

The Healthcare Concerns of COVID-19 in People with IDD and Dementia

Seth M. Keller, MD

Co-Chair NTG

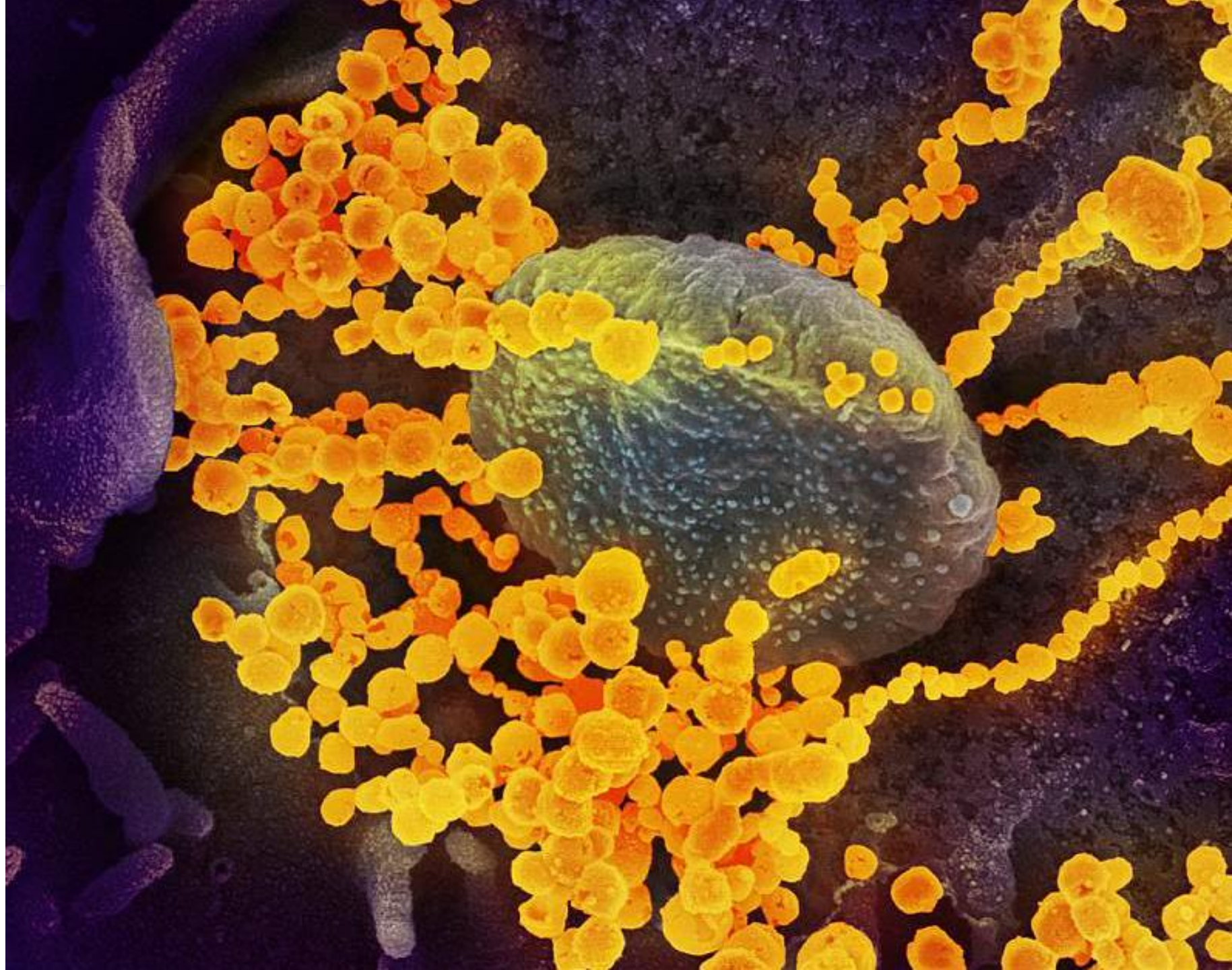
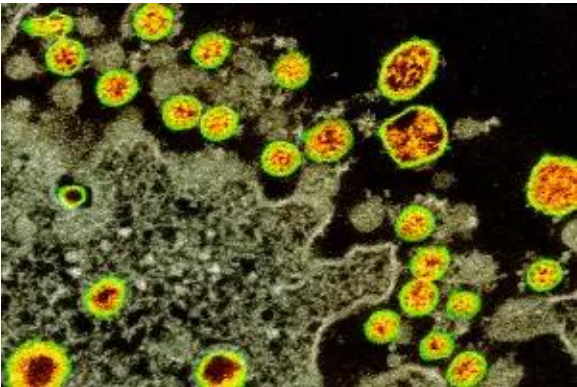
Past President AADMD

Chair Adult IDD Section AAN



Disclosures

- Relationships with financial sponsors: none to disclose
- Potential for conflict(s) of interest: none to disclose



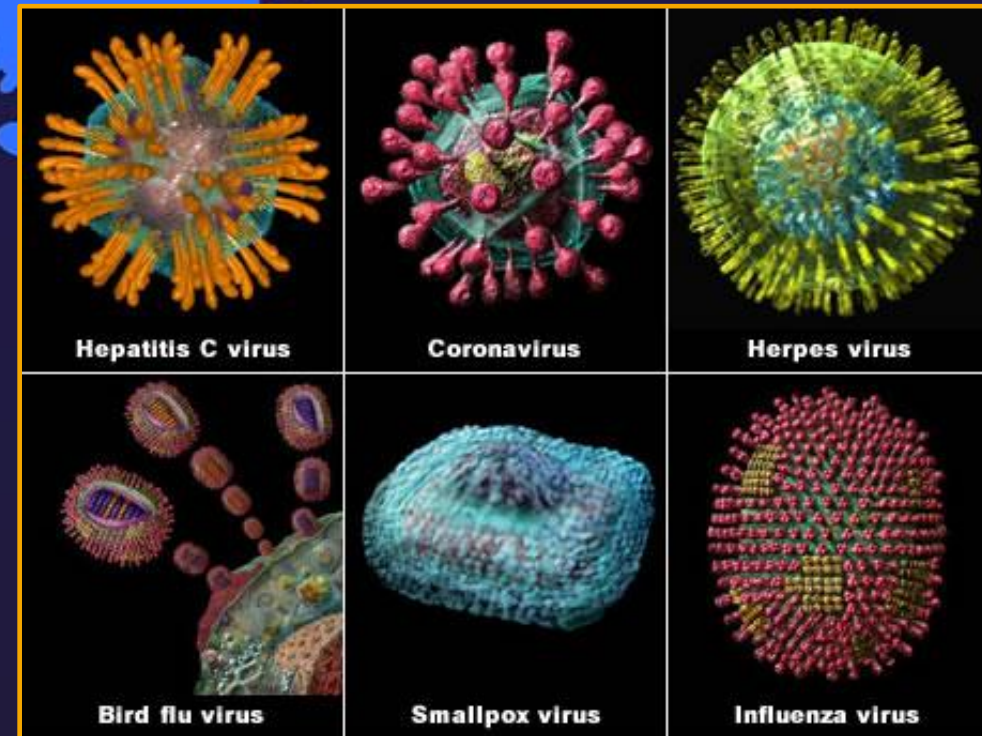
A microscopic image showing a cluster of yellow, spherical particles, likely viruses, on a cell surface. The cell is stained in shades of blue and purple. A white circular area on the left side of the image contains the text.

