respiratory cause. CIPOLD (Confidential Inquiry into Premature Deaths of People with Learning Disabilities) found that for every one person in the general population who dies from an avoidable cause, 3 people with learning disability die from a condition amenable to good quality care.


(Source: https://www.cfp.ca/news/2020/04/09/04-09-02)
• 48% of nursing home residents are living with dementia.
• 42% of residents in residential care facilities, including assisted living communities, have Alzheimer’s or another dementia.
• Residents with dementia are particularly susceptible to COVID-19 due to their age, their significantly increased likelihood of coexisting chronic conditions, and the community nature of these settings.

(Source: https://www.alz.org/get-involved-now/advocate/coronavirus-(covid-19)-recommendations-policy)
Dementia and COVID Prevalence in the UK

There were 33,841 Covid-19 deaths in March and April in England and Wales. The most common main pre-existing condition for people dying of Covid-19 in England and Wales was dementia and Alzheimer’s disease, with 6,887 deaths (20.4% of total). Taking into account all pre-existing conditions, dementia and Alzheimer’s accounted for 8,577 deaths (25.3%).


A second UK study showed that patients with dementia genotype (APOE e4e4) were at double the risk of developing severe COVID-19. By identifying this, scientists are able to see if there are specific causes in those proteins that preempt someone with dementia to be more susceptible to COVID and why.

Medical Challenges/increased risk for Special Populations—IDD

- Decreased mobility
- Diabetes
- Increased risk of stroke
- Loss of ADLs, flexibility
- Poor hearing and/or vision
- Respiratory complications
- Bowel and bladder dysfunction
Medical Challenges/increased risk for Special Populations—IDD

- Congenital Cardiac Abnormalities (50% of cases)
- Sleep Apnea (30-50%)
- Decreased Hearing (25-70%)
- Sinusitis
- Cerumen impaction
- Diabetes
- Hypo- and hyperthyroidism
- Celiac (6%)
- Difficulty swallowing (30-50%)
- Reflux
Medical Challenges/increased risk for Those with Dementia

• Decreased mobility, OR
• Very ambulatory
• Increased risk of stroke
• Poor vision/hearing
• Bowel/bladder dysfunction
Commonalities—IDD, dementia, mental illness

- Impairments in understanding and decision-making making them unable to follow infection control guidelines.
- Substance abuse, smoking*, poor lifestyle
- Clinical comorbidities—cardiovascular disease, diabetes, COPD, kidney disease
- Many of these residents come from/currently live in group homes, Memory Care Units, etc. where social distancing is difficult.
- Antipsychotic medications can cause impaired swallowing, sedation, and hypersalivations.

(Source: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7197583/)
Special Issues Related to Mental Illness

Concerns:
1. Closing of clinics for routine case manager visits.
2. Decrease in medication adherence and follow-up.
3. Relapse due to staff changes (different staff than usual, staff being unaware of the “tricks of the trade” of an individual, staff unconsciously overlooking medication hoarding, etc).
4. Difficulty in setting up telehealth and inability of normal therapists to enter the buildings.
5. Decrease in personal hygiene standards and compliance.
6. Anger, anxiety, fear, frustration.

Treatment:
Allowing therapists back in the homes or treating via telehealth.
Assessing and monitoring medication regimen.
Focusing on good sleep hygiene and relaxation.
Spending one-on-one time with resident as much as possible.
“People with ID living in the community have an extensive range of physical health vulnerabilities and premature mortality. This vulnerability becomes more pronounced in the wake of the COVID-19 pandemic. The risk to this group can be conceptualized as a.) Physical health: Increased risk of mortality and morbidity due to COVID-19 b.) Mental health: Increased risk of worsening mental health symptoms and behavior that challenges or increased risk of mental illness relapses and behavior that challenges.

Emotional & Behavioral Challenges

1. Change in routine—increased agitation, anxiety, acting out.
2. Change in usual staff members.
3. Inability to recognize usual staff members due to PPE.
4. Inability to move about freely.
5. Being constantly told “You can’t do this, you can’t go there.”
6. Inability to touch others or objects freely.

