

Keeping Healthy through COVID-19 with Infection Control and More for People with IDD and Dementia

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Disclosures +

- COVID-19 is an emerging, rapidly evolving situation and is current at the time of this presentation
- Relationships with financial sponsors and potential conflict(s) of interest: none to disclose
- This information is presented for the purpose of education and should not be used in place of the advice of your and those you support health care practitioners



Objectives

- 1. Discuss three strategies to prevent spread of the corona virus between a person with ID and dementia and the caregiver
- 2. Identify the existence and value of the review of an advanced directive in the plan of care
- 3. Describe a three ways that a caregiver can maintain optimum health for self and for the person for whom care is given

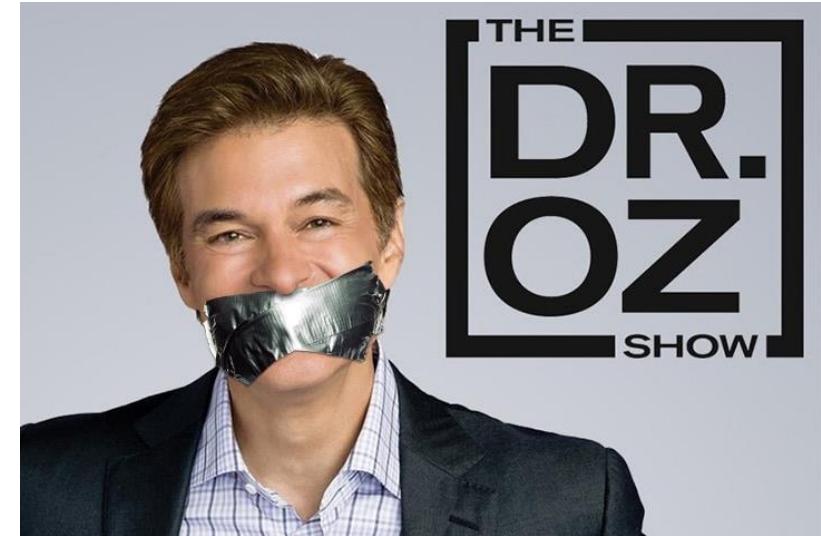


Information integrity

Navigating all these resources!!!!

Reliable Resources

- CDC, WHO
- Alzheimer's Association, ADI
- NTG, AADMD, AUCD, AAIDD, IASSID, HCARDD,
- State Guidelines (Overall and departments for IDD)
- City Public Health Departments
- Areas Agencies on Aging, GSA, AGS
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For people with ID →

- **Green Mountain Self Advocates** <http://www.gmsavt.org/>
 - COVID-19 Information By and For People with Disabilities
 - [*Coronavirus Plain Language Glossary – Words To Know*](#)
 - [Tips For Working With Support Staff During COVID-19](#)
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- **IASSID:** https://www.iassidd.org/covid-19-resources/?utm_source=sendgrid.com&utm_medium=email&utm_campaign=website
- **Health Care Access Research & Developmental Disabilities** <https://www.hcarddcovid.com/info>
- **Scottish Commission for Learning Disability** <https://www.sclد.org.uk/covid-19-guided-self-help-booklet-series/>
- **Social Care Institute for Excellence** <https://www.scie.org.uk/>
- **Wisconsin COVID-19 Resource Tool Kit** <https://wi-bpdd.org/index.php/2020/03/25/living-well-covid-19-resource-toolkit/>
- **Books Beyond Words** Available for free download at <https://booksbeyondwords.co.uk/downloadshop/beating-the-virus>
 - Beating the Virus
 - Good Days and Bad Days during Lockdown
 - When someone dies from coronavirus: a guide for families and carers
 - Jack plans ahead for coronavirus: a guide for families and carers

COMING SOON! Why is my staff wearing a gown and gloves and everything?

The CDC reports:

Symptoms may appear **2-14** days after exposure to the virus

- A wide range of symptoms – ranging from mild symptoms to severe illness. May be ASx
- Cough
- Shortness of breath or difficulty breathing**

Or at least two of these symptoms:

- Fever **
- Chills
- Repeated shaking with chills
- Muscle pain
- Headache
- Sore throat
- New loss of taste or smell

Older People . . .