Outline

- Virology 101
- COVID-19 Course of disease
- Down syndrome/IDD
- Alzheimer's disease
- Cruel Impact
- Maintaining Care
- Sounding the alarm
- Next steps

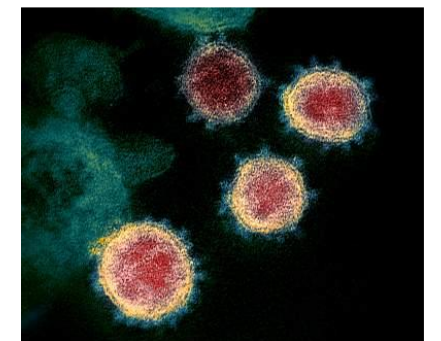
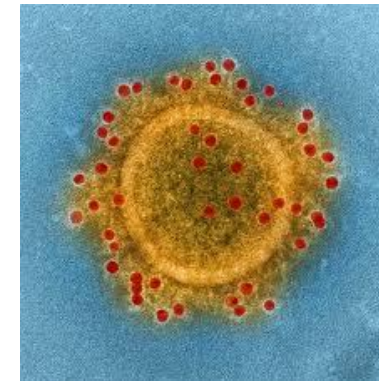
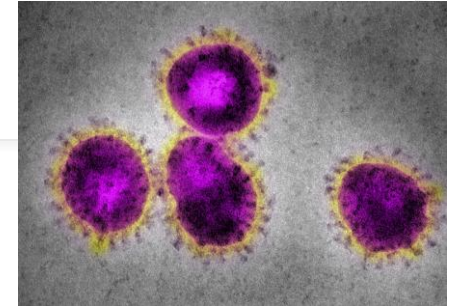
Virology 101

- A virus is genetic material contained within an organic particle that invades living cells and uses their host's metabolic processes to produce a new generation of viral particles.
- Vary in size, mode of transmission, DNA/RNA make up, infectivity and lethality



Coronavirus

- Severe Acute Respiratory Syndrome (SARS) 2002-2003
 - Guangdong Province China
 - Transmitted from bats to civets to humans
 - >8000 cases, 774 deaths, fatality rate approx. 9.6%
- Middle East Respiratory Syndrome (MERS) 2012
 - Saudi Arabia
 - Transmitted from camels to humans
 - >2400 cases, 858 deaths, fatality rate approx. 34.4%
- Novel 2019 Coronavirus (COVID-19) 2019-?
 - Wuhan Province China
 - Transmitted from ? Snakes to humans
 - >? cases, ?deaths, ?fatality rate approx.



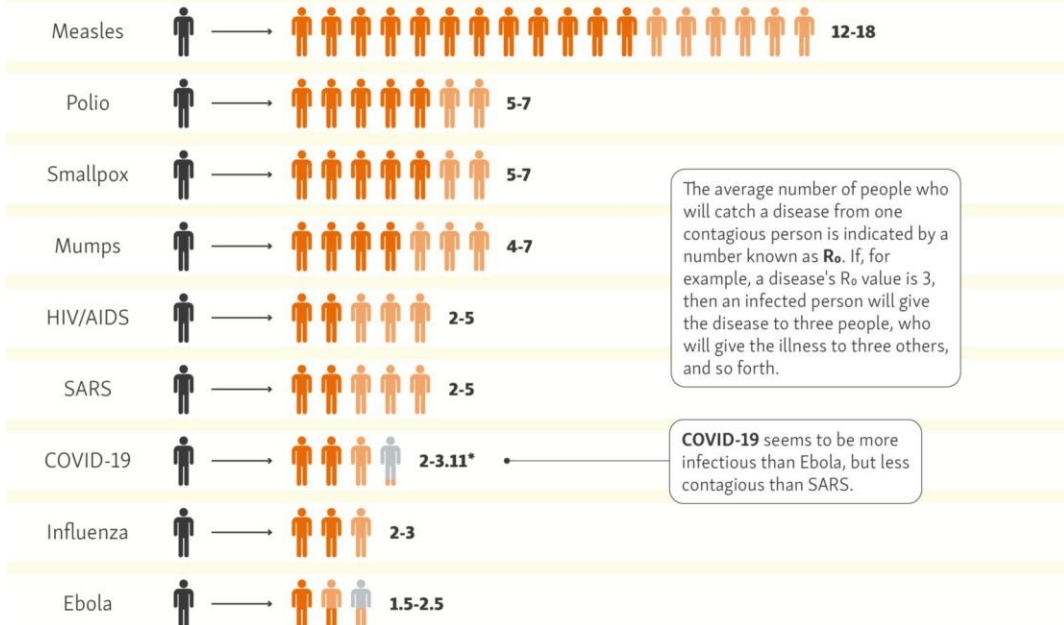
Not every Virus has the same impact

How Contagious Is COVID-19 Compared To Other Diseases?

According to preliminary estimates, a patient suffering from COVID-19 infects two to three other people on average.

