CAN WE TALK ABOUT CARE PLANNING?

A Guide to Starting Your Care Plan

Care plans allow you to identify and share everything that you need for a better, quality health care experience. Your doctors and care team need to know what's the matter with you, but more importantly, they need to know what matters to you.

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YOUR CARE PLAN

Putting together a care plan is empowering because it allows you to always have a say in your health care. Care planning involves communicating the care you want to your loved ones and health care team. This guide is designed to help you gather your thoughts on the priorities and concerns you have about your health and well-being to ensure that the care you receive is based on what matters to you.

Communicating what matters to you is the foundation to receiving person-centered care. That means that you are treated as a person with goals and fears, and not simply as a patient experiencing symptoms. Your care plan should include personal details about what is important to you, whether you are healthy or sick, 17 or 75. Those details are particularly useful if you are unexpectedly hospitalized or diagnosed with a complex or chronic condition.

There are different levels to care planning. It can be as basic as making sure you have what you need to take care of yourself—such as having health insurance and knowing where to get support if you get sick. Care planning can also involve steps to make sure others have what they need to take care of you and speak for you if you can't.

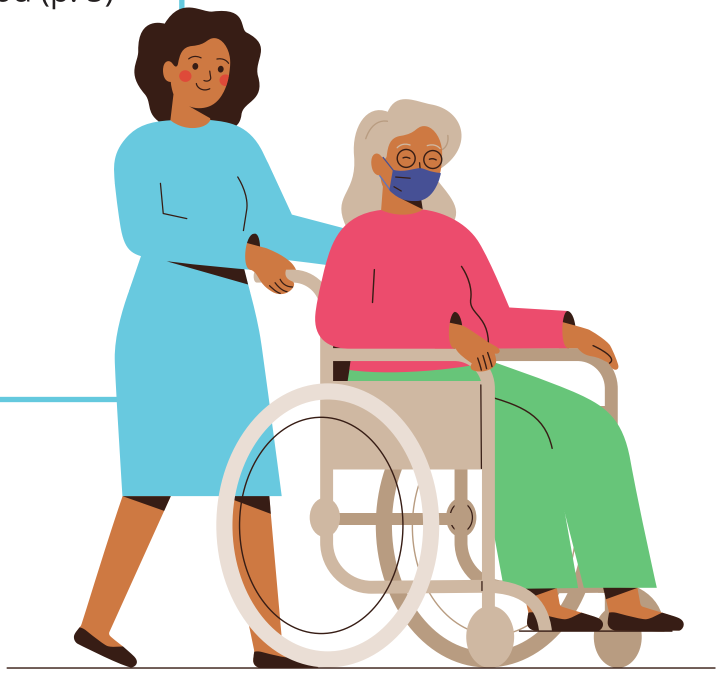
THIS GUIDE INCLUDES:

1) Step-by-step instructions on how to start a care plan (p. 4)

2) Care planning worksheets
   - **Worksheet 1:** What matters to you (p. 5)
   - **Worksheet 2:** Your backup person and caregiver(s) (p. 6)
   - **Worksheet 3:** Planning for your health and the unexpected (p. 8)

3) Frequently asked questions (p. 11)

4) Resources (p. 12)



GETTING STARTED

Getting started with preparing a care plan is not difficult, but it does require some dedicated time and a bit of organizing. This guide will help you pull together all of your information and help you advocate for yourself.

Sharing personal details about your background and goals can help doctors and your loved ones understand how you would make decisions about your care, especially if you aren't able to do so. Think of starting a care plan as a gift to yourself and your loved ones. If the COVID-19 pandemic has reinforced anything, it is that anyone's health circumstances can change at the drop of a dime. Having a care plan provides peace of mind for you, and gives confidence and comfort to your loved ones to understand and honor your preferred care.

MEETING YOUR FINANCIAL AND SOCIAL NEEDS

Part of care planning involves knowing where to go to get the help you need. Use the Resources section of this guide to locate the groups or organizations that can support your needs if there are changes to your health, a medical emergency or a life-changing event. If you don't have a backup person or caregiver support, these resources and programs are even more essential as a safety net to help support what you need.