Older People (*Kaiser Health News*)

- Several “atypical” symptoms ; “off” sleeping more, apathy, disoriented . . .
- Others: Chief complaint older adults sent to our ER is weakness, lack of appetite, altered mental status "lethargy" (hypodelirium) and lab values show severe dehydration.

My response (GAPNA Open Forum Exchange 4.26.20)

- Thank you so much for sharing this as knowing the 'typical' S&S of older people who have infections; i.e., the lack of fever; thus, the big endeavor to "take temps" to monitor people should not take on the 'weight' that it does. It reminds us to consider what we as gero nurses know about assessing and monitoring older people. I work with people with intellectual disabilities and am always reminded that the presenting sign is a **change from baseline** as an indicator that "something's not right".

I continue to be reminded that the notion of 'relationship' extends beyond the social and emotional realms, but into the physical. .

What is Delirium and why does it matter?

Source: Global Council on Brain Health /AARP

DELIRIUM

HARMS BRAIN HEALTH



Testing

(Source: New England Journal of Medicine)



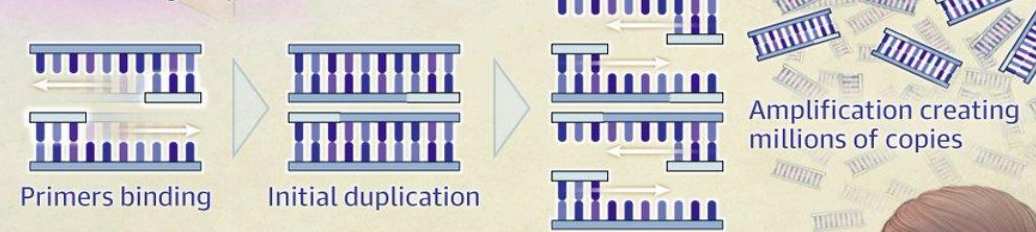
How does PCR testing for COVID-19 work?

Polymerase chain reaction (PCR) testing can detect even very small amounts of viral genetic material in a sample by duplicating it many times over through a complex laboratory process called amplification.

- 1 A test sample is swabbed from the back of the nose and processed to isolate genetic material.



- 2 Small pieces of specifically engineered genetic material, called primers, are introduced and bind to the isolated viral genetic material, initiating amplification.



- 3 Fluorescent markers bound to the copies during PCR are released and can be detected when amplification occurs.