Number of people infected by one person (selected diseases):

 Minimum range  Maximum range

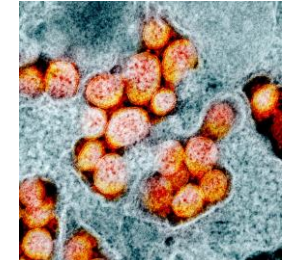
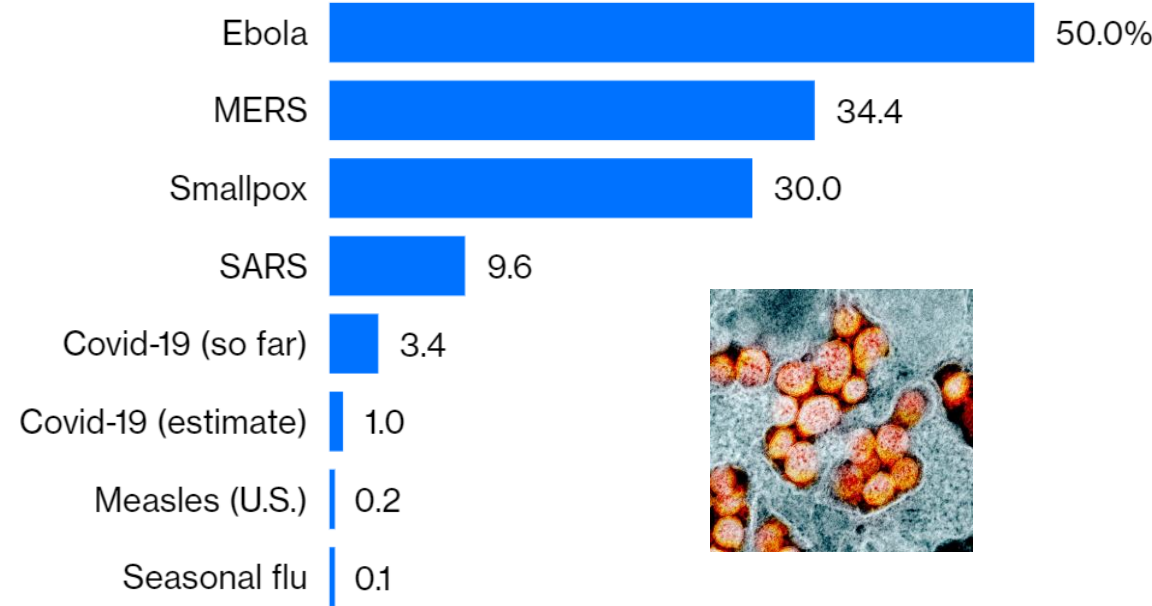


The average number of people who will catch a disease from one contagious person is indicated by a number known as R_0 . If, for example, a disease's R_0 value is 3, then an infected person will give the disease to three people, who will give the illness to three others, and so forth.

COVID-19 seems to be more infectious than Ebola, but less contagious than SARS.

*Preliminary estimate
 Note: The R_0 value might vary from patient to patient depending on the number of contacts and other factors.
 Kristyna Foltynova | Sources: WHO, The New York Times, Der Spiegel

How Deadly Is That Disease? Approximate case-fatality rate

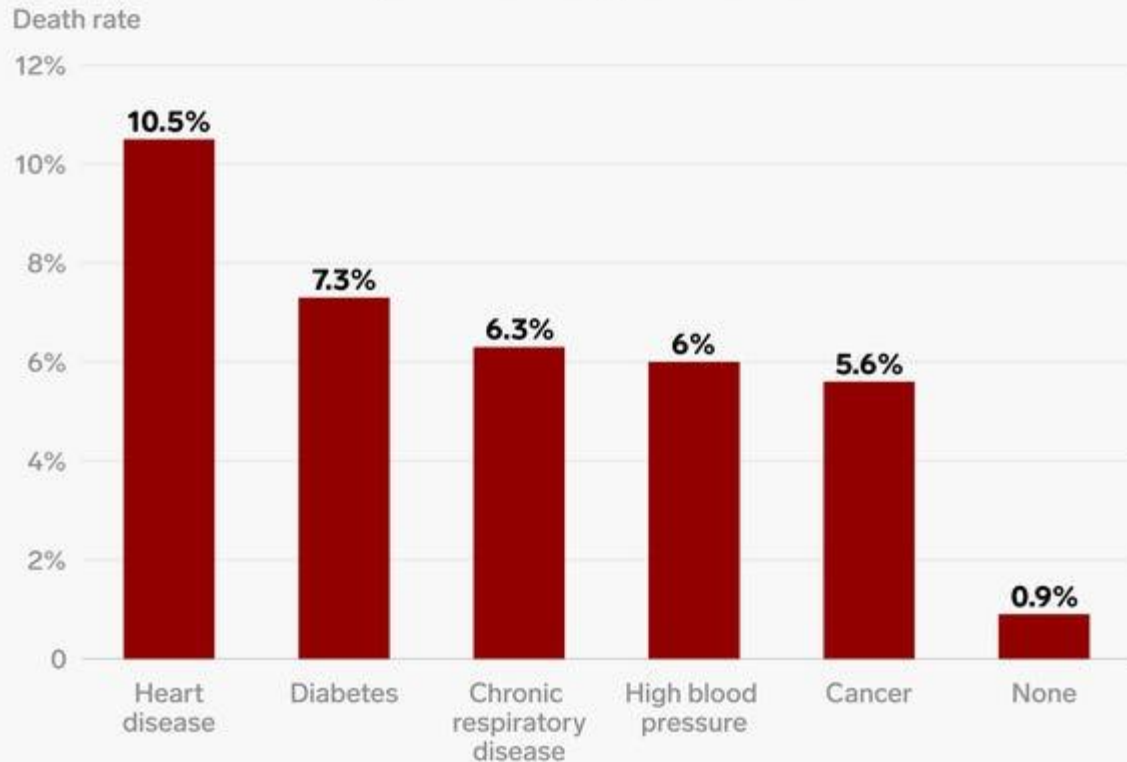


<https://www.rferl.org/a/how-contagious-is-covid-19-compared-to-other-diseases/30492988.html>

<https://www.bloomberg.com/opinion/articles/2020-03-05/how-bad-is-the-coronavirus-let-s-compare-with-sars-ebola-flu>

