

Planning Steps for Patients & Families During the COVID-19 Crisis

The global Coronavirus (COVID-19) pandemic presents new challenges for individuals, families, health professionals and health systems. Realities of the COVID-19 illness experience, particularly in circumstances where symptoms become severe enough for potential hospitalization, underscore the importance of thinking and talking about the care you want *before* any such hospital care may happen. Here, National Patient Advocate Foundation (NPAF) partnered with palliative care experts to develop this guide.

We are all in this together. You can do your part by making a plan. This plan can help you, your family, friends, and your medical providers

Medications

- Make a list of your medications and keep it on hand
- Look ahead and contact your clinic, hospital or pharmacy if you need a refill
- Call your pharmacy to see if your medicines can be sent to your home

Your Money and Bills

- Choose someone you trust who could help with your money and bills if needed
- Beware of scams. Do not give strangers information about your money
- If you get Social Security, your money will still come. To learn more, visit www.ssa.gov/coronavirus/
- Patient Advocate Foundation can assist you in finding resources to help decrease the financial burden of medical treatment. To learn more, visit <https://www.patientadvocate.org>

Your Pets

- Choose someone who could take care of your pets if needed
- Call your pet store as they may deliver pet food and supplies to your home, or you could use an online ordering service (e.g., Chewy.com)

Your Medical Care Plan: Three Action Steps

1. Choose a medical decision maker

- This person will speak for you if you cannot speak for yourself because of your condition. If able, choose a back-up medical decision maker.
 - They can make sure your doctors know about the care you want
 - Keep their phone numbers on hand
- A good medical decision maker is someone who:
 - Can talk to the doctors for you in person or by phone and knows your wishes about what is best for you
 - You trust to follow your wishes about the care you want and may not want
- Let your medical decision maker know they were chosen
 - This website can show you how: prepareforyourcare.org

2. Share Your Wishes About the Care You Want

- Think about what is most important in your life? Family, pets, hobbies, etc.?
- If you know what you want for your medical care, share this now
- Talk with your family, friends, and medical providers about the care you want
 - This website can show you how: prepareforyourcare.org
- You can share what care you want by phone and/or a selfie video. You can also talk to others by video call: <https://zoom.us/> or Facetime

3. Consider an advance directive

- This form allows you to name your decision maker and write down what you want for your medical care as guidance if you cannot speak for yourself because of your condition.
- If you have an advance directive, find it, review it, and share it
- To get a form go here: <https://prepareforyourcare.org/advance-directive>
 - It is OK if you can't sign it or get witnesses right now
 - Reading it can still help you learn a lot about what care you want
 - Filling out parts can still help your family and providers know more about the care you want and may not want
- You can scan/fax (the most secure), email, or even send pictures of the form from your cell phone to those you trust

Hospital Stay

Unlike usual circumstances, the COVID-19 crisis in hospitals often means that family and friends likely may not be able to visit. Bring what you may need from home.

- **Papers and information:**
 - Write down phone numbers for your key contacts to give your medical providers, including the person(s) you designate as your medical decision maker(s) (step 2 above)
 - List of your medications (or bring the pill bottles)
 - Your advance directive or medical wishes information (step 3 above)
 - Plans for your pets or bills while you are away
- **Equipment:**
 - **Phone, tablet and/or computer and their chargers.** This can help you stay connected to family and friends if visitors are not permitted in the hospital.
 - If you use glasses, hearing aids, dentures or other such items, plan to bring them with you. These are often lost in hospitals, so keep watch over them.
 - Ear plugs, sleep masks, books, or clothes you want from home

Links to patient and family COVID-19 information and resources are provided on the next page

COVID-19 planning in the midst of this national care crisis may be quite different from what patients and families are used to. Here are some of the unfamiliar circumstances that many individuals and families have been experiencing as part of this pandemic:

- You may not be able to talk to your regular doctor in person, only by phone
- Many people are getting very sick and going to the hospital
- If you need to go to the hospital:
 - Your family may not be allowed to visit you
 - You may be taken to a different hospital than where you usually get your care
- Some people with COVID-19 may get so sick they need a breathing machine (ventilator), possibly for many weeks in the ICU
 - They cannot talk when on the machine
 - Even with a breathing machine, many people will not survive
 - For people who survive, their health, physical function and quality of life may never be the same as it was before the illness happened

Links to More Information and Resources

CDC Resources on Coronavirus (COVID-19)

- Home Page: <https://www.cdc.gov/coronavirus/2019-ncov/index.html>
- How to Protect Yourself: <https://www.cdc.gov/coronavirus/2019-ncov/prepare/prevention.html>
- What to Do if You Are Sick: <https://www.cdc.gov/coronavirus/2019-ncov/if-you-are-sick/steps-when-sick.html>
- Symptoms: <https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html>
- Are You At Higher Risk for Severe Illness?: <https://www.cdc.gov/coronavirus/2019-ncov/specific-groups/high-risk-complications.html>
- How to Prepare: <https://www.cdc.gov/coronavirus/2019-ncov/prepare/index.html>

Family Conversation Support Tools: Determining the Care You Want

- PREPARE for your care step by step program with videos: <https://prepareforyourcare.org/welcome>
- *Hello* conversation game from Common Practice: <https://commonpractice.com>
- Respecting Choices COVID-19 Resources: <https://respectingchoices.org/covid-19-resources/>
- Can We Talk About What Matters to Me? Tip sheet from National Patient Advocate Foundation: <https://www.npaf.org/can-we-talk/>

Additional Support Tools:

- [National Patient Advocate Foundation COVID-19 Action Center](#) – Advocacy and Policy Information
- [Patient Advocate Foundation](#) resources and services to guide patients and families through complex health care challenges
- [Staying Calm and Strong in the Shadow of COVID-19](#) - Courageous Parents Network Video