Positive result

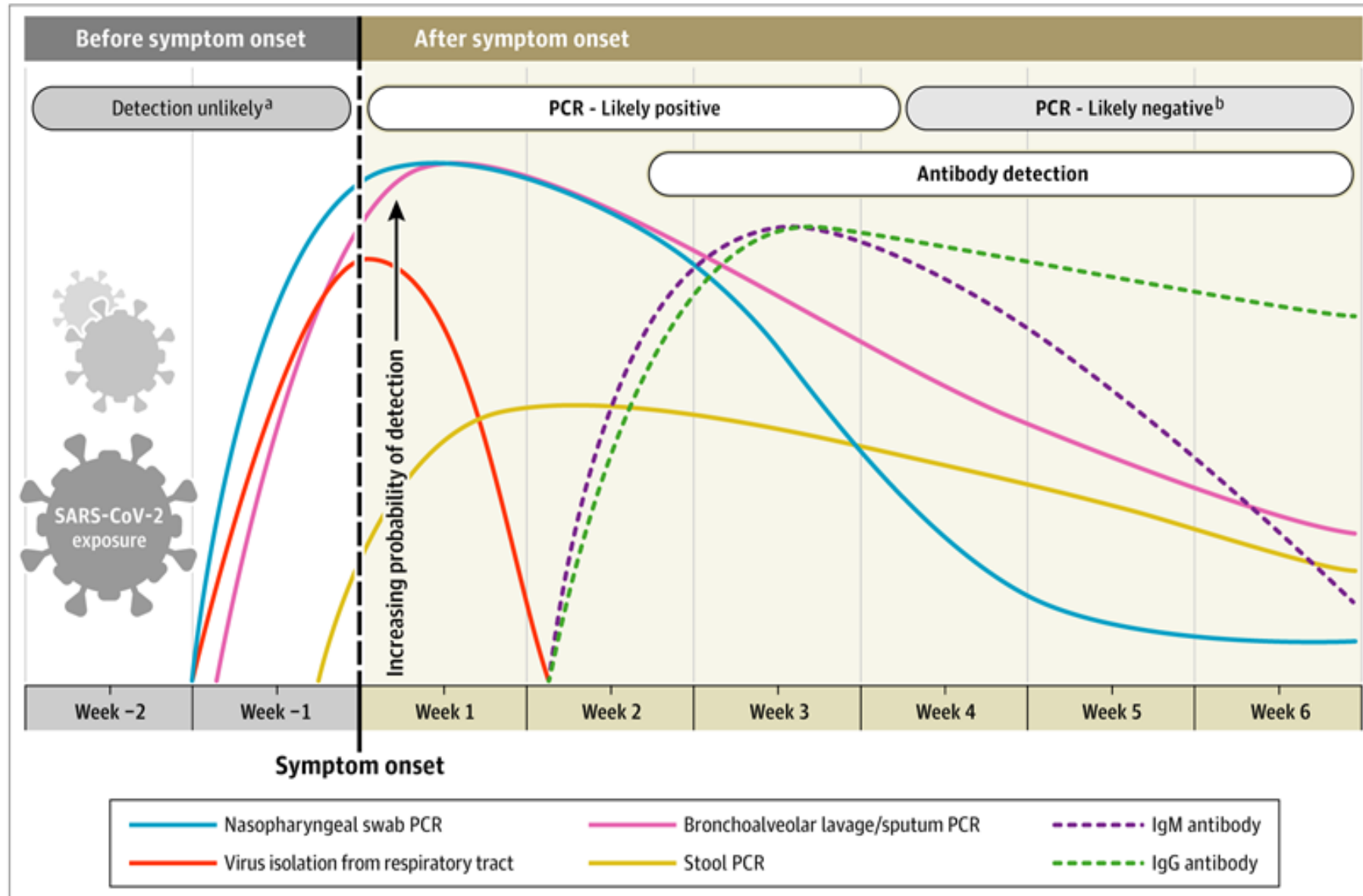
When there is viral genetic material in the sample, amplification occurs, releasing enough fluorescent markers to be detected.

Negative result

If there is no viral genetic material in the sample, amplification will not occur and no fluorescent markers will be detected.

- Antibody tests aren't intended to identify active SARS-CoV-2 infections. Instead of detecting viral genetic material in throat or nasal swabs, antibody tests reveal markers of immune response—the IgM and IgG antibodies that for most people show up in blood more than a week after they start to feel sick, when symptoms may already be waning.

Sethuraman et al (May 6, 2020) Interpreting Diagnostic Tests for SARS-CoV-2, JAMA



How to Protect Yourself & Others:

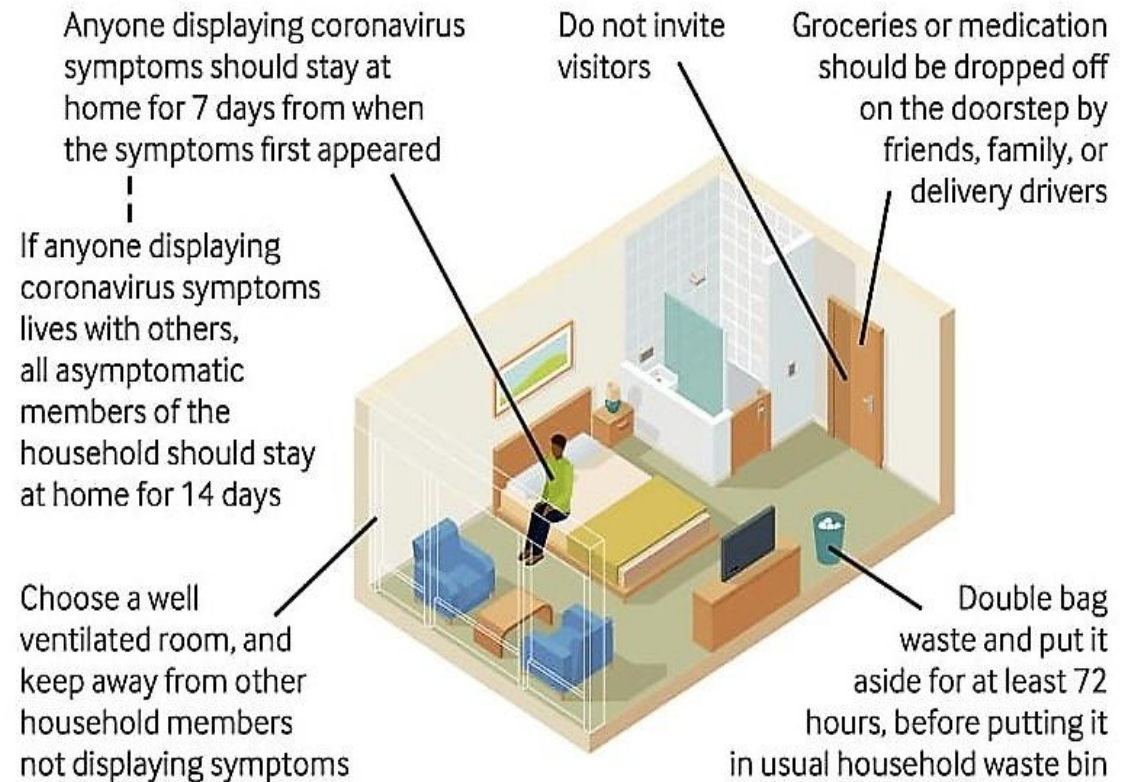
An ounce of prevention is worth a pound of cure

- Know how it spreads
- Wash your hands often
- Avoid close contact
- Cover your mouth and nose with a cloth face cover when around others
- Cover coughs and sneezes
- Clean and disinfect
 - <https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/prevention.html>

- WASH YOUR HANDS- “How many birthdays are there?”
- Personal Protective Equipment AKA PPE’s
 - Know when, how to use safely (‘don and doff’) and disposal
- PLANNING
- Physical Distancing (not social)
- Cleaning & Disinfectants
 - Know when, how to do safely disinfect often touched surfaces
- Use Technology to Stay Connected
- The most important test won’t involve swabs or temperature checks- Nancy Gibbs (Washington Post 5/3/2020)

Self isolation

Patients do not need to contact NHS 111 to go into self-isolation. If symptoms worsen during home isolation or are no better after 7 days, they should contact NHS 111 online. For a medical emergency, they should dial 999



UK government advice on self isolation is available at: <http://bit.ly/ukgovisol>

Physical and social distancing

- Physical and social distancing are terms that describe actions to stop or slow the spread of contagious diseases like COVID-19
- Distancing applies to day-to-day locations outside of your personal living space
- Distancing is best implemented by refraining from physical contact while remotely **maintaining (to the extent possible) the social connections** that help us thrive and stay healthy.
- Stay at least 6 feet apart from others when leaving your home for necessary activities.

- Clean frequently touched surfaces like doorknobs, light switches, countertops, and remote controls with disinfectant products or bleach to kill COVID-19 and other germs
- If someone needs to go to the HCP or ER, call first for instructions and guidance. A virtual visit may be possible.
- If you have been exposed to COVID-19, you could be asked to self-quarantine in your home. Make plans for childcare, caregiving, and deliveries of food or medicine. Stay away from others in the household. Do not share dishes, glasses, utensils.

Types of Personal Protection Equipment (PPE):

A barrier to protect the virus transmission

What kind is specific to the occupation and changes

- Gloves
- Face Masks
- Face Shields
- Gowns
- Goggles
- N95 Respirators, when appropriate

Mexican *lucha libre* wrestler Hijo del Soberano sews face masks since his matches have stopped due to the COVID-19 pandemic.