COVID-19 is worse for some than others

Death rate of COVID-19 patients with preexisting conditions

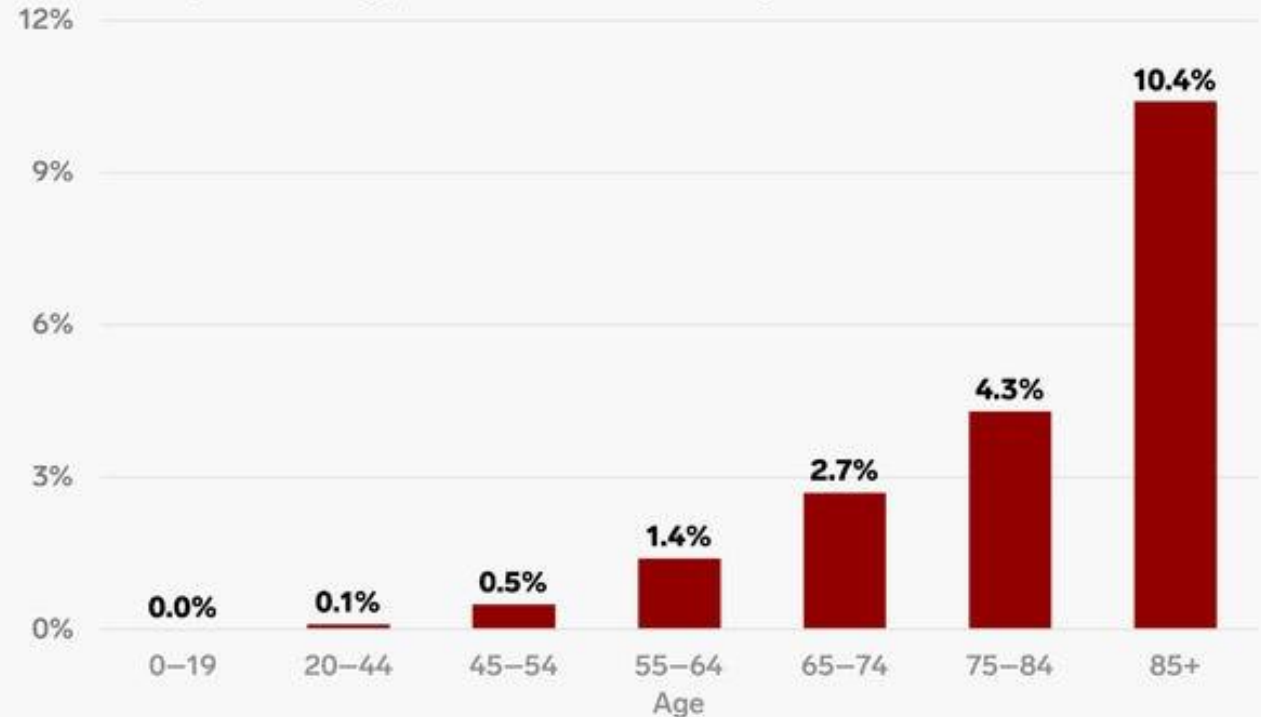


Source: Chinese Center for Disease Control and Prevention

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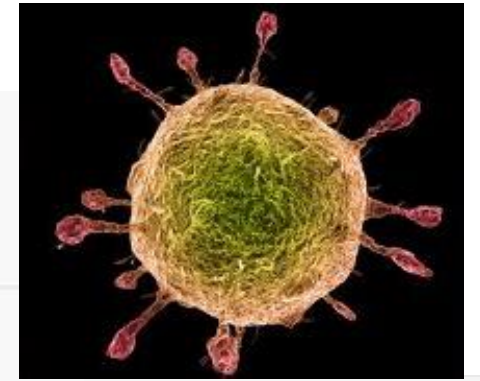
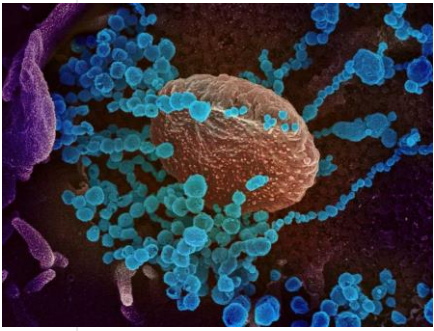
COVID-19 death rates in US by age

Case-fatality rate among patients with confirmed age



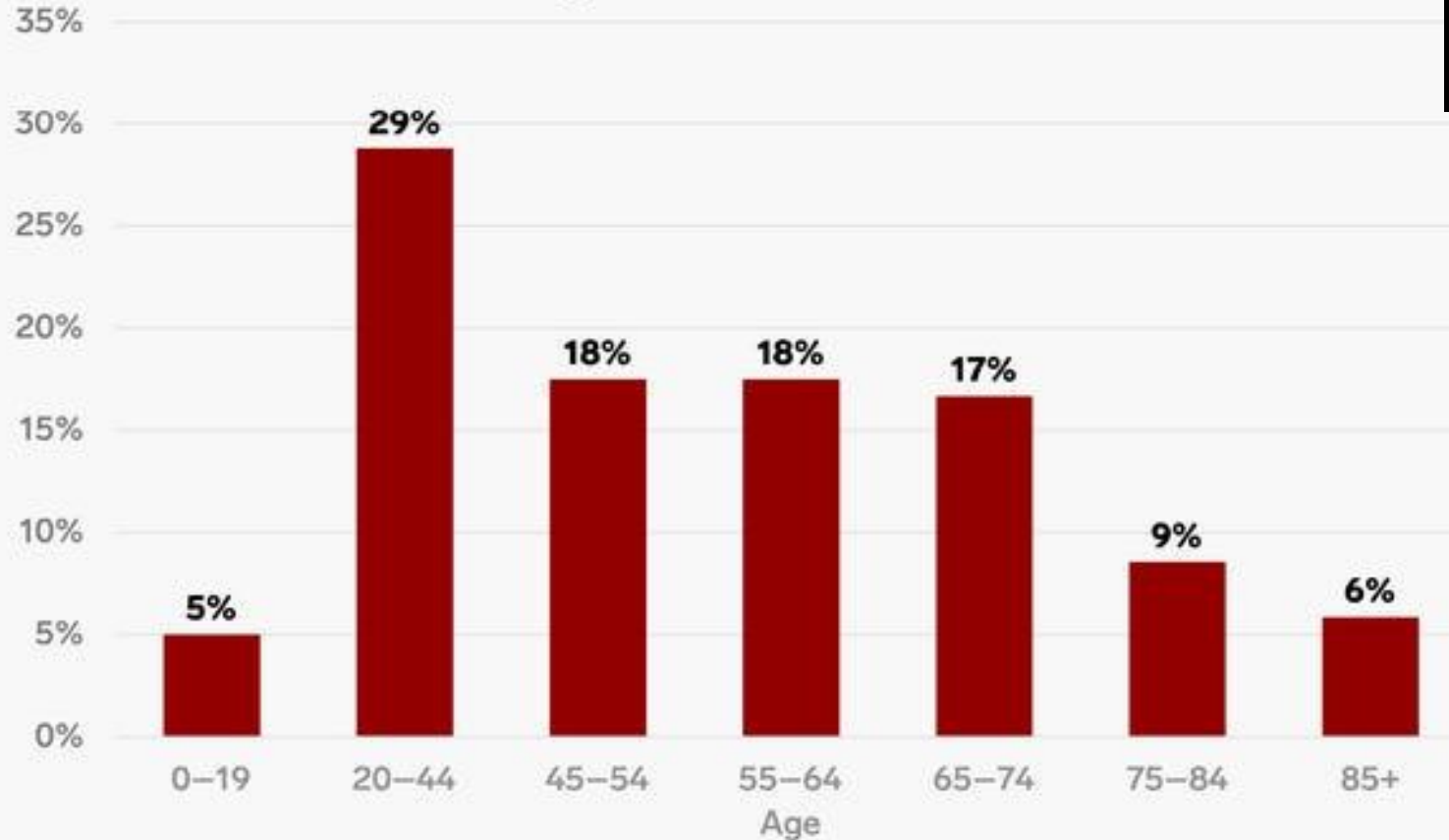
Source: Centers for Disease Control and Prevention COVID-19 Response Team

