

Preparing for a potential coronavirus infection in dementia: What are the odds and what are the options?

Family Caregiver Webinar Series –Coping with Dementia Care During the Coronavirus Pandemic

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The Summer Day

Who made the world?
Who made the swan, and the black bear?
Who made the grasshopper?
This grasshopper, I mean—
the one who has flung herself out of the grass,
the one who is eating sugar out of my hand,
who is moving her jaws back and forth instead of up and down—
who is gazing around with her enormous and complicated eyes.
Now she lifts her pale forearms and thoroughly washes her face.
Now she snaps her wings open, and floats away.
I don't know exactly what a prayer is.
I do know how to pay attention, how to fall down
into the grass, how to kneel down in the grass,
how to be idle and blessed, how to stroll through the fields,
which is what I have been doing all day.
Tell me, what else should I have done?
Doesn't everything die at last, and too soon?
Tell me, what is it you plan to do
with your one wild and precious life?

- Mary Oliver

Checking in

Today's Goal

Have a conversation about COVID-19 and consider a framework for how to prepare and think about medical decision making

We will discuss

1. What is the current situation of COVID-19?

Goal: Identify at least 3 ways COVID-19 has impacted older adults

1. How might you think about your medical options if you or your loved one get diagnosed?

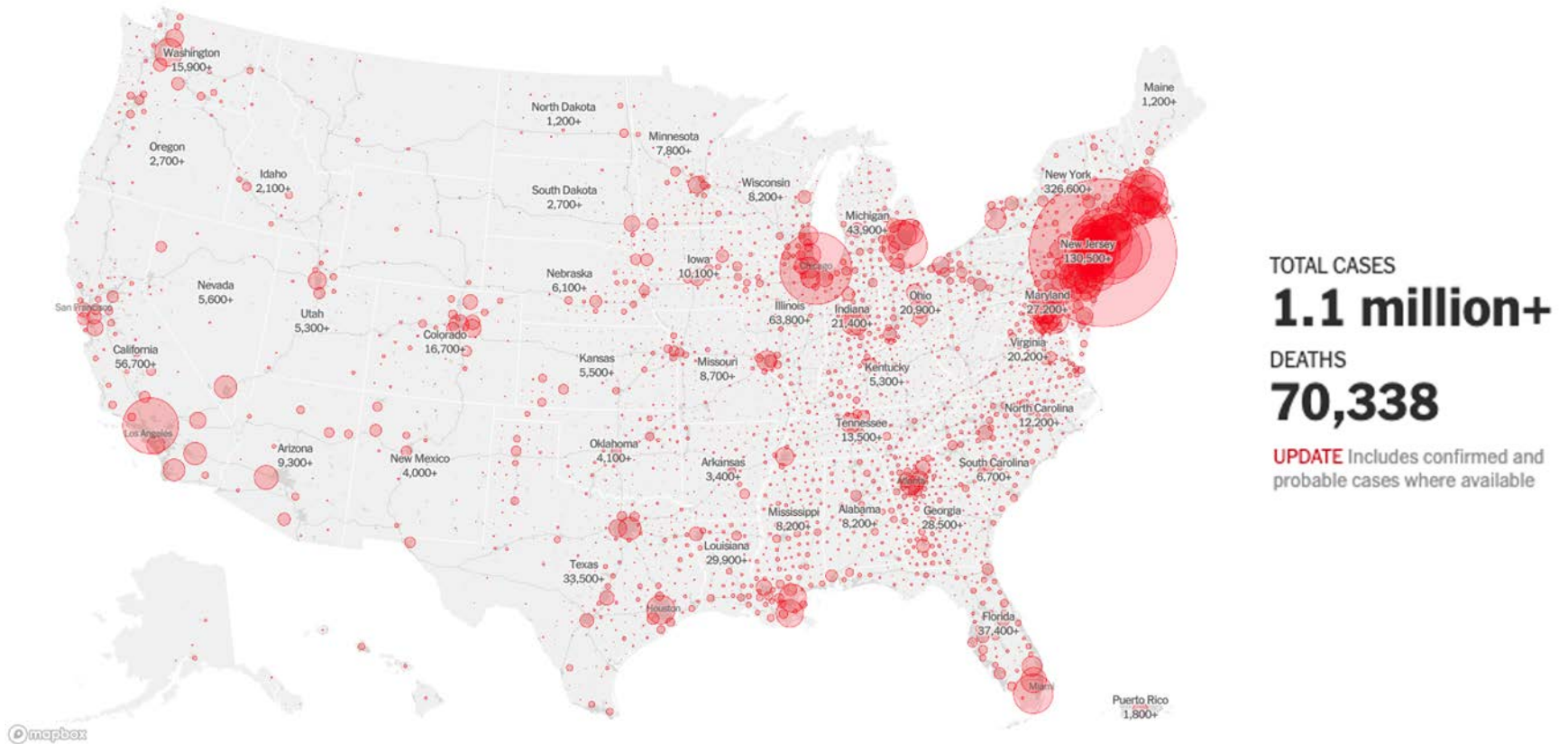
Goal: Understand at least 2 options for medical care or support

1. What can you do to prepare?

Goal: Apply tips for important conversations, preparation and documentation

The current situation of COVID-19

Coronavirus in the United States



Source: "Coronavirus in the United States." *New York Times*. Accessed: 5-5-2020

Coronavirus in the Bay Area



Coronavirus in Bay Area Facilities

Cases:

- 6 of 19 nursing home facilities in San Francisco with COVID positive residents (as of April 30th)
- Likely higher numbers in Assisted Living Facilities

Unique challenges for memory care units:

- Open units, wandering residents

Nursing Home Policies:

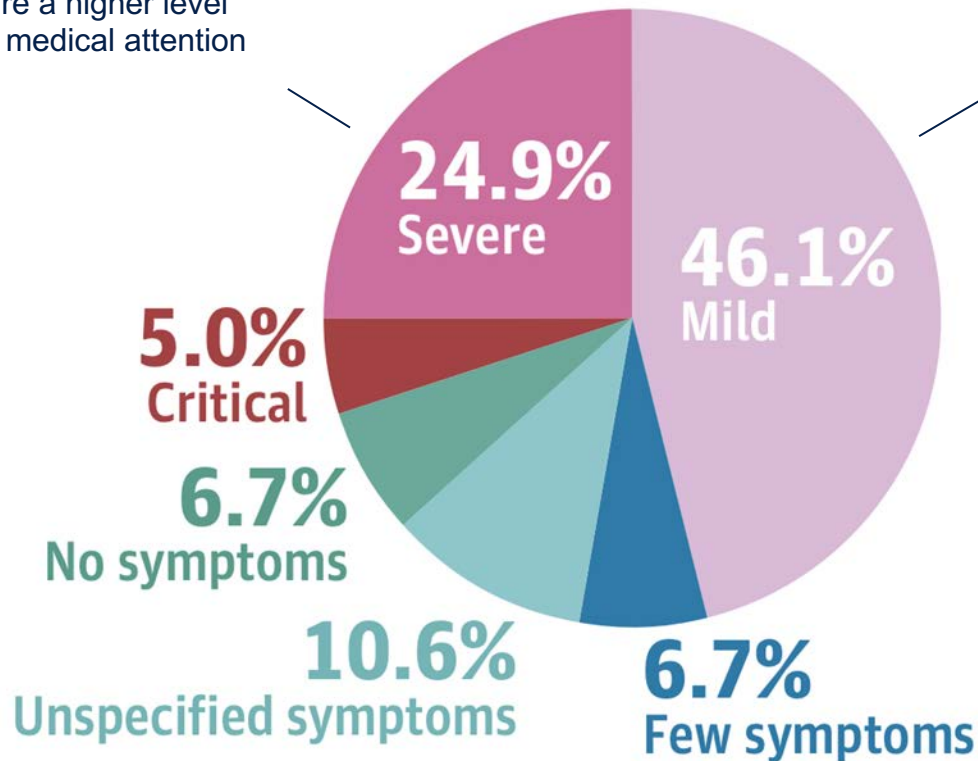
- March 16th: Restrictions on visitor policies
- May 1st: Universal testing of staff and residents every 2 weeks

How severe is COVID-19?

