MY MEDICAL CARE PROTOCOL™

What I need from my medical relationships, how I want information communicated, what questions matter to me and how I participate in my care.

I welcome medical expertise. I also bring my voice.

The people caring for me bring years of education, training, experience and medical knowledge to this journey.

I value that expertise.

I am grateful for the physicians, nurses, navigators, technicians, therapists, pharmacists and other professionals who bring their knowledge and skills to my care.

And I bring something important to the relationship, too.

I bring the lived experience of my body.

My history.

My values.

My beliefs.

My questions.

My priorities.

My faith.

My preferences.

My life.

Good medical care is not something that simply happens to me. I want to participate in it.

I Want a Relationship, Not Just a Treatment Plan

I want to know the people caring for me and I want them to know something about me.

Not everything.

But enough to understand the person sitting in front of them.

I want a medical relationship where questions are welcomed.

Where concerns can be expressed.

Where difficult information can be discussed honestly.

Where I can say, “I do not understand.”

Where I can say, “I need more information.”

Where I can say, “I need some time.”

Where I can say, “This matters to me.”

I do not expect my medical team to know everything about me.

But I do want my care to include me.

I Want Information I Can Understand

Medical information can become overwhelming very quickly.

I may be hearing unfamiliar words while also trying to process fear, uncertainty and decisions that affect my life.

I will ask for information in language I understand.

I may ask:

What exactly did you find?

What does that mean?

Would you explain that without medical terminology?

What do we know for certain?

What remains uncertain?

What are you recommending?

Why are you recommending it?

What happens next?

I may take notes.

I may record the conversation when permitted.

I may bring someone with me to listen.

I may ask for information in writing.

I may ask the same question more than once.

Understanding my care is part of participating in my care.

I Want to Understand the Recommendation

When treatment is recommended, I want to understand more than its name.

I may ask:

What is the goal of this treatment?

What benefit do you expect it to provide in my particular situation?

What are the significant risks and side effects?

Are there reasonable alternatives?

What happens if I choose not to do this?

How soon does this decision need to be made?

What would you want me to understand before deciding?

I am not asking these questions because I distrust medicine.

I am asking because I want to understand the care I am considering.

I Want Information About Me, Not Only About People Like Me

Statistics and clinical evidence can help guide medical care.

I want to understand them.

But I also want to understand how that information applies specifically to me.

I may ask:

What does this statistic mean for someone with my particular diagnosis and circumstances?

What factors about me influenced your recommendation?

Is this recommendation standard for everyone with this diagnosis, or are there reasons it is particularly appropriate for me?

What might cause you to recommend something different?

Population data can inform my care.

But I am not a population.

I am one person receiving care.

I Will Tell You What I Am Experiencing

My care team cannot respond to information I do not share.

I will do my best to communicate honestly about:

Pain.

Side effects.

Symptoms.

Medications and supplements I am taking.

Changes in my body.

Emotional distress that may affect my care.

Concerns about treatment.

Problems following a care plan.

Financial or logistical barriers when they affect my ability to receive care.

And questions I have been afraid to ask.

I will not assume something is too insignificant to mention when it concerns me.

I can ask:

“Is this something you need to know?”

I Will Bring My Whole Self Into My Care

My medical condition is part of what is happening to me.

It is not everything that is happening to me.

My emotional well-being matters.

My spiritual life matters.

My relationships matter.

My responsibilities matter.

My quality of life matters.

My sexuality and body image may matter.

My work may matter.

My finances may matter.

My ability to sleep, eat, move, think and function matters.

My hopes for my future matter.

When these things influence a medical decision, I will bring them into the conversation.

Whole-person care requires the whole person to be present.

I Will Ask Who Else Can Help

My physician does not have to meet every need I have.

There may be times when another professional can help.

I can ask about:

Nurse navigation.

Spiritual care or chaplaincy.

Nutrition.

Physical therapy.

Rehabilitation.

Mental health support.

Social work.

Financial navigation.

Sexual health.

Lymphedema care.

Palliative and symptom-support services.

Genetic counseling.

Integrative care when available and medically appropriate.

Supportive resources within my community.

Part of participating in my care is knowing when to ask:

"Who else should be part of this conversation?"

I May Seek Another Medical Opinion

Seeking another opinion does not have to mean that I distrust my physician.

Sometimes another opinion confirms the original recommendation.

Sometimes it provides additional information.

Sometimes it presents another reasonable option.

Sometimes it simply gives me greater confidence in the decision I am making.

When circumstances allow and I believe another opinion would help me make an informed decision, I give myself permission to seek one.

I do not need to apologize for wanting to understand my choices.

I Want My Faith Respected as Part of My Care

My spiritual beliefs are part of who I am.

I may pray before appointments, treatments, procedures and decisions.

I may seek spiritual counsel as I make significant choices.

I may ask for a moment of prayer before treatment begins.

I may invite a pastor, chaplain, family member or prayer partner to accompany me when appropriate.

I do not expect my medical professionals to share my beliefs.

I do ask that the role faith plays in my life be treated with respect.

I can value medical wisdom and spiritual wisdom in the same healing journey.

I Will Recognize When Time Matters

Not every medical decision can wait.

There may be situations when delaying care creates additional risk.

I want my medical team to tell me clearly when a situation is urgent.

I may ask:

"How much time do I reasonably have to make this decision?"

"What are the medical consequences of waiting?"

"Is this something that needs to happen today, or do I have time to consider my options?"

Knowing when time matters helps me distinguish urgency from the feeling of being rushed.

I Will Speak When Something Does Not Feel Right

If I am confused, I will say so.

If something seems inconsistent with what I was previously told, I will ask.

If I believe important information has been overlooked, I will speak.

If I am uncomfortable with how something is being communicated or handled, I can respectfully say so.

If I need help communicating, I can ask someone I trust to help advocate with me.

Speaking up does not make me difficult.

It makes me a participant.

What I Ask From My Medical Team

I respect your knowledge and your responsibility to provide medically appropriate care.

In return, I ask you to help me participate fully.

Please tell me the truth.

Please explain what you know and acknowledge what remains uncertain.

Please communicate important information in language I can understand.

Please welcome reasonable questions.

Please help me understand the purpose, benefits, significant risks and alternatives associated with the care you recommend.

Please tell me when a decision is medically urgent.

Please recognize that my values, quality of life, personal priorities and spiritual beliefs may be important to my decisions.

Please speak to me, not merely about me.

Please remember that behind my medical record is a person living a life.

What I Bring to Our Partnership

I will show up.

I will listen.

I will ask.

I will learn.

I will communicate.

I will tell you what I am experiencing.

I will consider your recommendations seriously.

I will ask for clarification when I need it.

I will share information that may affect my care.

I will respect your expertise.

And I will remain present in decisions concerning my body and my life.

You bring your medical expertise.

I bring me.

Let us meet there.

What I Bring to Our Partnership

What I most need from my medical relationships:

How I prefer important information to be communicated to me:

When receiving difficult information, what helps me most:

The questions I want to remember to ask:

The people I want included in important medical conversations:

The personal values or quality-of-life considerations I want my team to understand:

What I want my medical team to understand about my faith:

Something else I want the people caring for me to know about me:

Name: _____ **Date:** _____

My Medical Care Protocol™ is a personal communication, reflection and self-advocacy tool. It does not provide medical advice or replace informed consent, emergency care, medical evaluation or communication with qualified healthcare professionals.