Keeping Healthy

Physically ++

- **Taking care of your self**
 - Healthy Living (Eating Well, Physical Activity, Sleep, Stress management, Laughter, a Dose of Outdoors)
 - **Routines**
 - **Planning** =a sense of control
 - Understand that some things are in and some things are not in your control
- **Taking care of those you support**
 - Same as above
- **BE KIND to others and to yourself.. .**

Mentally

- **Mental Well-being**
- *(Source: SHRM)*
- Routine (Maintain)
- Outdoors (Sun)
- Sleep (Rest)
- Technology (Advantage)
- News (Balance)
- Positivity (Try)
- Gratitude (Pause)

Disability COVID-19 Forms

Stony Brook University

<https://you.stonybrook.edu/disabilitycovid19forms/2020/04/08/preparing-individuals-with-intellectual-developmental-disabilities-for-medical-treatment-at-hospitals/>

COVID-19 DISABILITY FORM

Please answer the questions on this form to help physicians provide you with proper medical treatment, in case you need to go to the hospital for COVID-19 related symptoms. Complete as many of the questions as possible.

What is your name? _____	
Is this form being completed by someone else other than you? <input type="checkbox"/> yes <input type="checkbox"/> no	
<input type="checkbox"/> legal guardian <input type="checkbox"/> aide or staff member <input type="checkbox"/> family member <input type="checkbox"/> other	
If you checked yes, what is the person's name _____ Relationship to you _____	
Do you receive or have you received services from the Massachusetts Department of Developmental Services (DDS)?	
<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> I don't know	
***Note to doctors: This means there may be special laws in place to protect me and a special process needs to be followed if my usual decision maker/guardian requests to withhold or withdraw life sustaining treatment. Please check in with your institution's social worker or risk management department to be sure the appropriate process is being followed.	
How do you communicate best? (check all that apply)	Do you need anything to help you communicate? (E.g. assistive devices) <input type="checkbox"/> no
<input type="checkbox"/> Talking <input type="checkbox"/> Writing or typing things down	<input type="checkbox"/> yes (please describe) _____
<input type="checkbox"/> Pictures <input type="checkbox"/> Using sign language	Does anyone help you communicate? <input type="checkbox"/> no
<input type="checkbox"/> Pointing to words <input type="checkbox"/> Using a voice app	<input type="checkbox"/> yes, person's name _____
<input type="checkbox"/> I cannot communicate in a way you will understand, please ask my family, staff or guardian (circle the person)	Do you use any assistive devices for mobility? <input type="checkbox"/> no
<input type="checkbox"/> Other (please describe) _____	<input type="checkbox"/> yes list the device(s) _____
Do you have any triggers (e.g., being touched, trauma, doctors of a particular gender, noises, lighting, smells, textures): _____	What is your typical response to a medical exam?
What is your response to triggers? _____	<input type="checkbox"/> Fully/partially cooperates <input type="checkbox"/> Fearful
How can you best be helped when triggered? _____	<input type="checkbox"/> Aggressive <input type="checkbox"/> Resistant
	I like it when health professionals (please describe) _____
	I do not like it when health professionals (please describe) _____
Do you have any medical problems that you go to the doctor for? <input type="checkbox"/> yes <input type="checkbox"/> no	Please list the name of the doctor you would like contacted if you are at the hospital.
What are they? _____	Name _____
	Phone Number _____
Are there any diagnoses, medical problems or behaviors that we should consider as cautions? (e.g., aggression, biting, pica, aspiration risk): _____	Do you have seizures? <input type="checkbox"/> no
Are there any specific modifications that could help with these cautions? _____	<input type="checkbox"/> yes, list the type and frequency _____

Do you take any medication at home every day? <input type="checkbox"/> yes <input type="checkbox"/> no	Over the counter? <input type="checkbox"/> no
By prescription? <input type="checkbox"/> no	<input type="checkbox"/> yes, list the names and dosage _____
<input type="checkbox"/> yes, list the names and dosage _____	_____
_____	Do you have any allergies? <input type="checkbox"/> no
_____	<input type="checkbox"/> yes, please list _____

- My Health Passport Florida Center for Inclusive Communities [http://flfcic.fmhi.usf.edu/docs/FCIC Health Passport Form Typeable English.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf)
- About My Health -Surrey Place <https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/03/5.1-About-My-Health.pdf>

So, what about people with dementia?