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Age distribution of US COVID-19 cases

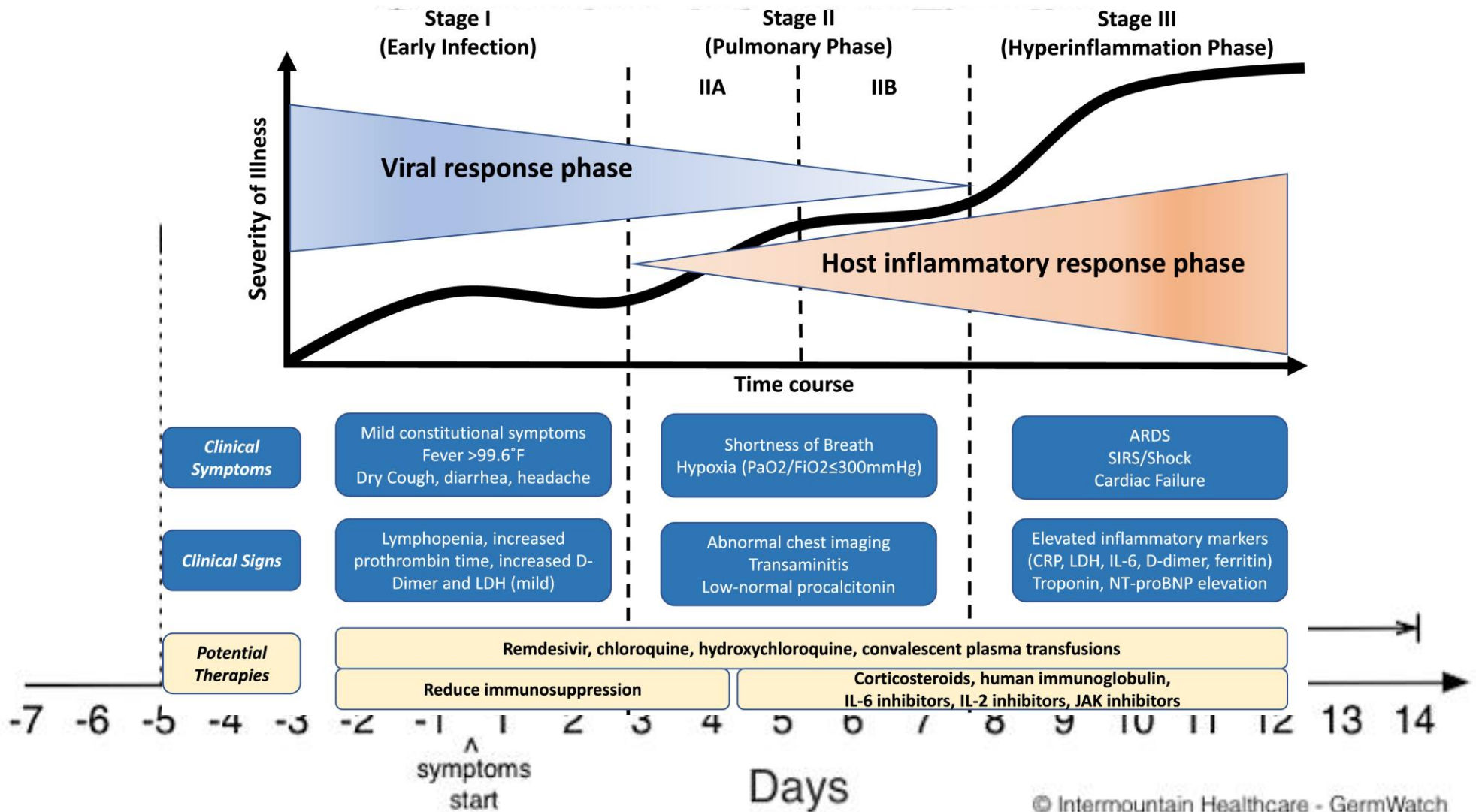
Percent share of cases in each age bracket



Source: Centers for Disease Control and Prevention COVID-19 Response Team.
Percentages don't add to 100% due to rounding.

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<https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6912e2-H.pdf>



Dementia and COVID-19

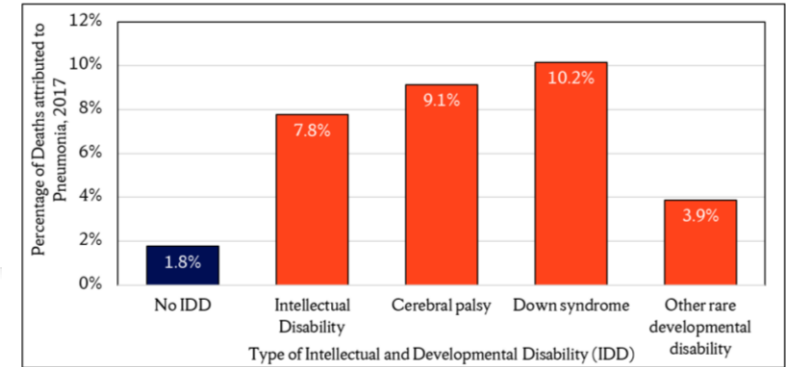
- Generally most over 65 years old, except for early-onset Alzheimer's disease
- May not be able to understand or appreciate hygiene instructions and able to follow them
- May be around others who can pass on virus;
congregate living
- Advanced disease associated with weakened immune system, breathing and swallowing difficulties
- Challenges with caregiver stress and availability



IDD/DS and COVID-19

- Breathing and swallowing difficulties; history of lung diseases
- Sleep apnea in those with DS
- Cardiac difficulties
- Weakened immune systems
- Higher degree of chronic diseases
- In relatively proximity to others at risk; **congregate living**
- Ability to follow and maintain adequate hygiene guidelines
- Impact associated with caregiver issues and concerns
- Insufficient data to know for certain

Potential Impacts of COVID-19 on Individuals with Intellectual and Developmental Disability: A Call for Accurate Cause of Death Reporting



Landes, S.D., Stevens, J.D., & Turk, M.A. (2019). Obscuring effect of coding developmental disability as the underlying cause of death on mortality trends for adults with developmental disability: A cross-sectional study using US Mortality Data from 2012 to 2016. *BMJ Open*, 9(2), 1-10.

