



Planning for Quality Care at Every Stage of Health

A conversation with Elizabeth J. Collins MD,
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Dr. Elizabeth Collins guides us through creating goals for care and planning documents at every stage of health. Planning gives you and your doctors a road map for the best possible care all through your life.

Stage One: Staying Healthy and Independent

What are the general goals for care?

I always ask why a patient is accessing care at any particular point in their lives. What is a patient's goal in seeking my medical help? At this stage of generally good health, the goal is usually focused on addressing a specific health issue and recommending proactive and preventive measures to stay healthy and independent. An essential part for me is to understand what is important to each patient. It helps me to know about a person's life, work, family support, religious or cultural beliefs, and how that all fits into his or her personal goals for care. As your doctor, your medical partner, it is important to know not only the medical issues, but also the person experiencing them.

What planning documents are recommended?

I recommend that every competent adult, 18 years old and older, sign a Health Care Proxy and have a copy placed in the patient's medical record. As much as I know about a patient, I can't predict who he or she would choose as a Health Care Agent. This can be especially true for healthy 18-30 year olds, where their Health Care Agent may not be next of kin but someone who knows them well, like a friend, a neighbor, or a 'preferred' family member. If an unforeseen or unexpected event happens like a motor vehicle accident or sudden illness and I can't communicate with my patient, I need to know who he or she appointed to make medical decisions on their behalf. Having a Health Care Proxy in your medical record gives me that information. I would also recommend that patients consider signing a Personal Directive.

Stage Two: Managing illness for the best possible quality of life

What are the general goals for care?

Knowing a patient's personal goals for prolonging good health and improving their everyday quality of life becomes essential at this stage as medical conditions are first diagnosed and progress overtime. In my experience how people define quality of life is so individually based that we can never make assumptions. For example, if a patient is first diagnosed with diabetes and you learn is afraid of needles, the next step is



to figure out how to help that person manage treatment. Similarly, if a patient is a professor with a dementia diagnosis, he may be emotionally struggling with the loss of mental capacity as his illness progresses. My job is to listen carefully to each individual to understand what quality of life means, and work together to find effective treatments.

What planning documents are recommended?

I recommend that patients sign a Health Care Proxy and a Personal Directive and place a copy into their medical records, if they have not already. A Personal Directive is a great communication tool in which you give instructions to your Health Care Agent for the care you want so your family and your health care team know how to care for you. It can't outline every possible medical situation, but it can offer us a philosophy of what a person would want and not want. Having a Personal Directive in your medical record gives your doctor the opportunity to review it with you regularly, and record any changes in your preferences for care as an illness progresses. It may be appropriate for some patients to consider MOLST at this stage to make decisions about life-sustaining treatments.

Stage Three: Transitioning to End of Life Care

What are the general goals for care?

People have very individual goals about end of life care and life-sustaining treatments. At this stage, the general goal is to continue to support the best possible quality of life, manage symptoms, and provide comfort care. For example, a patient may say if I can't eat any longer, extending my life would be unacceptable to me because eating and preparing meals is a joy for that person. Likewise, a patient who is bedbound and needs round the clock care for feeding and toileting may say if all I can do is open my eyes and see my wife and children, then I want you to keep me alive. The health care team respects each decision and formulates recommendations that continue a person's quality of life for as long as possible, while doing everything possible within their care goals. Each person will always be treated for symptoms and comfort, no matter what they choose for end of life care.

What planning documents are recommended?

I recommend a Health Care Proxy, Personal Directive and if appropriate a MOLST or CC/DNR be available in a patient's medical record. We carefully review and if needed update the Health Care Proxy, Personal Directive and a patient's goals for care. If a person has made decisions about life-sustaining treatments, a MOLST form can be signed by a clinician and the patient to document those decisions. Unfortunately at this stage, we also see families left with a terrible burden of not knowing what to do if a patient has not made a plan and no longer can tell us what they want for care. It's real suffering for the family. The family struggles to make care decisions when having a simple written plan in a loved one's own words would give the family a needed roadmap to honor his or her choices.

Doctors can help people live out their lives in comfort and create quality time with family and friends, instead of worrying about what is left unsaid and undecided. We tell our patients that having a written plan and placing a copy in your medical record can give you and your family peace of mind that you will be made comfortable and your care choices will be honored.