



Know Your Options

A guide for patients with serious illness

This brochure is available to all patients at BIDMC. Not every patient has a serious illness, but we make it available to everyone so that patients who *are* seriously ill will be aware of their full range of options.

If you have a serious illness, it is important that you understand the types of care available to you. This may include primary, specialty, palliative, and hospice care. It is also important that your health care providers know what matters most to you and how you feel about possible treatments.



In this packet you will find information about different types of care that may be right for you. This packet also includes a guide to talking with your care team about health and treatment options. When you understand your options, and your health care providers understand what matters most to you, together you can find the best course of care. The resources listed in this packet also offer information about selecting a Health Care Proxy and other advance care planning.



Contents:

- Talking with Your ProviderInsert
- Primary and Specialty Care 2
- Palliative Care 3
- Hospice Care 4

PRIMARY AND SPECIALTY CARE

What is the role of primary care in serious illness?

Your primary care provider (PCP) can be your main point of contact in the health care system. He/she can help you with a range of needs. If you are hospitalized, a provider called a “hospitalist” may coordinate your care along with your PCP.

What is the role of specialty care in serious illness?

Specialty care focuses on a particular condition or area of medicine. For example, cardiology focuses on heart disease, oncology on cancer, and pulmonology on lung disease.

When should I see a specialist?

Many patients with chronic, complex, or serious illness can benefit from seeing a provider who is specially trained in a certain area of medicine. A specialist can often help diagnose and treat your condition. Depending on your insurance, you may need a referral from your PCP to see a specialist.

I’ve already seen a specialist. Can I get a second opinion?

Yes. You should feel comfortable seeking the opinion of more than one specialist. Ask your health care providers about getting a second opinion and how that may help you.

Does my insurance cover specialty care?

Most insurance plans cover specialty care when it is seen as “medically necessary.” But every insurance provider is different, so check with your insurer to find out if visits to a specialist are covered. You may need to get a referral from your primary care provider before seeing a specialist.

What about new treatments and clinical trials?

Depending on your condition, your provider may suggest you consider participating in a voluntary research study about a new treatment. This is called a “clinical trial.” Before enrolling in a clinical trial, patients are given detailed information about the possible risks and benefits so they can make an informed decision about whether or not to participate.

RESOURCES

To find a primary or specialty care provider in the BIDMC network, contact:

BIDMC Find a Doctor
800-667-5356

services.bidmc.org/find_a_doc

For information about clinical trials, visit:

clintrial.bidmc.org or

clinicaltrials.gov

For information about selecting a Health Care Proxy, visit:

bidmc.org/proxy

For information about other advance care planning, visit:

bidmc.org/conversationready

PALLIATIVE CARE

What is palliative care?

Palliative care helps patients with serious illness live as well and fully as possible. It can help at all stages of illness and be provided along with other treatments. Palliative care helps treat pain, shortness of breath, fatigue, and other physical symptoms. Palliative care also provides emotional and spiritual support to patients and families and helps them make decisions and coordinate care.

Who provides palliative care?

Palliative care can be provided by any member of your care team, including your primary care provider, specialist, nurse, social worker, or chaplain. Some patients may also benefit from a consultation with a palliative care specialist.

Who can receive palliative care?

Anyone with a serious illness can receive palliative care, regardless of stage of illness or other treatment plans.

Is palliative care the same as hospice?

No. Palliative care can be delivered at any point in time during a serious illness. It is appropriate for people who expect to get better and people who do not. (See the next page for more on hospice care.)

Where can I receive palliative care?

Palliative care can be provided anywhere, including in the hospital, at a nursing facility, or at home.

Does my insurance cover palliative care?

Most insurance plans, including Medicare and Medicaid, cover some medical services that are considered palliative care. For specific information about your coverage, contact your insurance plan.

May I keep my current provider if I am receiving palliative care?

Yes. In fact, your current primary and specialty care team are often the providers delivering palliative care. And if you do see a palliative care specialist, you can continue to see your current care providers as well.

RESOURCES

For more information about palliative care, visit:
bidmc.org/palliativecare

To request a palliative care consultation at BIDMC, contact:
Palliative Care Consultation Services
617-667-1320

For information about selecting a Health Care Proxy, visit:
bidmc.org/proxy

For information about other advance care planning, visit:
bidmc.org/conversationready



HOSPICE CARE

What is hospice care?

Hospice care does not focus on lengthening life. Instead, when the goal is no longer to cure a serious illness, hospice can help you live the rest of your life in the way that matters most to you. By working to ensure your comfort and dignity, hospice care can help make your remaining life as meaningful and fulfilling as possible for you and those closest to you.