The New York Times

'It's Hit Our Front Door': Homes for the Disabled See a Surge of Covid-19



<https://www.nytimes.com/2020/04/08/nyregion/corona-virus-disabilities-group-homes.html>

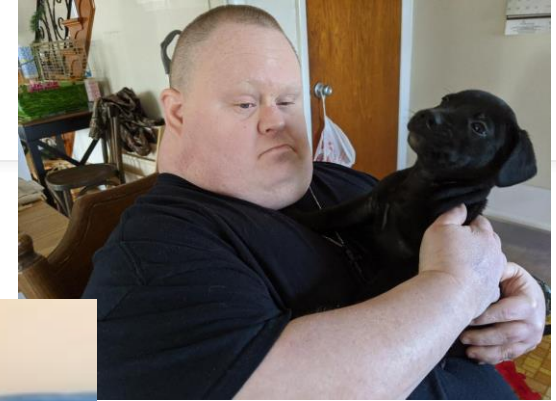
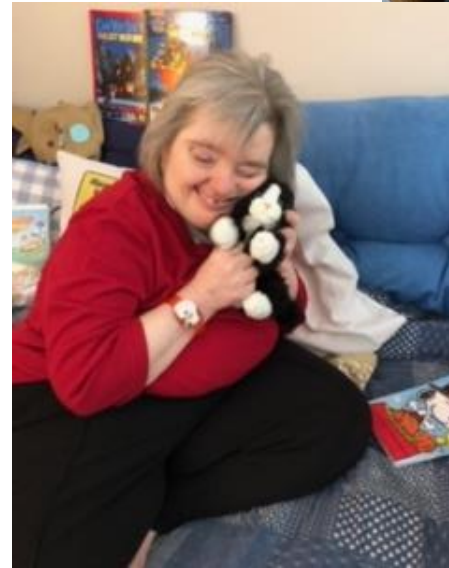


The Timeline of COVID-19 and its Impact

- Social distancing and under quarantine
- Getting sick
- Going to the hospital
- Recovery

Social distancing and isolation

- A change of routine in a restricted environment
- Stress and maintaining “normal”
- Being scared
- Keeping safe



Maintaining Care

- Chronic conditions do not go away
- Active mental health concerns
- Ensuring caregiver supports are considered
- Telehealth
- Staying connected





Getting sick

- Signs of the illness
- Testing; checking for fever, GI difficulties, Respiratory complaints and COVID-19 testing
- Care practices
- Quarantine
- Personal Protection Equipment (PPE)
- Deciding when a higher level of care is needed
- Stress management

Getting Information

VOLUME 4 ISSUE 1 NTG CAREGIVER NEWS PAGE 3

COVID-19 Information By and For People with Disabilities



What is COVID-19?
It is a new illness spreading around the world. Its nickname is coronavirus.



How do you get it?
Someone with COVID-19 gives you their germs. When they cough or sneeze, their germs get in the air, on you, and on things. Germs get into your body through your mouth, nose, and your eyes.



What happens if you have it?



A fever of 100.4 or higher



Coughing



Hard time breathing

If these things happen to you, it does not mean you have coronavirus. Lots of people get a fever or cough. You could just have a cold or the flu.


If I am sick, when should I call a doctor?



Call if you have been out of the country.
Call if you have been with someone who has the virus.
Call if you have been at a place where people with COVID-19 got medical treatment.
Call your doctor, do not go to the office.


Adapted from COVID-19 Information By and For People with Disabilities, Green Mountain Self-Advocates www.gmsavt.org
To access the complete booklet visit the Green Mountain Self-Advocates website at this link:
<https://selfadvocacyinfo.org/wp-content/uploads/2020/03/Plain-Language-Information-on-Coronavirus.pdf>

THE ROLE OF THE DSP AND THE CORONAVIRUS



PART THREE: LIVE

Featuring: Rick Rader, MD
April 3rd | 1:00 PM EST



<https://nadsp.org/covid-19resources/>



DMIG-USA
Down Syndrome Medical Interest Group-USA

GLOBAL
DOWN SYNDROME FOUNDATION

Lumind
IDSC

NATIONAL
DOWN SYNDROME
CONGRESS

ndss
National Down Syndrome Society

ontg
National Task Group
on Intellectual Disabilities
and Ombuds Practices

Covid-19 & Down Syndrome Q & A

NTG Joins National Groups in Issuing Q&A on COVID-19 and Down Syndrome

With the constantly changing status of the COVID-19 pandemic in the United States, the NTG joined in with an effort by national organizations to produce and issue a Q&A on COVID-19 and Down Syndrome. The Q&A has two versions, one a brief series of content answers, and another longer version covering numerous questions that have arisen. The Q&A is directed toward families and others concerned with impact of COVID-19 upon persons of all ages with Down syndrome.

Download Abbreviated Version in English

Descargue la versión abreviada en español

Download Expanded Version in English

Descargue la versión ampliada en español

<https://www.the-ntg.org/projects>

Going to the hospital

- Testing
- Treatment
- Getting the necessary care
- Quarantine
- Communication
- Palliative Care
- Death and dying



Improving Care in the Hospital

- Communication and Accurate Information; Health Passport/summary
- Support of the Caregiver/DSP; Cares Act Provision
- Hospital Visitation Rights; NY DOH, NJ, TN, National advocacy effort
- Ensure equity of care

CAUTION: POSSIBLE COVID-19 CASE

Patient Summary for Person with Developmental Disability
Emergency Contacts, Allergic Reaction History, Medication Regimen, Allergy Information, Assistance Needs

I have a developmental disability. My caregiver(s) or support professional believes I am showing signs of COVID-19 infection. If they cannot come with me into the hospital, please refer to the information provided here and call my guardian, service provider, and the county board of DD for any clarifications.