These changes in a normal day cause increased anxiety, acting out, and agitation. Add to that defined boundaries via COVID units, no or limited dining room, activity, and day room access, and negative tension and exhaustion of worried staff, it’s a recipe for a mess.
“Touch without Touching”

1. Introduce yourself each time you see the person, ideally with your mask on. However, if they are still scared, stand a minimum of 6-feet back and remove your mask momentarily so they can see your face.
2. Talk slowly, clearly, and slightly louder than usual.
3. Meet their eyes as you are speaking so they understand that you are talking to them.
4. Give them time to process.
5. Use a communication board to assist you.
6. Most of all, be caring and compassionate—and let it show in your eyes, your slow, gentle movements, and in the tone of your voice. Try it! It’s easier than you think to show you care—be the smile behind the mask.
EMOTIONAL & BEHAVIORAL CHALLENGES—PPE

• Face masks can also impact communication and emotions at minimum 3 ways.
  1. The face mask will hide important facial expressions which assists in the ability to understand what someone is saying.
  2. Face masks can make it hard to understand or even hear what someone is saying making it difficult to follow instructions or follow what someone is saying.
  3. Face masks can be scary, yielding to a fight or flight response, or at the least shutting down and responding with a flat affect.
GETTING THEM to wear a mask

1. Put masks on favorite stuffed animals. Let the patient put the mask on their toy and leave it for awhile. Let them see they aren’t bothered by the mask. Assist in putting it on if need be but let the patient do as much as possible by themselves. By touching the mask it will become less scary to them.

2. Before you try to get your patient to wear one, let them have a mask to carry around and feel. Try different fabric swatches if that helps. BE PATIENT—while it’s old news to us, it’s going to take time for them to be okay with it.

3. Remind them when they wear their mask, they’re just like everybody else and that they’re helping keep people safe—make it a positive thing. Tell them they’re superheroes.
“My brother was supposed to move into his first “independent” home in mid-March. In his late 20s, and a person with an intellectual disability, he had finally gathered up the courage and the will to move out of our family home and live in a group home. Because of the coronavirus pandemic, my brother’s move is now delayed indefinitely, and his world remains mostly his bedroom. He can’t go to his part-time job, the library, or to church.”

**Key Emotional Challenges**

- **Loneliness**
- **Boredom**
- **Fear**
- **Confusion**

(Source: https://www.weforum.org/agenda/2020/04/covid19-coronavirus-intellectual-disabilities-loneliness/)
From the CDC regarding COVID and dementia:

• Routines are very important for residents with dementia. Try to keep their environment and routines as consistent as possible while still reminding and assisting with frequent hand hygiene, social distancing, and use of cloth face coverings (if tolerated). Cloth face coverings should not be used for anyone who has trouble breathing, or is unconscious, incapacitated, or otherwise unable to remove the mask without assistance.

• Dedicate personnel to work only on memory care units when possible and try to keep staffing consistent. Limit personnel on the unit to only those essential for care.

• Continue to provide structured activities, which may need to occur in the resident’s room or be scheduled at staggered times throughout the day to maintain social distancing.

How do I know if they’re coming down with COVID?

- Fever or chills
- Cough
- Shortness of breath or difficulty breathing
- Fatigue
- Muscle or body aches
- Headache
- New loss of taste or smell
- Sore throat
- Congestion or runny nose
- Nausea or vomiting
- Diarrhea
- Foot lesions* noted in several cases, not on official CDC list
- Rash* noted in younger adults and children, not on official CDC list
Behaviors as a sign of illness

- GI distress*--aggression around meal times, hand-mouthing, pica
- Headache/earache*--head banging or head butting, putting objects into the ears or nose, putting hand over mouth or ears, sitting with head down in the lap
- Dental issues—hands in or over mouth, refusing to eat
- Changes in bowels (diarrhea/constipation)*--guarding abdomen, rocking, lying in fetal position
- Seizures
- Pneumonia
- Chest pain*--scratching, hitting, or rubbing chest, yelling out, increased anxiety, shortness of breath

*These are also s/s of COVID.

(Source: Craig Escude, MD, FAAFP, craig@hrstonline.com)
Behaviors as a Sign of Illness

- Do not assume that distress and acting out behaviors are necessarily a relapse of mental illness.
- Review the medications and follow your normal protocols for root cause analysis.
- Work in conjunction with family members and caregivers to allay patient anxieties. Encourage alternatives to face to face visits—e.g.: telephone calls, use of Skype, etc. so as to maintain contact.
- Take TIME. Simply listening, observing, and being with that person may give you more information than a laboratory panel.
When residents on a memory care unit are suspected or confirmed to have COVID-19

- As it may be challenging to restrict residents to their rooms, implement universal use of eye protection and N95 or other respirators (or facemasks if respirators are not available) for all personnel when on the unit to address potential for encountering a wandering resident who might have COVID-19.