Hospice care looks at the whole person and asks: "Knowing your time is limited, how can we make each day as good as possible?"

How do I know when hospice care is right for me?

When a serious illness becomes advanced, hospice care may be right for you. If you are wondering about hospice care, talk with a member of your health care team.

Who provides hospice care?

Hospice care is provided by teams that may include doctors, nurses, social workers, counselors, home health aides, clergy, therapists, and trained volunteers. Together, the team provides complete medical, emotional, and spiritual care in the last stages of life.

Where can I receive hospice care?

Hospice services may be provided in a range of settings, including your home, a hospital, a nursing or long-term care facility, or a hospice residence.

Does my insurance cover hospice services?

Many insurers, including Medicare and Medicaid, will cover hospice care services if a patient's provider documents that the person has a terminal illness. Usually, coverage is only available to those expected to live less than six months. For specific information about your coverage, contact your insurance plan.

RESOURCES

For more information about hospice care, visit:

National Hospice and Palliative Care Organization
caringinfo.org

To find out more about hospice options, speak with your BIDMC provider.

For information about selecting a Health Care Proxy, visit:

bidmc.org/proxy

For information about other advance care planning, visit:

bidmc.org/conversationready



Talking With Your Health Care Providers

It is important to talk with your health care providers about what matters most to you. Having this conversation is a key step in getting the care that's right for you. This guide can help you plan this important conversation.

Who?

Think about the members of your health care team you feel most comfortable with and who know you and your health status best. For instance, you may want to include your:

- | | | |
|----------------------------------------------------------------------------|------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| <input type="checkbox"/> Primary care doctor | <input type="checkbox"/> Caregiver at a nursing home or assisted living facility | <input type="checkbox"/> Therapist (e.g. social worker, psychologist, or psychiatrist) |
| <input type="checkbox"/> Nurse, nurse practitioner, or physician assistant | <input type="checkbox"/> Spiritual advisor (e.g. chaplain, imam, priest, or rabbi) | <input type="checkbox"/> Hospitalist (if you are staying in the hospital overnight) |
| <input type="checkbox"/> Specialist (e.g. heart, lung, or kidney doctor) | | <input type="checkbox"/> Other _____ |

What?

Ask about your health:

- *What is the name of my illness? Can you write it down for me? How can I learn more about it? How sure are you of my diagnosis?*
- *What tests have been done? What were the results?*

Discuss what the future may hold:

- *What can I expect from this illness? Should I watch for any symptoms or changes?*
- *What is my life likely to look like 6 months from now, 1 year from now, or 5 years from now?*
- *What can I do to plan ahead? Can we talk about a Health Care Proxy or Advance Care Planning?*

Tell your provider what matters most to you:

- *Have you had experiences that have influenced your views on serious illness? (Seeing my dad very sick was hard because...)*
- *Are there milestones you want to reach? (My daughter is graduating...)*
- *What types of care do you want or not want? Why? (I do/don't want _____ because...)*
- *Are you worried about certain aspects of your care? (I'm worried about returning home because...)*
- *Does religion/spirituality play a role in your views on health care? (In my faith...)*

Discuss your options for care:

- *What are my treatment options? What kind of improvements and side effects are likely?*
- *Should I see a specialist? Would a second opinion be helpful for me?*
- *Are there clinical trials that I should consider?*
- *Could palliative care help with my symptoms?*
- *What emergencies are most likely to come up and how can I best prepare for them?*
- *Would hospice care be right for me now or in the future?*

When and Where?

You might want to think about having the conversation:

- At your next clinic visit
- Before you get very sick
- When a provider calls to check up on you
- When you stay overnight in the hospital
- When a provider visits your home
- Other _____

Remember, it often feels like it's too early to talk about this, until it's too late. Many people find it helpful to pick a date and time:

Date: _____ Time: _____

How?

Call or email your provider ahead of time to say that you'd like to have a conversation.

It's important that he/she is prepared for the conversation and has set aside time to talk.

It's also important that you are prepared for the conversation. Here are a few planning tips:

- If English is not your primary language, please ask your health care team to arrange for a trained medical interpreter to be part of the conversation. It's best not to have family members or friends interpret because they may not be familiar with medical terms.
- Bring copies of any advance care planning paperwork you may have, including a Health Care Proxy form, a living will, or other documents.
- Bring this planning sheet or other notes with you.
- Think about inviting your Health Care Proxy, a friend, or family member to be part of the conversation—in person or by phone.

For more tips on planning the conversation with your provider, your Proxy, or those closest to you, visit bidmc.org/conversationready.

Notes:

Consider using this space to make note of any goals, hopes, or concerns you may have.