

800-813-HOPE (4673) info@cancercare.org www.cancercare.org

COPING WITH HEALTH CARE DISPARITIES THROUGH SELF-ADVOCACY

While health care providers aim to provide patients with the best care possible, they may not know or understand everything about an individual's personal situation. No treatment plan is "one size fits all," and providers' assumptions about cultural backgrounds and other aspects of identity may lead to recommendations that are right for some people, but not for everyone. It is important to advocate for the care that fits your beliefs, values and traditions.

DIFFERENCES IN HEALTH CARE TREATMENT

Health care disparities refer to preventable differences in opportunities for optimal health. Groups may experience differences in access to or quality of care based on race or ethnicity, age, gender identity, sexual orientation, socioeconomic status, physical ability, intellectual or developmental ability, preferred primary language, national origin, immigration status, religion, geographic location and other factors. Any person can be affected by more than one type of disparity.



RECOGNIZING HEALTH CARE DISPARITIES

In practice, health care disparities can appear in different ways. Here are a few examples:

- A clinic located in an area where most of the population speaks only English may not have much experience with medical interpreters. A patient at this clinic who is most comfortable speaking another language, especially a less common language, may experience difficulties communicating with their treating health care team.
- A provider may not be familiar with the cultural implications of hair loss within some cultures, so they may not understand why the patient is being reluctant to pursue chemotherapy, even if medically it is considered the "best" option.
- A standard infusion schedule may be too taxing for a patient who cannot travel easily, whether due to physical, financial or practical concerns. If that patient misses appointments, a provider may assume they are not committed to their treatment—when instead there could be a variety of other factors affecting their attendance.

 A transgender person may face discrimination from their health care team unwilling to use preferred pronouns and chosen name. They may also not be covered for prostate screening, despite having an intact prostate, or breast cancer screening, due to the gender listed by their insurance.

The concept of "cultural humility" is gaining traction among health care providers. Cultural humility encourages providers to question their own assumptions and to have open discussions with patients about traditions or beliefs that may affect the care that is most appropriate for them.

However, you do not have to wait for your health care team to start these conversations. No medical decision should be made without your full consent and understanding, and you can start advocating for yourself or your loved one at any time during the cancer experience.

ADVOCATE FOR YOURSELF

Both you and your treating health care team have the same goal: to provide the best possible care and quality of life. Health care professionals typically focus on the best medical and scientific course of action. However, your beliefs and values are equally as important when your quality of life is at stake. You have the right and the power to make your wishes known.

For instance, a provider may suggest that a patient pursue an aggressive form of treatment that is shorter, but involves harsh side effects like severe nausea and fatigue. That patient may want to continue working, preferring a less aggressive but longer course of treatment that could help them keep their job. Open and respectful communication is vital in cases like this: the provider may assume the patient would prefer a shorter treatment schedule, and the patient may assume that this aggressive plan is the only option. It is only by speaking up that the realities of situations like these can become clear.

Keep in mind that while providers are experts in medicine, you are the expert on your needs. As a consumer of health care, you have the right to have a full understanding of the options available to you, and you are not required to accept a decision about your treatment that you disagree with. If you find you cannot communicate effectively with a member or members of your treating health care team, ask if there is a patient navigator or hospital social worker. They can act as an advocate on your behalf.

Disparities in the health care system are a major issue, one too big for any single person to dismantle. Broader cultural conversations are drawing more attention to the disparities that individuals face—but self-advocacy can begin for you today. By communicating actively and openly with your health care providers, you can make better-informed treatment decisions, improve your quality of life and encourage your providers to have similar conversations with others.

CancerCare® Can Help

Founded in 1944, Cancer*Care* is the leading national organization providing free support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include case management, counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All Cancer*Care* services are provided by master's-prepared oncology social workers and world-leading cancer experts.

To learn more, visit www.cancercare.org or call 800-813-HOPE (4673).

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Edited by Angelique Caba, LSCW-R and Yvette Colón, PhD, BCD, LMSW