Cases by severity

May require a higher level of care or medical attention

Mild cases mean someone can be managed or observed at home or in their current setting.



Who is at highest risk of severe case of COVID-19?

Older Age (e.g., > 65 years)

Lung disease

Heart disease

Diabetes

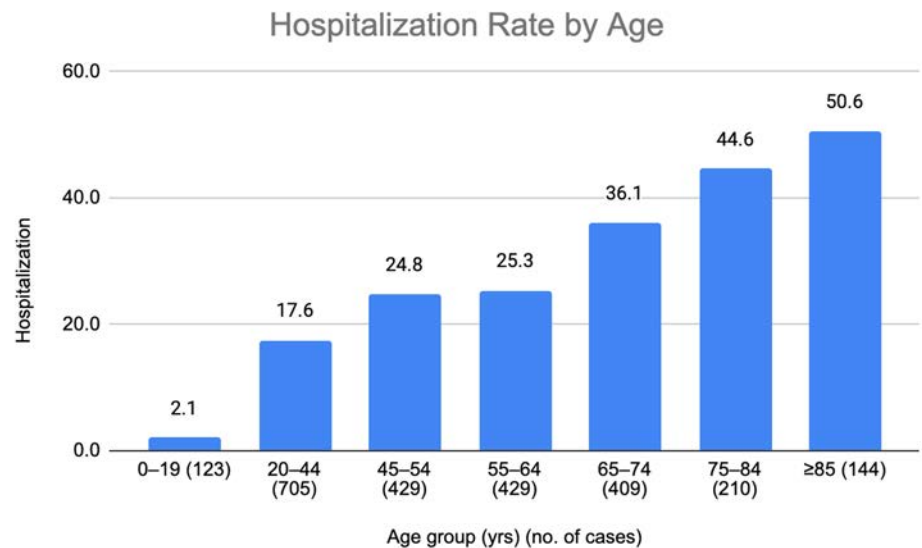
Obesity

Immunocompromised

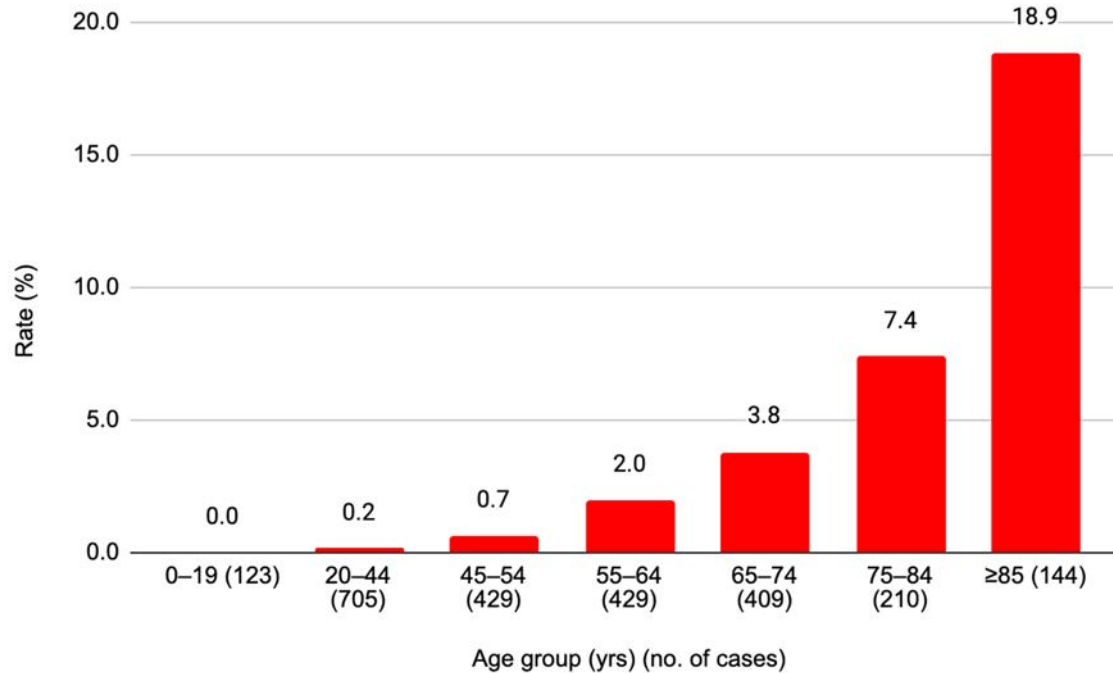
Severe Kidney Disease

Liver disease

Nursing home Residents



What are the chances of death?



How might you think about your medical options if you or your loved ones get diagnosed?

What is Advance Care Planning?

Making decisions for the health care that you or a loved one would want if you become unable to speak for yourself or for situations requiring urgent decision making

The decisions are based on personal values, preferences, and discussions

Advance Care Planning can help align treatment options with values and preferences and avoid making medical decisions under duress