- Many people with dementia need care and have problems with memory, thinking or behavior which can significantly complicate physical distancing and be challenging to ensure proper safety measures. (awareness of these risks)
- Difficult decisions about hospital admission and triage
- Weigh the benefits and risks of hospital admission since admission has associated risks
- COVID-19 is a new illness, so we know little

Changing Focus in I/DD Care

Before the diagnosis of dementia

- Learning new skills
- Independence and autonomy are valued and encouraged
- Behavior modification
- Providing choices, stimulation, and community outings –the more and varied, the better, Community membership !!!!
- Focus on “doing”

After the diagnosis of dementia

- Maintaining function and social interactions as much as possible
- “Hands-on” personal care
- Providing support and failure free activities, timing of activities
- Predictable, consistent routine, stabilizing environment
- Limiting choices
- Focusing on “feeling or being”

Source: Service, 2017

- **No data** providing evidence that people with dementia have **more severe COVID-19 symptoms** than others of similar age and health
- **Proactive and preventative strategies** by caregivers, so that out-of-home evaluation abrupt changes in usual baseline. Use of technology such as video- or tele-visits.
- With hospital admissions, **advocate for visitors !**
- **Triage decisions (dementia + ID)**
Duration of survival should NOT be “adjusted” based on presumptions regarding quality of life.
- The concern is that clinicians who are not trained in dementia care may underestimate – or even devalue – the quality of life of many persons with dementia.

Decisions. . Decisions. . .

What matters most to you matters to us.

<https://respectingchoices.org/covid-19-resources/#resources-for-individuals>

- **What is the most important for you to live well? If you were having a good day, what would happen?**
- **What personal, cultural, or spiritual beliefs, if any, do you have that would impact care?**
- **What would you want if you became very ill? For example: Would you want medical care to focus upon: Living longer, maintaining current health, comfort care?**
- **What worries you the most about the situation? What fears do you have?**
- **What else would you want us to know what is important at this time**

Decisions. . . Decisions. . .

- **Respecting Choices**
- <https://respectingchoices.org/covid-19-resources/>
- [Resources to have Planning Conversations in COVID-19](#)
[Tools to support specific treatment decisions](#)
[Resources for individuals](#)

The Conversation Project

<https://theconversationproject.org>

- <https://theconversationproject.org/wp-content/uploads/2020/04/tcpcovid19guide.pdf>

PRIORITIES FOR MEDICAL CARE

- **LIVING LONGER**

- • Live as long as possible, even if I do not know who I am or who I am with
- • Be in the hospital and receive all care my doctors think will help me, even if it means relying on machines to keep me alive

- **MAINTAINING CURRENT HEALTH**

- • Live longer, if quality of life and comfort can be achieved
- • Be in the hospital, if needed, for effective care
- • Stop treatment that does not work or makes me feel worse
- • Allow a natural death if my heart or breathing stops

- **COMFORT**

- • Live the rest of my life focusing on my comfort and quality of life
- • Avoid the hospital and being on machines
- • Allow a natural death if my heart or breathing stops

NICE recommends that the risks, benefits and possible likely outcomes of the different treatment options should be discussed with patients, families, and carers using decision support tools (where available) so that they can make informed decisions about their treatment wherever possible. (Source; BMJ)

<https://www.ficm.ac.uk/critical-futures-initiative/care-end-life>

- How will critical care treatments help the person in the short and long term?
- Could critical care treatments offer a quality of life that is acceptable to the person?
- Could critical care treatments help achieve a patient's goals for a good life?
- Are there non-critical care treatments that may help the person and be more comfortable for them?

Medications. . .

- Antibody-rich convalescent plasma is thought to give recipients' immune systems a running start
- **Evidence still lacking for prophylactic chloroquine, hydroxychloroquine in COVID-19; plus, CV issues**
- **FDA authorizes emergency use of remdesivir for COVID-19**

Just a few more resources

- <https://adsresources.advocatehealth.com>
- <http://radiant.nhs.uk/coronavirus-covid-19.html>
- Social Care Institute for Excellence.
<https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/carers-family>



Alison Shepherd BMJ 2020;369:bmj.m1699



So what (who) really matters. . .