- Consider potential risks and benefits of moving residents out of the memory care unit to a designated COVID-19 care unit.
  - Moving residents with confirmed COVID-19 to a designated COVID-19 care unit can help to decrease the exposure risk of residents and HCP; however,
  - Moving residents with cognitive impairment to new locations within the facility may cause disorientation, anger, and agitation as well as increase risks for other safety concerns such as falls or wandering.
  - Additionally, at the time a resident with COVID-19 or asymptomatic SARS-CoV-2 infection has been identified, other residents and personnel on the unit may have already been exposed or infected, and additional testing may be needed.
Moving residents with dementia due to COVID

If residents with COVID-19 will be moved from the memory care unit, provide information about the move to residents and be prepared to repeat that information as appropriate.

• Prepare personnel on the receiving unit about the habits and schedule of the person with dementia and try to duplicate it as much as possible.

• Move familiar objects into the space before introducing the new space to the resident. Familiar objects such as favorite decorations or pictures can help make the person feel more comfortable; this applies to their new surroundings as well if residents are moved to new spaces.
**What if they have to go to the hospital?**

- If your loved one has **advanced dementia** and needs to be hospitalized for COVID-19, make sure hospital staff know that your in-person assistance might be required to communicate important health information and emergency support. Here are several important issues to consider:
  - Be prepared to be in a healthcare setting with your loved one.
  - Be prepared to use personal protective measures as recommended by the hospital staff if you are in the room with your loved one.
  - Be aware that you and healthcare providers may face difficulties caring for your loved one because he or she:
    - May not cooperate with care and may not follow personal protective measures such as wearing a cloth face covering or practicing social distancing
    - May refuse diagnostic procedures


The reality is, most likely your resident will be at the hospital alone. So give your fellow nurses all the help you can—what is their routine? Their fears and habits? How do you calm them down at the home? Or who calms them down? Would talking to them via Skype help?
WHAT IS COVID-19?
A Resource for People with Aphasia

What’s happening?
A virus is spreading around the world. It is called COVID-19, or coronavirus.

Who is affected?
- Anyone can get and pass on the virus.
- Most people will have a mild case (80%).
- People who are already sick, have chronic conditions (heart disease, breathing problems, or diabetes), or elderly are most likely to get very sick.
- It is killing around 2% of people who catch it.

What are the symptoms?
COVID-19 affects the lungs. Symptoms include:
- Fever
- Cough
- Difficulty Breathing
Severe cases may turn into pneumonia.
**Good Things you can do!**

- Give your staff training an extra boost when it comes to persons in special populations.
- Think outside the box in terms of communication, infection control, activities, and socialization opportunities.
- Update those care plans!
- Double-up on personal hygiene! Now is time to really scrub those teeth, wash those hands, *clean those fingernails!!!* (If you need help on getting this done with persons in this population, give your QIPMO nurse or coach a call.)
- Nurses, Inspect, Auscultate, Palpate—back to basics—folks with dementia and IDD are especially at risk for coronavirus—take a look at those legs, check for DVTs, listen to those lung fields anterior and posterior, listen to that heart rate for more than 30 seconds, look them over for rashes, lots of Kleenex on the floor, clearing their throat or coughing after eating more than usual.
COMMUNICATION HELP

• Disseminate information that uses clear and simple language. Provide information in accessible formats, like braille, large print. Offer multiple forms of communication, such as text captioning or signed videos, text captioning for hearing impaired, online materials for people who use assistive technology.

Dealing with Covid-19
Resources for Special Educators, Therapists, & Families

Curated resources for those working with Individuals who have developmental disabilities.
Thanks to all the creators from around the globe whose work is listed here. Your generosity in making these resources freely available is greatly appreciated.

I wash my hands
1. Wet hands
2. Turn on water
3. Wet hands
4. Rub hands
5. Rinse hands
6. Turn off water
7. Dry hands

Wash your hands
Scrub your hands
Sing "Happy Birthday" with water
Rinse your hands
Dry hands

(Source: https://www.somore.com/udqm2-covid-19-preparedness?fbclid=IwAR2xlAuAGOX-m8PnTMKjY75o0Wk8O31SqwpSazt4pelkY2laoS6YShI4Zs)
Activity Tips

1. One-on-one time! You can’t replace the human interaction.
2. Laughter!
5. Going outside.
6. Tippy-dipping (dipping your toes in a kiddie pool)*
7. iPads*
8. Sensory boards, lights, blankets*
10. Individualized sundae buffets.

*these items can be multi-use once washed and/or disinfected.
For kids of healthcare superheroes
Mini Webinar Series — COVID-19 Prevention Training for Long-Term Care Staff

COVID-19 cases have been reported in all 50 states, the District of Columbia, and multiple U.S. territories, and many of these areas have wide-spread community transmission. Because of the high risk of spread once COVID-19 enters a long-term care facility, fast action is needed to protect residents, families, and staff from serious illness, complications, and death.