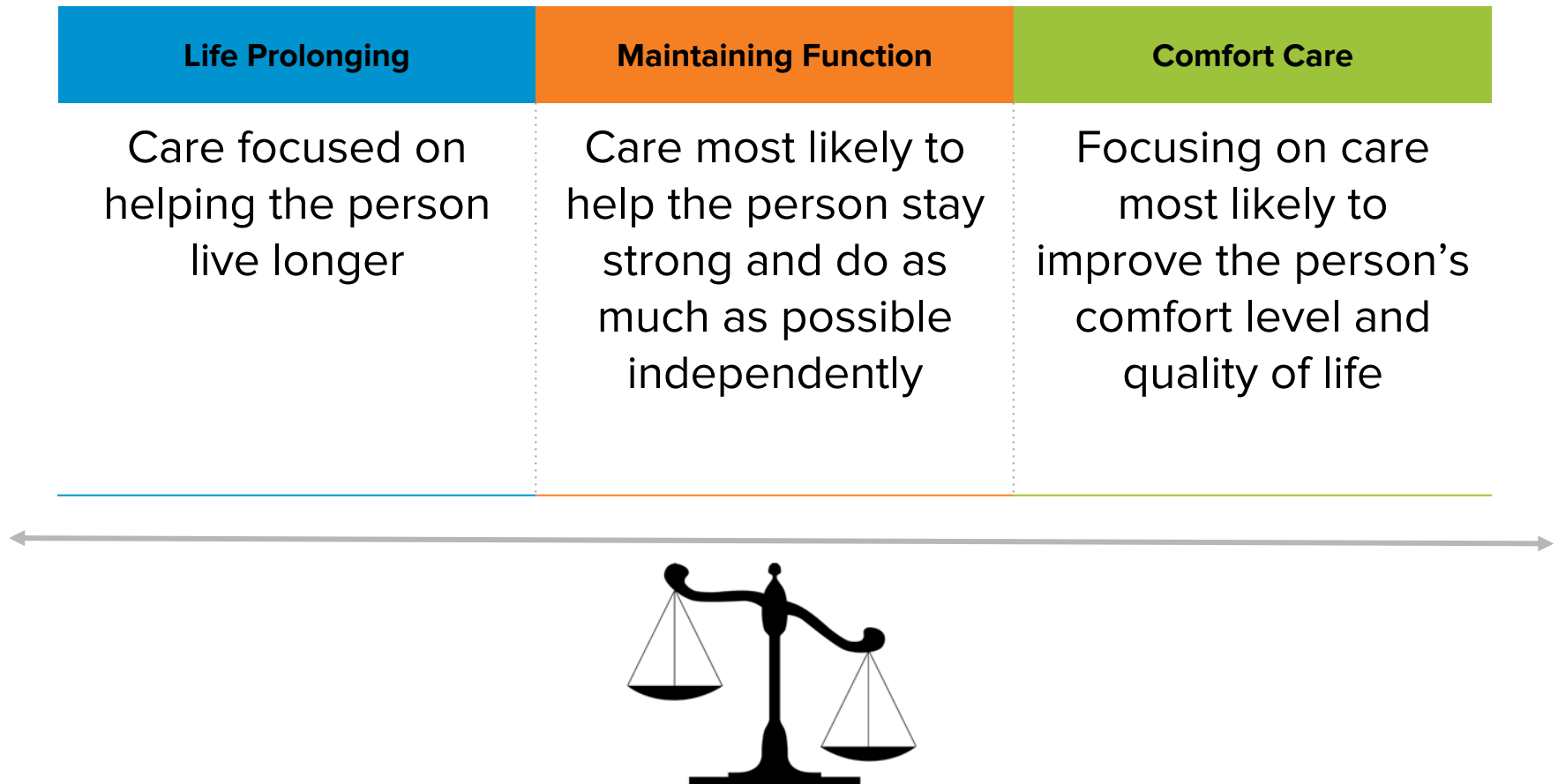
Advance Care Planning during COVID-19

People can become sick quickly which can require urgent decision making

Loved ones including decision makers are not able to visit the ER or the hospital

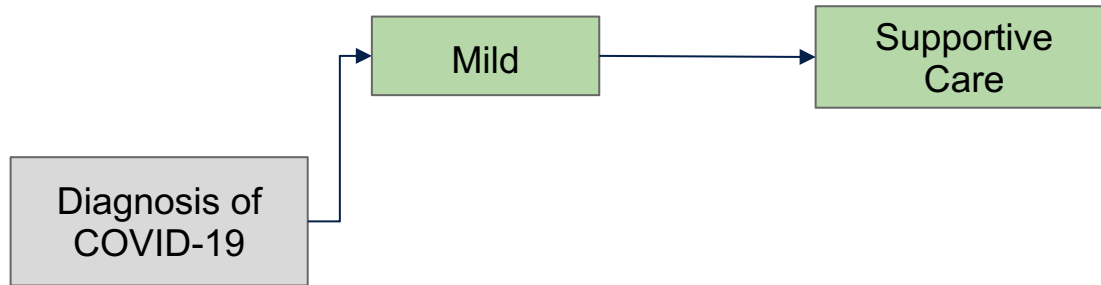
Healthcare workers are desperate to know information about patients, especially their wishes

Framework for Advanced Care Planning



Aligning Personal Treatment **P**references with COVID-19 Treatment **O**ptions

Treatment Pathway



“Mild” Cases

50% of older adults who get COVID-19 have mild cases.

Common symptoms:

Fevers, lethargic, body aches,
headache, cough

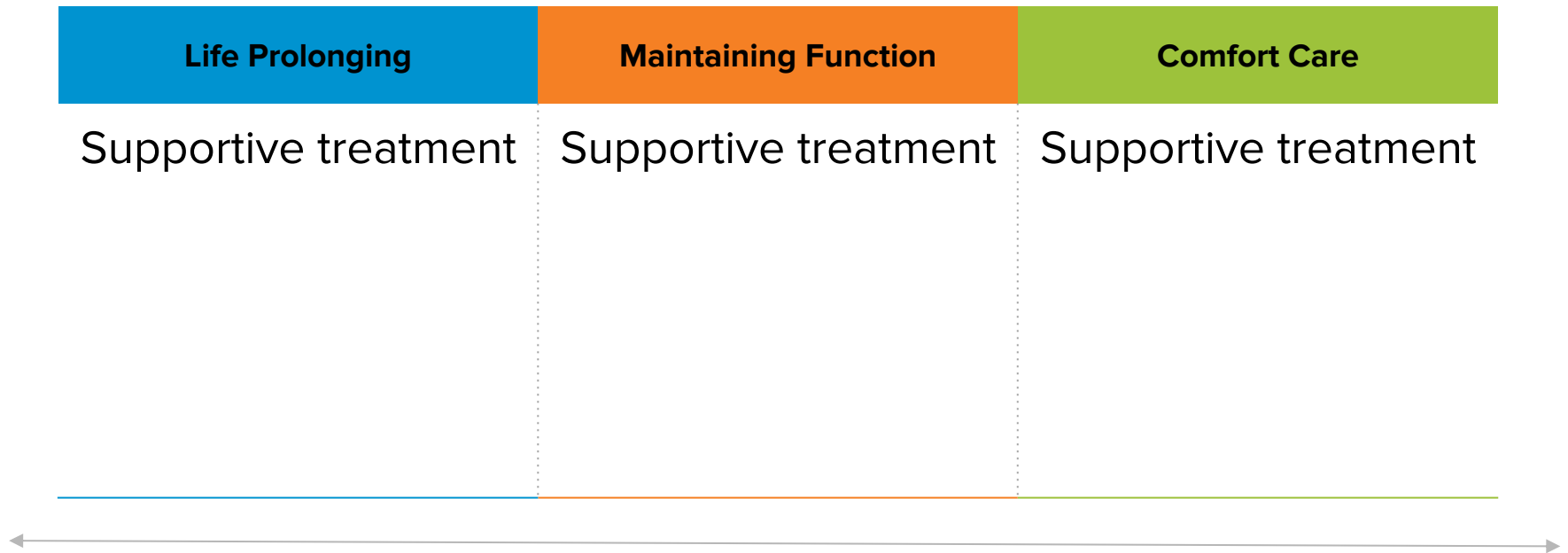
Treatment:

Supportive treatment at home or
care facility with frequent check-
ins

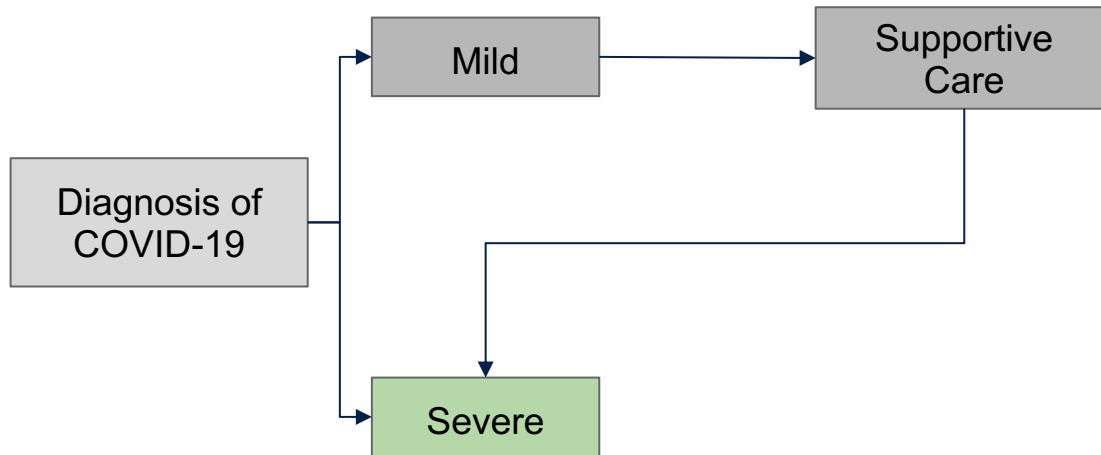
Persons with Dementia:

Confusion or delirium
Decreased abilities
Falls

Treatment For “Mild” Cases



Treatment Pathway



“Severe” Cases

Up to 50% of older adults who get COVID-19 have severe cases.

Common symptoms:

Fever, cough, lethargy, body aches, headaches

+ altered mental status, low oxygen, difficulty breathing, low blood pressure, or other concerning signs

Two patterns:

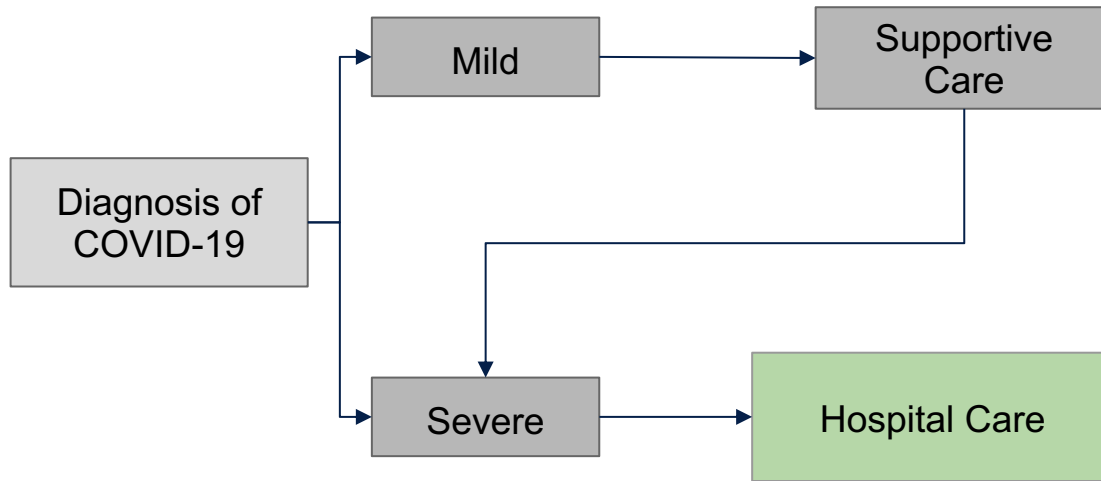
1. Sudden severe illness
2. Severe illness after 7-10 days of mild illness

Treatment:

Depends on Goals of Care

1. Hospital Care
 - may require decisions about ICU level care
1. Comfort care +/- Hospice Services

Treatment Pathway



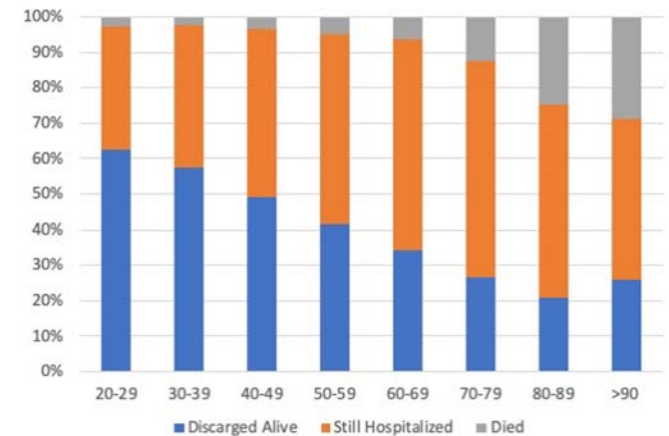
Hospital Care

- Can be used to evaluate or stabilize medical conditions, or provide treatment to prolong life
- Treatments include antibiotics, oxygen therapy, closer monitoring, and intensive care
- Considerations during COVID-19
 - Limited Visitor Policies: exceptions for certain caregivers, urgent legal issues, or being in the last 48 hours of life
 - Residents of care facilities may not be able to return quickly due to the risk of exposing other residents to the virus

Hospital Care and COVID-19

Among all hospitalized patients in a New York Health System, among adults > 70 years old:

- **20-25%** were sent home
- **45-70%** are still hospitalized
- **10-30%** of individuals over 70 years old died



Hospital Care For “Severe” Cases

Life Prolonging

Consider going to the hospital and utilizing therapies that the medical team believes will help

Maintaining Function

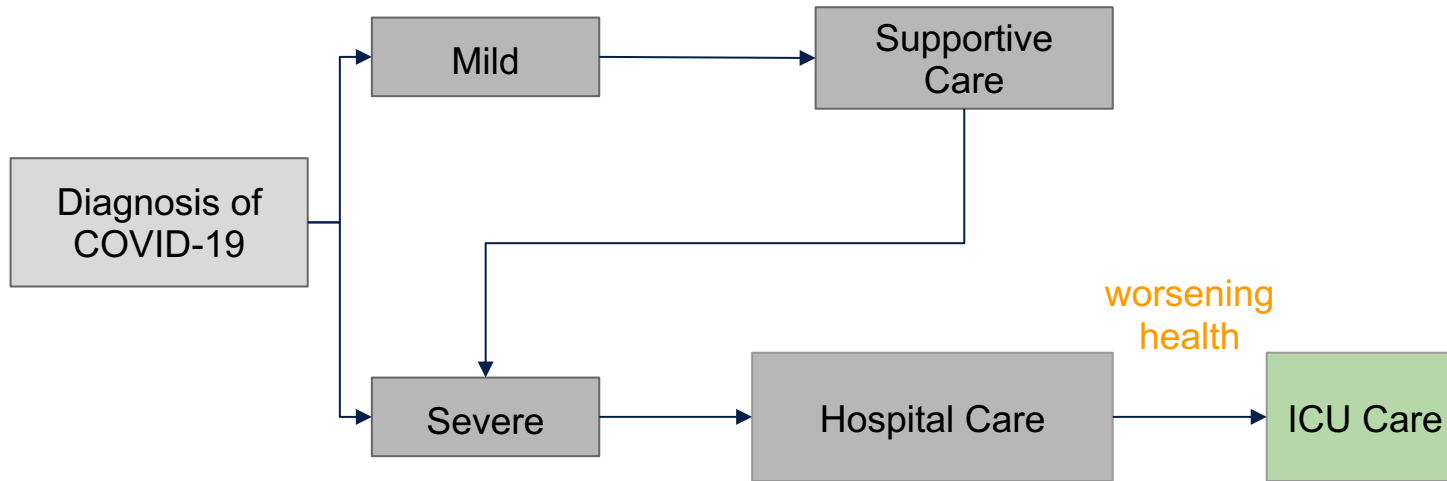
Consider the hospital for selective treatments such as antibiotics, IV fluids, oxygen therapy