If you are worried about paying medical or household bills, transportation costs, prescription co-pays or insurance premiums, help is available to guide you:

Patient Advocate Foundation (PAF) has resources, direct assistance programs and navigation services available to address financial and social needs that many people confront as part of their health conditions. You can access PAF resources by phone at 1-800-532-5274, or online at [patientadvocate.org.](patientadvocate.org)

National Patient Advocate Foundation (NPAF) also has patient and caregiver advocacy resources to help you, available at [npaf.org.](npaf.org)

STEP-BY-STEP INSTRUCTIONS

1 Write down what matters to you.

Take time to think about and write down the things that matter most to you, using Worksheet 1. This is essential to starting a care plan because it helps you and others know your preferences, goals and needs that should guide care decisions, so they align as closely as possible with what matters to you.

2 Identify your backup person and caregiver(s).

Think about whom you would want to serve as your backup person, or medical decision-maker, to speak on your behalf and/or whom you would want to serve as caregiver(s) if you can't take care of yourself. Use Worksheet 2 to help you identify your backup person and/or caregiver(s).

3 Make a plan.

Using the prompts on Worksheet 3, document the plan for your care that you'd want your backup person and caregiver(s) to know.

4 Share your plan.

Share a copy of your care plan with your backup person, caregiver(s) and health care team. Use the information you've recorded in these worksheets to have a conversation with them about what matters to you and how they can support your health and well-being.

#NPAF ProTips

Use the checklist below to gather important health documents in one place. Knowing where all your documents are located will be helpful for you and your loved ones under any circumstances you may face.

✓Checklist: Important health documents to help with care planning.

- ☐ Insurance card(s)
- ☐ Prescription drug coverage card
- ☐ List of medications and allergies
- ☐ List of doctors and contact information
- ☐ Worksheets 1–3 that are a part of this guide

WORKSHEET 1: What matters to you

Use the following prompts to help identify what matters most to you. You can use this worksheet to start a care planning conversation with your loved ones, your doctor or others on your health care team, so they know what's important to you and how they can support care decisions that reflect your personal preferences.

1) **Think of at least three things that bring you joy, strength or comfort.** *For example, you may make a list that includes particular hobbies, pastimes, music, time with family or friends, spirituality, pets, or perhaps preparing or eating favorite foods.*

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2) **What are your biggest worries about your health care?** *If your health became an issue, what circumstances would cause you to feel distressed or not in control? For example, many people worry about keeping their jobs or affording their medications, or even daily living expenses because of a health condition.*

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3) **Identify up to five key words or phrases that sum up what you think is important for your quality of life.** *Think about what would be essential for you to feel happy and fulfilled if your health became an issue, or if an existing condition was to deteriorate. For example, is it important for you to be as independent as possible when caring for yourself? Do you need to stay active or social?*

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4) **How do you prefer to get information about your health?** *Do you want to know all the facts, or does too much information overwhelm you? Is it important to be an equal partner with your doctor in making decisions about your care, or do you prefer to lean on your doctor's advice?*

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5) **In order to provide you with the best care possible, what three non-medical facts should your doctor know about you?** *Having some personal background context about you as a person can help doctors and your loved ones understand how you would make decisions about your care. For example, some people may answer by sharing, "I am a mother of two teenage boys, I have a dog that I adore, I love to garden."*

#NPAF ProTips

- Use NPAF's "Can We Talk" resources, Can We Talk About What Matters to Me? and Can We Talk About Telehealth?, for tips to help you prepare for talking to your backup person, doctor(s) and others on your health care team.
- Consider using Common Practice's "Hello," to talk about the things that matter with the people who matter. There's even a shorter, virtual version, "Hi," that you can play over video chat.

WORKSHEET 2: Choose your backup person and caregiver(s)

When a person gets sick, they often need to rely on others besides their doctor to get better and ease any stress or discomfort they may have. When choosing your backup person and/or caregiver(s), think about the person or people whom you would want to take action to support you in the event of a medical emergency or a life-changing event.