PERSONAL INFORMATION

First Name:	Middle Initial:	Last Name:	DOB or Age:
Address:			
City, State, ZIP:		Phone Number:	
Name of Parent/Guardian:		Parent/Guardian Phone/Email:	
Name of Direct Support Professional (DSP):		DSP Phone/Email:	
County Board of DD Contact:		County Board Contact Phone/Email:	

CURRENT SYMPTOMS / RISK FACTORS

<p>Current COVID-19 Symptoms:</p> <input type="checkbox"/> Temp. Over 100°F <input type="checkbox"/> Dry Cough <input type="checkbox"/> Malaise/Fatigue <input type="checkbox"/> Shortness of Breath <input type="checkbox"/> Bloodshot Eyes <input type="checkbox"/> Diarrhea <input type="checkbox"/> Loss of Smell/Taste <input type="checkbox"/> Other (please specify): <input type="checkbox"/> Other (please specify):	<p>When Did it Start?</p>	<p>Patient's COVID-19 Severity Risk Factors (check all that apply):</p> <input type="checkbox"/> Age 60 or Older <input type="checkbox"/> Blood Disease <input type="checkbox"/> Cancer <input type="checkbox"/> Central Palsy <input type="checkbox"/> Chemotherapy <input type="checkbox"/> Chronic Heart Disease <input type="checkbox"/> Chronic Lung Disease <input type="checkbox"/> Diabetes <input type="checkbox"/> On Prostate, Chemotherapy, or any medication ending in the letters "ol" <input type="checkbox"/> Down's Syndrome <input type="checkbox"/> Hypertension <input type="checkbox"/> New Chest Pain <input type="checkbox"/> Parkinson's Disease <input type="checkbox"/> Recurrent Pneumonia <input type="checkbox"/> Severe Scoliosis <input type="checkbox"/> Other: <input type="checkbox"/> Other:
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PERSONAL ASSISTANCE NEEDS

<input type="checkbox"/> Independence <input type="checkbox"/> Needs Assistance <input type="checkbox"/> Telephone <input type="checkbox"/> Social <input type="checkbox"/> Typical	<input type="checkbox"/> Needs Assistance <input type="checkbox"/> Needs Assistance <input type="checkbox"/> Limited Speech <input type="checkbox"/> Not Social <input type="checkbox"/> Inert/Not	<input type="checkbox"/> Needs Total Assistance <input type="checkbox"/> Needs Total Assistance <input type="checkbox"/> Needs Assistance Device <input type="checkbox"/> Needs Assistance Device <input type="checkbox"/> Voice <input type="checkbox"/> Incontinent/Variable	<p>ADDITIONAL NOTES:</p>
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PATIENT HAS DNR ORDER:
 YES NO UNSURE
 If yes, list order location if known:

PATIENT HAS LIVING WILL:
 YES NO UNSURE
 If yes, list will's location if known:

PATIENT HAS MASKFACE SENSITIVITY (IF YES, SPECIFY IN NOTES ABOVE):
 YES NO

PATIENT HAS GENERAL TOUCH SENSITIVITY (IF YES, SPECIFY IN NOTES ABOVE):
 YES NO

To download this form, visit www.oacbdds.org/covidform

This form was created and distributed by the Ohio Association of County Boards of DD. ©2020 Ohio Association of County Boards of DD. All rights reserved. Please refer to the Ohio Association of County Boards of DD website for more information.

<http://www.oacbdds.org/news/2020/04/08/releases/oacb-creates-health-passport-to-assist-people-served-unable-to-enter-hospitals-with-staff-family/>

DR NJ DISABILITY RIGHTS NEW JERSEY

Due to COVID-19 Hospital Visitation Policies Exclude Caregivers of People with Disabilities: What We're Doing to Change the Policies

<https://myemail.constantcontact.com/--Hospital-Visitation-Policies-Exclude-Caregivers-of-People-with-Disabilities---What-We-re-Doing-To-Change-It.html?soid=1102624420023&aid=POHFyW4NBHw>

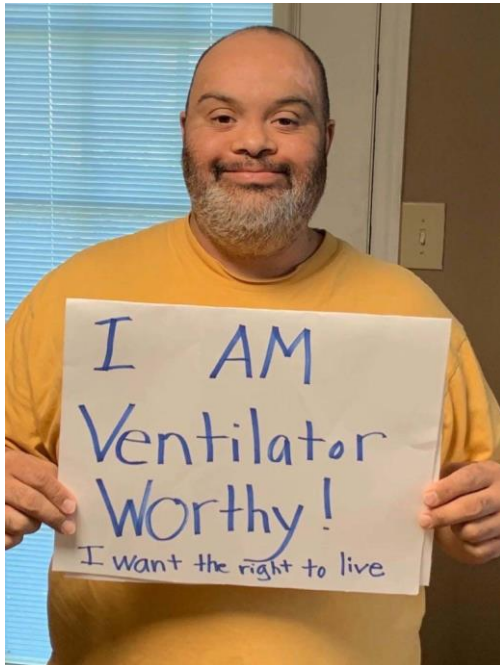
https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf

Sounding the Alarm

CORONAVIRUS AND INEQUALITY

Published — April 8, 2020

STATE POLICIES MAY SEND PEOPLE WITH DISABILITIES TO THE BACK OF THE LINE FOR VENTILATORS



<https://www.propublica.org/article/people-with-intellectual-disabilities-may-be-denied-lifesaving-care-under-these-plans-as-coronavirus-spreads>

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES



Safeguard Against Disability Discrimination During COVID-19

Including individuals with disabilities in the COVID-19 response to ensure equitable care



THINK EQUITABLE CARE - TAKE ACTION!

- Inform key medical personnel immediately that individuals with disabilities have equal rights to COVID-19 testing and treatment.
- Make equitable decisions to ensure that allocation of COVID-19 resources, supplies, and care are not based on inaccurate assumptions about life with a disability.
- Provide accommodations to make sure all individuals can access COVID-19 testing and treatment. This requirement includes accommodations for behavioral, intellectual, or physical disabilities that may impact someone's ability to comply during testing and treatment.



KNOW THE BEST PRACTICES - TAKE ACTION!