Comfort Care

Avoid the hospital.
Pursue comfort care at home or facility



Treatment Pathway



Hospital - Intensive Care Unit

What ICUs provide:

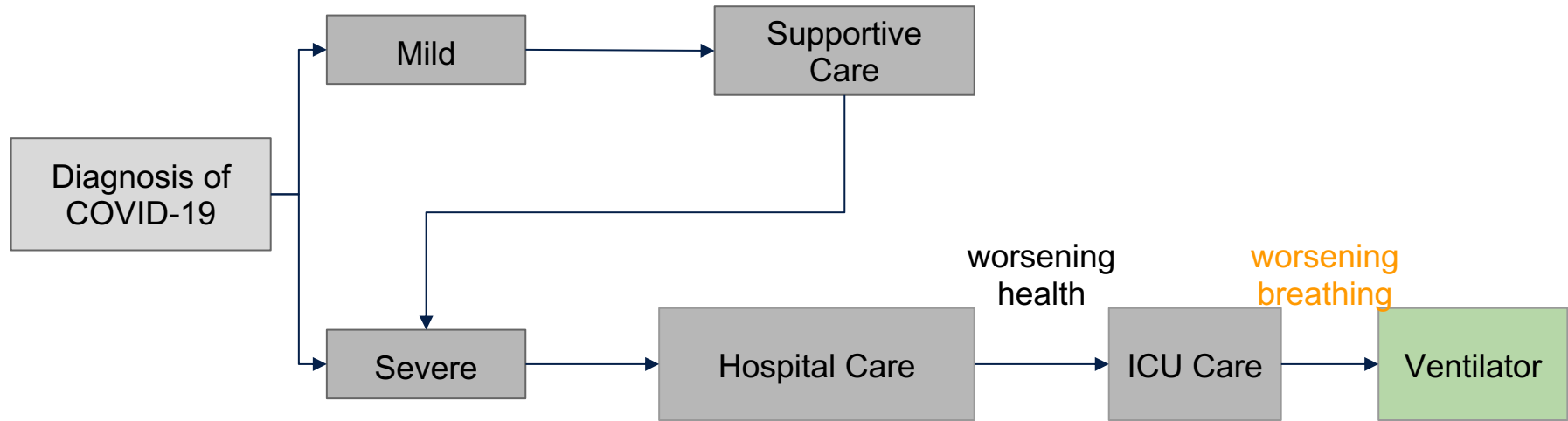
- Closer monitoring
- Life supporting medications
- Ventilators for breathing



Harms:

- Can be uncomfortable
- Medical complications: infections, ventilators can be traumatic, development of delirium
- Even if one survives people can be severely debilitated
- Most do not survive
 - 7 in 10 older adults die in the ICU due to COVID-19

Treatment Pathway

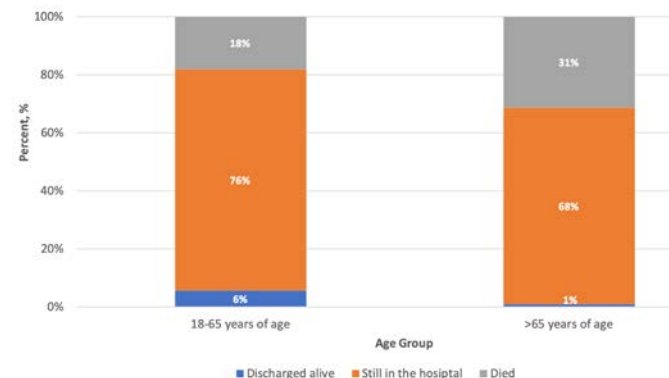


Ventilators and COVID-19

Individuals are typically on ventilators for **more than 7 days**.

In a New York Health System, among adults >65 years old on a ventilator:

- **1%** have been sent home alive
- **31%** have died
- **68%** still in the hospital



ICU Care For “Severe” Cases

Life Prolonging	Maintaining Function	Comfort Care
Consider going to the ICU and utilizing therapies that the medical team believes will help	Avoid certain ICU therapies like being on a ventilator. Focus on comfort care if available treatments cannot maintain function	Avoid the ICU Consider hospice



“Severe” Cases

50% of older adults who get COVID-19 have severe cases.

Common symptoms:

Fever, cough, lethargy, body aches, headaches

+ altered mental status, low oxygen, difficulty breathing, low blood pressure, or other concerning signs

Two patterns:

1. Sudden severe illness
2. Severe illness after 7-10 days of mild illness

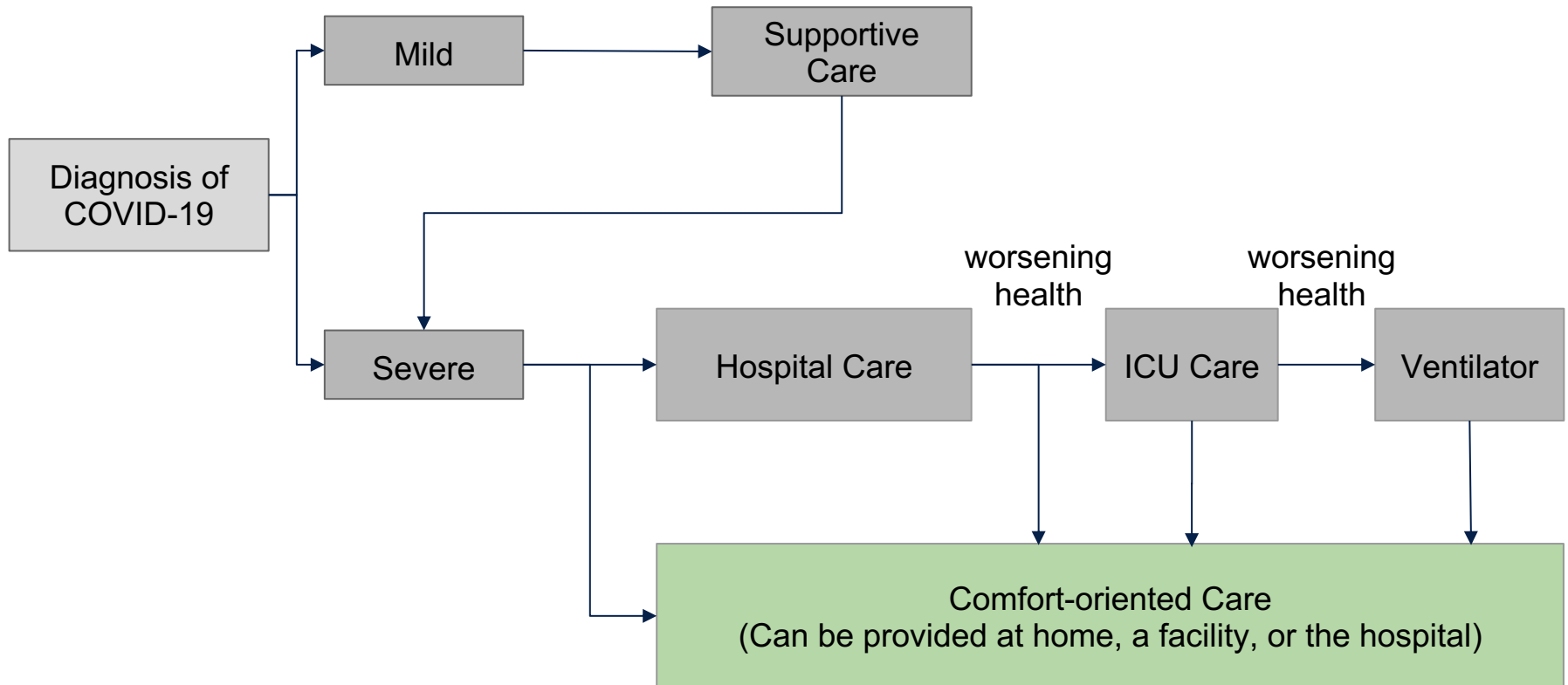
Treatment:

Depends on Goals of Care

1. Hospital Care
 - may require decisions about ICU level care

1. Comfort Care +/- Hospice Services

Treatment Pathway



Comfort Care & Hospice

- **Comfort-oriented Care:** Treatment of difficulty breathing, fevers, or other uncomfortable symptoms
- **Hospice Care:** Comprehensive care for individuals in the last days, weeks, or months of life.

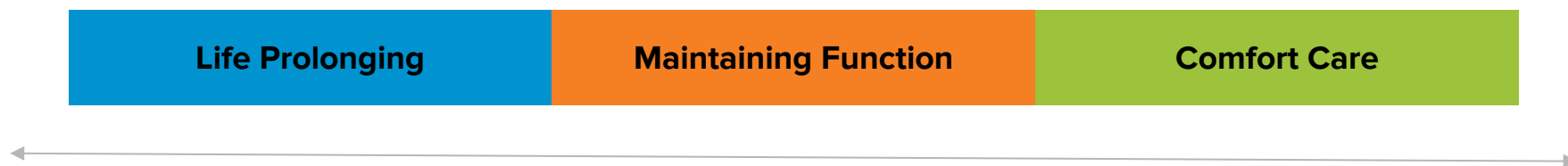
What they do:

- Hospice teams include the medical director (MD), NPs, RNs, social work, chaplains, and volunteers
- Hospice agencies visit the home or living facility
- 24/7 phone assistance, in-person visits vary

During COVID-19:

- Hospice agencies are enrolling patients who have COVID-19 to help optimize comfort, support families, and address symptoms
- Utilizing telemedicine and dedicated teams

Quality of Life and Comfort



Key point: While there are tradeoffs, there are always ways to care for you or a loved one and ease suffering from illness.

Palliative care teams can help assist in improving quality of life and talking through what is important at any stage in serious illness.

How about Cardiopulmonary Resuscitation (CPR)?

This involves firm chest compressions administered when a person's heart and breathing stop.

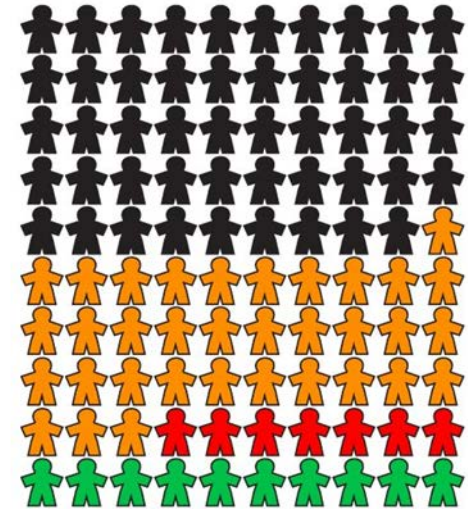
- Goal is to restart cardiopulmonary function
- Medical orders include “Full Code” or “Do Not Resuscitate (DNR)”

Benefits:





- May prolong life in 1 of 10 older adults

Harms:

- Survivors almost always have brain damage
- Broken ribs and organ damage
- Requires Intubation and ICU care



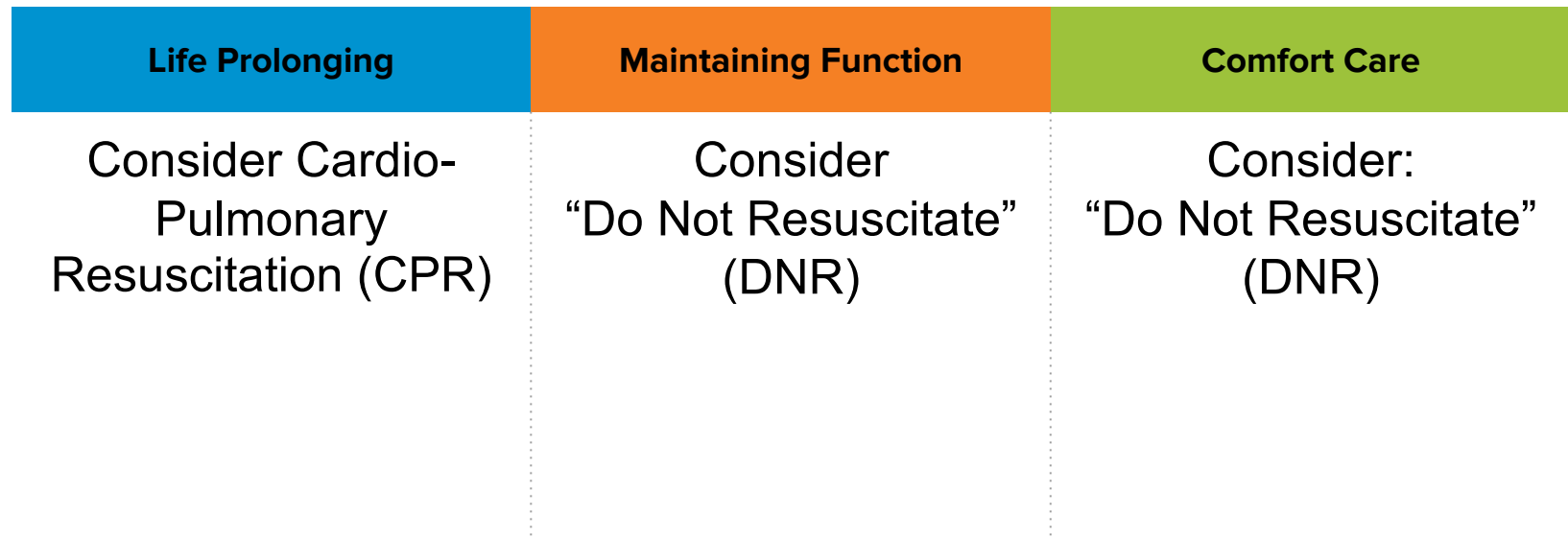
Among “elderly patients who undergo resuscitation after in-hospital cardiac arrest”, at one year:

-  49 died during resuscitation²
-  34 died before hospital discharge²
-  7 died after hospital discharge¹
-  10 are alive¹

CPR during COVID-19

2 in 100 adults over 60 years old survive for 30 days if they require CPR.