The Roles

Backup Person: This is your medical decision-maker—the one person you would want to make and implement medical decisions on your behalf if you cannot speak for yourself, and who would honor the priorities you have identified and shared on Worksheet 1. *This role is also called a health care surrogate, health care proxy or health care agent.*

When choosing your backup person, it's important that you ask if this person would be willing to take on this role for you. It should be a mutual decision, and they should be given the freedom to decline. It's also important that the backup person be involved in the care planning process, especially since they would need to fully comprehend and communicate what matters to you.

Name and contact information for your backup person:

Alternate backup person and contact information (if applicable):

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- Many people choose one backup person and an alternate if the primary backup person cannot serve in that role.
- Don't feel obligated to choose your next of kin, such as your spouse, mother, sibling or child, as your backup person. Your backup person should be someone you trust to honor what is important to you when speaking on your behalf.

Visit www.prepareforyourcare.org for short video examples and information that show how people made choices about their backup people/surrogates.

Caregiver(s): These are the people besides your doctor (such as family, friends, loved ones) who will do things for you to support your well-being that you are not able to do yourself, or need assistance doing if a medical condition comes up or worsens. These may include helping you with daily living, preparing meals, organizing or administering your medications, accompanying you to appointments or driving you, etc.

Name(s) and contact information for your caregiver(s):

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- Your backup person and caregiver may be the same person. Some people prefer to designate different people for these two roles, or divide duties among multiple caregivers where possible to help lighten the load.
- At least once a year, or whenever circumstances change, review the choices you have made about your backup person and caregiver(s), so you can make adjustments as needed.
- It's important to tell your doctor whom you chose as your backup person and caregiver(s), so they can include these names, roles and contact information in your medical record. If you don't have a backup person or caregiver, it is equally important to tell your doctor that these supports are not available to you, so they can advise you about other options and resources to help. Check out Patient Advocate Foundation (patientadvocate.org) as a place to start.

WORKSHEET 3: Care planning for your health and the unexpected

Your care plan is a guide for you, your loved ones and doctors to understand what matters most to you. Once you've reflected and written down the things that matter (see Worksheet 1), and identified your backup person and caregiver(s) (see Worksheet 2), you are ready to complete the rest of your plan.

This worksheet is organized to show the different levels to care planning, with prompts to help you record and share this information with your backup person, caregiver(s), doctors, or others who may be in a position to help you.

Primary Care Planning

Care planning starts with making sure you have what you need to protect and take care of yourself. Do you have health insurance coverage that meets your particular needs? For example, are you enrolled in insurance through the Affordable Care Act (ACA) health exchange, Medicare, Medicaid, Tricare, your employer or some other provider? Do you have a primary care provider (PCP) who takes the time to listen to your concerns? In case of an emergency, do you prefer a certain hospital?

Write this information below and share it with your backup person, caregiver(s) and doctors.

Health insurance plan provider and member number:

Prescription coverage provider and member number:

Primary care provider, address and phone number:

Preferred hospital and address:

#NPAF ProTips

If you are not currently enrolled in an insurance plan, visit healthcare.gov and use National Patient Advocate Foundation's ACA Plan Guide or Medicare Plan Guide to help you compare coverage options and select the plan that best fits your situation.

Intermediary care planning

Care planning also involves preparing for the unexpected with your daily life in mind. Taking actions now will help you and your backup person/caregiver(s) feel more prepared to handle a health care crisis. Write down the everyday things that are important to you that you would need others to take care of if you aren't in a position to do those things yourself. For instance, whom do you want to take care of your house and yard, mail, pets, plants, bills and finances if you experience a medical emergency? For each item you write down, designate whom you would want to take care of these different things.

TASK	PERSON	CONTACT INFO	NOTES
Pet care	*John Smith*	*999-999-9999*	*Daily walks and feeding schedule*

Advanced care planning

Advanced care planning helps others have the knowledge and resources they need to guide care decisions on your behalf if you can't speak for yourself. Use Worksheet 1 as a reference to talk about what matters to you with your backup person and caregiver(s), and tell them how they can honor your personal preferences. When you're ready to take this step, visit prepareforyourcare.org to find the forms that will help you describe the care that you would like to have if you are hospitalized, which your backup person needs to communicate for you. These forms include a durable power of attorney for health care (or health care proxy) and an advance directive (see the FAQ section for a description of an advance directive).