CDC has launched a Long-Term Care Frontline Staff Training Webinar Series for staff who care for vulnerable residents of nursing homes and assisted living facilities. These five short webinars review basic infection prevention steps essential for preventing the spread of COVID-19:

**Sparkling Surfaces** (7 min) - [https://bit.ly/2yulKr2](https://bit.ly/2yulKr2)
- Keep long-term care and nursing home residents healthy by knowing how and when to clean and disinfect environmental and equipment surfaces.

**Clean Hands** (7 min) - [https://bit.ly/35JaNgH](https://bit.ly/35JaNgH)
- Keep long-term care and nursing home residents healthy by knowing how and when to perform hand hygiene as part of preventing the spread of COVID-19.

**Closely Monitor Residents** (7 min) - [https://bit.ly/3b9odK1](https://bit.ly/3b9odK1)
- Learn the importance of recognizing new or worsening infections quickly in long-term care facilities and nursing homes. The earlier sick residents can be identified, the faster COVID-19 can be prevented from spreading throughout the facility.

- Learn what staff, vendors, and consultants should do to protect residents and keep COVID-19 out of the facility. Understand the importance of wearing facemasks and cloth face coverings appropriately.

**PPE Lessons** (12 min) - [https://bit.ly/2zn0yjQ](https://bit.ly/2zn0yjQ)
- Learn what personal protective equipment (PPE) should be used in long-term care facilities and nursing homes as well as when and how to use PPE correctly to help protect yourself and residents from COVID-19.

These webinars are open access. You are free to use them in any communication channels and are encouraged to share widely with frontline staff:

CMS released **QSO 20-34-NH**, which announced that CMS is ending the blanket emergency waiver regarding the Payroll-Based Journal (PBJ) system. **Effective immediately**, all nursing homes are required to resume submission of staffing data through the PBJ system by August 14, 2020. Specifically, facilities must submit the staffing data for Calendar Quarter 2 (April – June) 2020 through the PBJ system by August 14, 2020.

In addition, while not required, CMS is encouraging nursing homes to submit data for Calendar Quarter 1 (January – March) 2020. Calendar Quarter 1 data will not be used to calculate staffing measures or ratings; however, CMS will continue to post the data in a public use file on data.cms.gov. **Due to the waiver being lifted, CMS will update staffing measures and ratings in October 2020 based on data submitted by August 14, 2020.**
FYI on F884 citations

CMS has been issuing F884 citations each week for facilities that fail to submit data to the NHSN, along with escalating per instance CMPs. As you know, the citations are not being issued in the normal fashion. If incomplete or erroneous data is submitted by SNFs, the NHSN system triggers the issuance of a 2567 to the QIES/CASPER reporting system. **It is imperative that facilities log in to CASPER to see if they have a citation or not.**
“Missouri’s data indicates at the COVID-19 peak in Missouri, the average age of new COVID cases was 56 years,” said Herb B. Kuhn, MHA President and CEO. “By June 20, the average age had dropped to 38. Because younger Missourians are more likely to be asymptomatic or avoid the worst effects of the disease, they have a special responsibility to safeguard others.”

Missourians under age 45 make up 57% of the population they’re also the most likely to be exposed to coronavirus by returning to work or participating in social events. During the first week of March, Missourians under age 45 accounted for 23% of COVID-19 cases in the state. Data from the third week of June finds they now account for 63% of new cases.

2. Coronavirus social story—for children and adults with intellectual disabilities (Great, small book 😊 !) [https://www.flipsnack.com/KeshetChicago/coronavirus-social-story/full-view.html?fbclid=IwAR0laVqOJ7aPBTsONhglPOWeNm42jOZPLPCElPMfbzU5RJ75-iWP-muCRJw](https://www.flipsnack.com/KeshetChicago/coronavirus-social-story/full-view.html?fbclid=IwAR0laVqOJ7aPBTsONhglPOWeNm42jOZPLPCElPMfbzU5RJ75-iWP-muCRJw)


4. Waisman Center, University of Wisconsin-Madison [https://www.waisman.wisc.edu/covid-19/disabilities/](https://www.waisman.wisc.edu/covid-19/disabilities/)

5. “FOR YOU—” [https://www.smore.com/udqm2-covid-19-preparedness?fbclid=IwAR2xlAuAGOX-m8PnTMKjY75o0Wk8O3ISqwpSazt4pelkY2laoSBiYShl4Zs](https://www.smore.com/udqm2-covid-19-preparedness?fbclid=IwAR2xlAuAGOX-m8PnTMKjY75o0Wk8O3ISqwpSazt4pelkY2laoSBiYShl4Zs)
REFERENCES


REFERENCES


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