Cardiopulmonary Resuscitation (CPR)



What can you do to prepare?

1. Reflect

What brings me or my loved one joy? What makes life worth living?

What would be important to me or my loved one if seriously ill or near the end of life?

What quality of life would be unacceptable?

Uncertainty is expected



2. Talk to your doctor and loved ones

Need to know your health status
before anything else

Don't be afraid to ask your doctor the
tough questions

Consider involving important family
members before, during or after this
conversation

Resource: theconversationproject.org



3. Choose a Health Care Proxy or DPOA

A good decision maker...

Knows they are your DPOA
(Designated Power of
Attorney)

Is available and easy to reach

Knows your values

Can make decisions on your
behalf



4a. Write it down: Advance Directive

A written document that tells us how you want to be treated

Everyone over the age of 18

Signed by two witnesses or notary

California Advance Health Care Directive


This form lets you have a say about how you want to be cared for if you cannot speak for yourself.

This form has 3 parts:

Part 1 Choose a medical decision maker, Page 3
A medical decision maker is a person who can make health care decisions for you if you are not able to make them yourself. This person will be your advocate. They are also called a health care agent, proxy, or surrogate.

Part 2 Make your own health care choices, Page 7
This form lets you choose the kind of health care you want. This way, those who care for you will not have to guess what you want if you are not able to tell them yourself.

Part 3 Sign the form, Page 13
The form must be signed before it can be used.



Source: www.prepareforyourcare.org

4b. Write it down: POLST

Physician Orders for Life Sustaining Treatment (POLST)

Those who have a serious health condition at risk of medical crisis

Resuscitation, medical interventions, artificial nutrition

Filled out with your doctor

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, then contact physician. This is a Physician Order Sheet based on the person's current medical condition and wishes. Any section not completed implies full treatment for that section. A copy of the signed POLST form is legal and valid. POLST complements an Advance Directive and is not intended to replace that document. Everyone shall be treated with dignity and respect.

EMSA #111 B (Effective 6/1/2011)

EMSA #111 B (Effective 6/1/2011)

Patient Last Name: _____ Date Form Prepared: _____

Patient First Name: _____ Patient Date of Birth: _____

Patient Middle Name: _____ Medical Record #: (optional) _____

A CARDIOPULMONARY RESUSCITATION (CPR): *If person has no pulse and is not breathing. When NOT in cardiopulmonary arrest, follow orders in Sections B and C.*

Check One

Attempt Resuscitation/CPR (Selecting CPR in Section A requires selecting Full Treatment in Section B)

Do Not Attempt Resuscitation/DNR (Allow Natural Death)

B MEDICAL INTERVENTIONS: *If person has pulse and/or is breathing.*

Check One

Comfort Measures Only Relieve pain and suffering through the use of medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. *Transfer to hospital only if comfort needs cannot be met in current location.*

Limited Additional Interventions In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.

Full Treatment In addition to care described in Comfort Measures Only and Limited Additional Interventions, use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/ cardioversion as indicated. *Transfer to hospital if indicated. Includes intensive care.*

Additional Orders: _____

C ARTIFICIALLY ADMINISTERED NUTRITION: *Offer food by mouth if feasible and desired.*

Check One

No artificial means of nutrition, including feeding tubes. Additional Orders: _____

Trial period of artificial nutrition, including feeding tubes. _____

Long-term artificial nutrition, including feeding tubes. _____

D INFORMATION AND SIGNATURES:

Discussed with: Patient (Patient Has Capacity) Legally Recognized Decisionmaker

Advance Directive dated _____ available and reviewed → Health Care Agent if named in Advance Directive: _____

Advance Directive not available Name: _____

No Advance Directive Phone: _____

Signature of Physician

My signature below indicates to the best of my knowledge that these orders are consistent with the person's medical condition and preferences.

Print Physician Name: _____ Physician Phone Number: _____ Physician License Number: _____

Physician Signature: (required) _____ Date: _____

Signature of Patient or Legally Recognized Decisionmaker

By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known wishes of, and with the best interest of, the individual who is the subject of the form.

Print Name: _____ Relationship: (circle self if patient) _____

Signature: (required) _____ Date: _____

Address: _____ Daytime Phone Number: _____ Evening Phone Number: _____

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Example 1:

Mr. Jones is 78 years old, he has no diagnosed medical conditions and is physically active. His spouse, Ms. Jones, has dementia and he is her primary caregiver. He has never filled out an advance directive before, and has been reading a lot about the coronavirus.

He thinks about his values, talks with his family, and medical team.

He completes an advance directive and chooses a DPOA as his close friend. He also works with his medical team to establish the DPOA of his spouse.

Life Prolonging	Maintaining Function	Comfort Care
He is open to hospitalization	He wants selective treatment in the ICU and to avoid a ventilator	In the case of COVID-19, he would like to be DNR

Example 2:

Ms. Lee is a 84 year old nursing home resident with moderate Alzheimer's Disease. She is frequently found humming songs and enjoys spending time with grandchildren. Her daughter, Helen, has been thinking about coronavirus, especially since she was told by the facility that a healthcare worker there recently tested positive. They talk with their doctor.

They completes an advance directive and a POLST form. They indicate:

Life Prolonging	Maintaining Function	Comfort Care
No hospitalizations or ICU treatments	Provide supportive treatments in the nursing facility, including antibiotics and oxygen, but prioritize comfort.	She would like to be DNR.

Example 3:

Ms. Smith is a 82 year old with high blood pressure and was recently diagnosed with mild cognitive impairment. She lives alone and is active in her community and her extended family. She considers her values and preferences, and thinks them through with her doctor.

She completes an advance directive naming a friend as a DPOA and speaks to this person about her wishes.

Life Prolonging	Maintaining Function	Comfort Care
She would like to be hospitalized if necessary. She would like a trial of ICU treatments that her medical team deems might be helpful. She would like to be Full Code.		

Key Takeaways

1. Older adults are at higher risk of severe cases of COVID-19.
2. Consider planning ahead so your preferences are aligned with available treatment options.
3. We discussed simple steps you can take today to have conversations & document your wishes.

Thank you!

Acknowledgements:

Susan Hickman, PhD

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Eric Widera, MD

Many others...