- When communicating with individuals with disabilities:
 - Talk directly to them.
 - Ask permission before speaking with their caregivers, if possible.
 - Ask the caregiver for assistance if you need help communicating with a patient.
 - Use plain language to tell individuals and caregivers about COVID-19 test results and anticipated procedures.
 - Keep in mind that you may have difficulty understanding the patient, however, in most cases they understand you.
- Make these accommodations:
 - Allow a caregiver to go with a patient to ensure adequate support for decision-making and treatment.
 - Provide ramps and rooms with enough access for a wheelchair.
 - Provide qualified interpreter services for the deaf or hard of hearing.
 - Use prompts, such as picture cues, for those with limited use of verbal communication.
 - Provide the time needed for individuals to speak, respond, and understand.

THINK EQUITABLE!

This information is based on guidance from the Department of Health and Human Services Office for Civil Rights. For more information, visit [HHS.gov/ocr](https://www.hhs.gov/ocr) and [btl/2WXEscv](https://www.hhs.gov/btl/2WXEscv)

<https://www.ucucedd.org/safeguard-against-disability-discrimination-during-covid-19/>



HHS Office for Civil Rights in Action



March 28, 2020

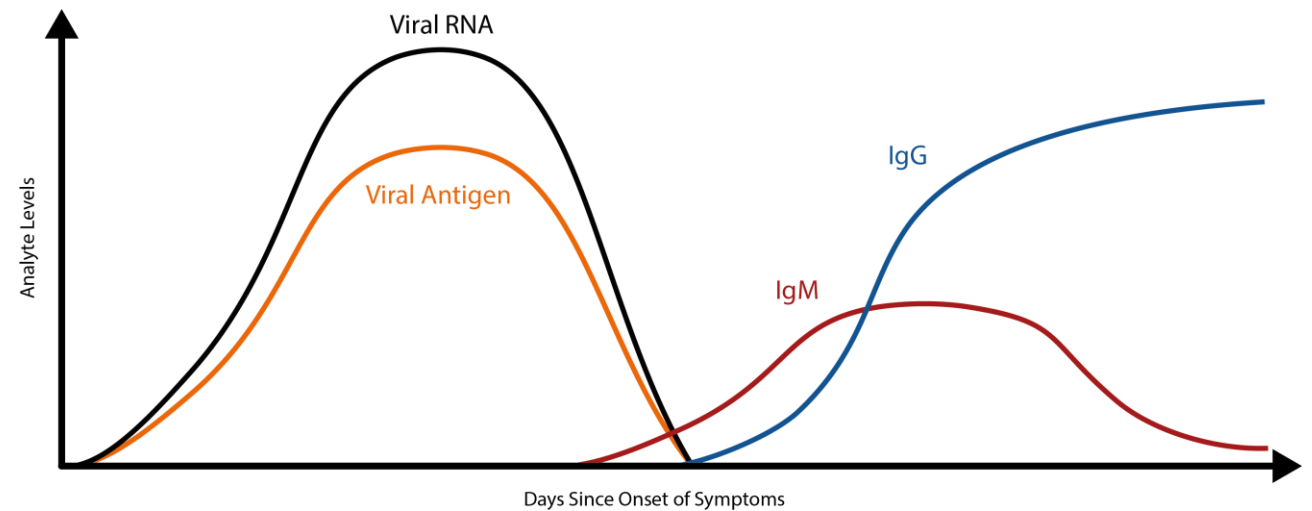
BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)

In light of the Public Health Emergency concerning the coronavirus disease 2019 (COVID-19), the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) is providing this bulletin to ensure that entities covered by civil rights authorities keep in mind their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience and religion in HHS-funded programs.¹

<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

COVID-19 Work up

- Nasal, oral, blood, fecal for evidence of the the virus
- How long to get back results
- How accurate are the tests results?
- Symptoms/signs
- Chest x-ray/CT Scan
- Blood; CRP, Ferritin, LDH, CPK, LDH
- Exclude other pathogens



<https://thenativeantigencompany.com/why-we-need-antigen-and-antibody-tests-for-covid-19/>



COVID-19 Treatment

- Prevent further spread
- Reduce fever
- Fluids/nutrition
- Respiratory and cardiac support
- Antiviral therapy; stopping the virus along its life cycle
 - ?? Hydroxychloroquine
 - ?? Remdesivir, Favipiravir
- Stress Management
- Communication
- Planning ahead

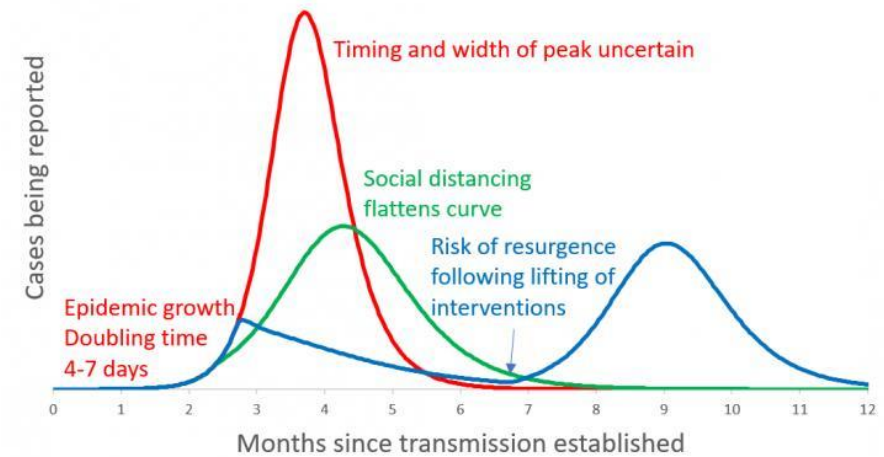
Prevention

- Social distancing/hygiene
- Adequate Personal Protection Equipment (PPE)
- Convalescent plasma
- Vaccines



Recovery

- Post COVID-19 stress
- Transitioning and rehabilitation
- Getting back to “normal”
- Preparing for next wave
- Lessons learned



In the USA in 2020, nurses are left to make gowns from garbage bags?

SHOCK

Bandanas??? Are you f#ckin' kidding me?

BETRAYAL

ENVY

Social distancing much???

FRUSTRATION

FEAR

TOTAL CARES SYSTEM CAPACITY

FOREBODING

13 hour shift
need to inhale
exhale
do we have enough TP at home?
documentation
kids want sleep in their own beds...

EXHAUSTION

due to covid-19 NO VISITORS

GRIEF

NIGHTMARES PANIC ATTACKS DREAD
CAN'T SLEEP SOBING IN THE PARKING LOT
HEART RACING SWEATS PIZZY OVERWHELMING HELPLESS DOOM

TERROR

SOLIDARITY

COURAGE

HOPE



@whiteboardpsych