SHARE YOUR PLAN

Congratulations on making your care plan! The final step is to share your care plan and talk about the information you've recorded in these worksheets with your backup person, caregiver(s) and your doctors, including your primary care doctor. It's important that these individuals fully understand the things that matter to you, and agree to support you when you need it.

#NPAF ProTips

Ask your doctors to include your care plan as part of your medical record.

FREQUENTLY ASKED QUESTIONS

1. What is a care plan?

A care plan is a guide that allows you to always have a say in your health care in the event that you are unexpectedly hospitalized, or are diagnosed with a complex or chronic condition. It is a roadmap for your loved ones and your health care team to follow to ensure that the care you receive is based on what matters to you.

2. What is an advance directive?

An advance directive is a legal document that details your care preferences if you are hospitalized and your backup person needs to communicate for you. The care planning steps that are a part of this guide will make completing an advance directive much easier. If you need an advance directive, visit prepareforyourcare.org/advance-directive

3. I'm young and healthy. Why should I start a care plan?

At some point, we will all be a patient, or caring for someone who's sick. Starting a care plan is a heroic act that can ease uncertainty during a health crisis and will allow you to always have a say in your care. Making a care plan can also help you and your loved ones prepare for, and possibly avoid, the financial or emotional distresses that come with dealing with hospitalization or illness.

4. Do I need a witness or lawyer to start a care plan?

No, you do not need a witness or lawyer to start a care plan, though those individuals may be helpful to completing more advanced planning documents. The people you should involve when starting your care plan are your backup person, caregiver(s) and your doctors.

5. Where should I keep my care plan?

Keep this workbook and your important health documents all together in a secure place that you share only with your backup person and caregiver(s).

CARE PLANNING RESOURCES

ENROLLING IN HEALTH INSURANCE

- **Healthcare.gov (ACA Coverage)** www.healthcare.gov
- **Medicare** www.medicare.gov
- **National Patient Advocate Foundation**
    - ACA Plan Guide www.npaf.org/wp-content/uploads/2020/11/ACA-Marketplace-Guide.pdf
    - Medicare Plan Guide www.npaf.org/wp-content/uploads/2020/11/Medicare-Guide.pdf

SAFETY NET SERVICES AND SUPPORTS

- **Patient Advocate Foundation services**
    - PAF Case Management Services www.patientadvocate.org/connect-with-services/case-management-services-and-medcarelines
    - National Financial Resource Directory www.patientadvocate.org/explore-our-resources/national-financial-resource-directory
    - PAF’s Financial Aid funds www.patientadvocate.org/connect-with-services/financial-aid-funds
- **Social Security Administration –** This website provides helpful resources in one place to government programs and services for anyone in a position to help another person. www.ssa.gov/thirdparty

CARE PLANNING CONVERSATION SUPPORT TOOLS

- **Common Practice –** Creators of Hello, a conversation game about living and quality of life. www.commonpractice.com

- **The Conversation Project –** A website dedicated to helping people talk about their wishes for end-of-life care.
  theconversationproject.org/nhdd/advance-care-planning

- **PREPARE For Your Care –** An interactive website that serves as a resource for families navigating medical decision-making. prepareforyourcare.org

- **National Patient Advocate Foundation Can We Talk Resources –** Tip sheets to help you prepare for appointments with your doctor. www.npaf.org/can-we-talk
  - Can We Talk About What Matters to Me?
  - Can We Talk About Telehealth?

ADDITIONAL SUPPORT TOOLS

- **Foundation for Financial Planning –** Free consumer resources for individuals who need financial planning support. ffpprobono.org/consumer-resources

- **Get Palliative Care –** Palliative care focuses on maximizing quality of life for patients and caregivers, and it is appropriate at any age and any disease stage. These resources provide information about holistic care available to patients and caregivers. www.getpalliativecare.org