Please write your questions in the Q&A box at the bottom of your Zoom screen, and share any tips and strategies that have worked for you and your loved one.



University of California
San Francisco

A recording of this webinar can be found on our
website:

<https://memory.ucsf.edu/covid>

Thank you!



University of California
San Francisco

<https://onlinelibrary.wiley.com/doi/epdf/10.1111/jgs.16520>

<https://onlinelibrary.wiley.com/doi/epdf/10.1111/jgs.16507>

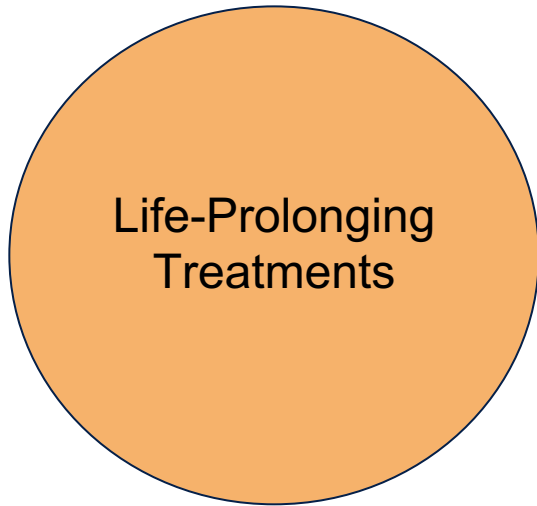
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<https://onlinelibrary.wiley.com/doi/10.1111/jgs.16482>

<https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2764748>

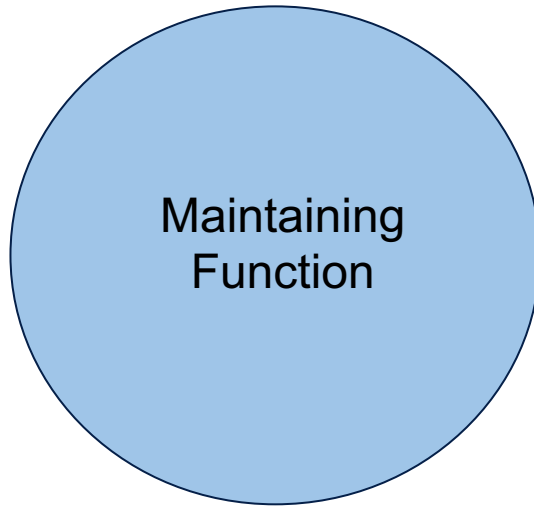
Appendix

“Mild” Cases



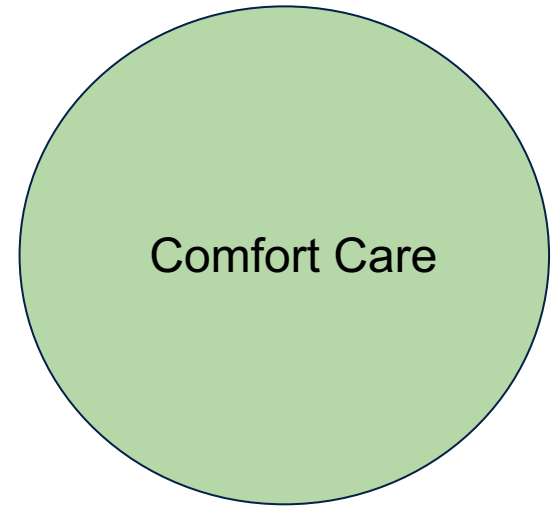
Life-Prolonging
Treatments

Supportive
treatment



Maintaining
Function

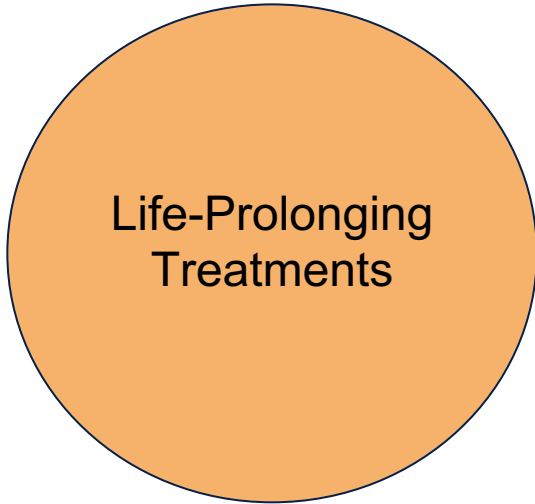
Supportive
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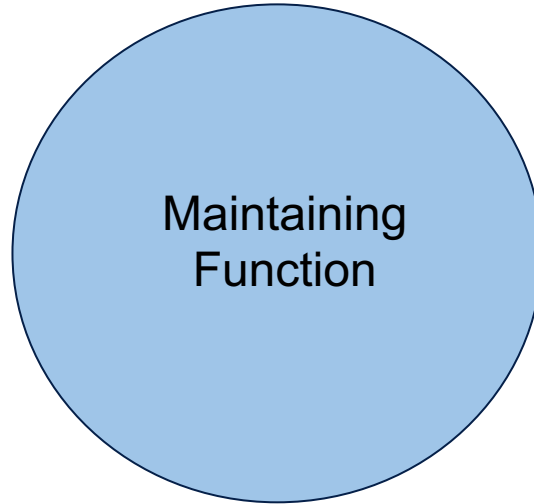
Comfort Care

Supportive
treatment

“Severe” Cases

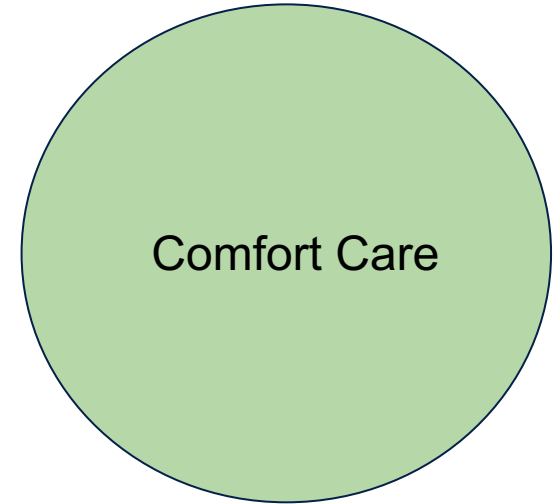


Consider utilizing ICU therapies that the medical team believes will help



Avoid certain ICU therapies like being on a ventilator.

Focus on comfort care if available treatments cannot maintain function



Avoid the ICU.
Consider hospice

“Severe” Cases

Severe or Critical Illness
(50%)



Common symptoms:

Fever, cough, lethargy, body aches, headaches

+ altered mental status, low oxygen, difficulty breathing, low blood pressure, or other concerning signs

Treatment:

Depends on Goals of Care

1. Hospitalization
2. **Comfort-oriented care +/- Hospice Services**

Cardiopulmonary Resuscitation (CPR)



Life-Prolonging
Treatments

Consider Cardio-
Pulmonary
Resuscitation (CPR)



Maintaining
Function

Consider
“Do Not Resuscitate”
(DNR)



Comfort Care

Consider:
“Do Not Resuscitate”
(DNR)

Example 2

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