



# Missed Opportunities: Important Discussions About Serious Illness and End of Life

**Californians want to know as much as possible about their serious illnesses.** People with serious illness face a barrage of decisions — what treatments they will (or won't) pursue, who will care for them, how the rest of their life and responsibilities will fit into their care plan, and what changes to the care plan should be made as new challenges emerge. To make the best decisions for themselves and their families, patients rely on their health care providers for information and guidance.

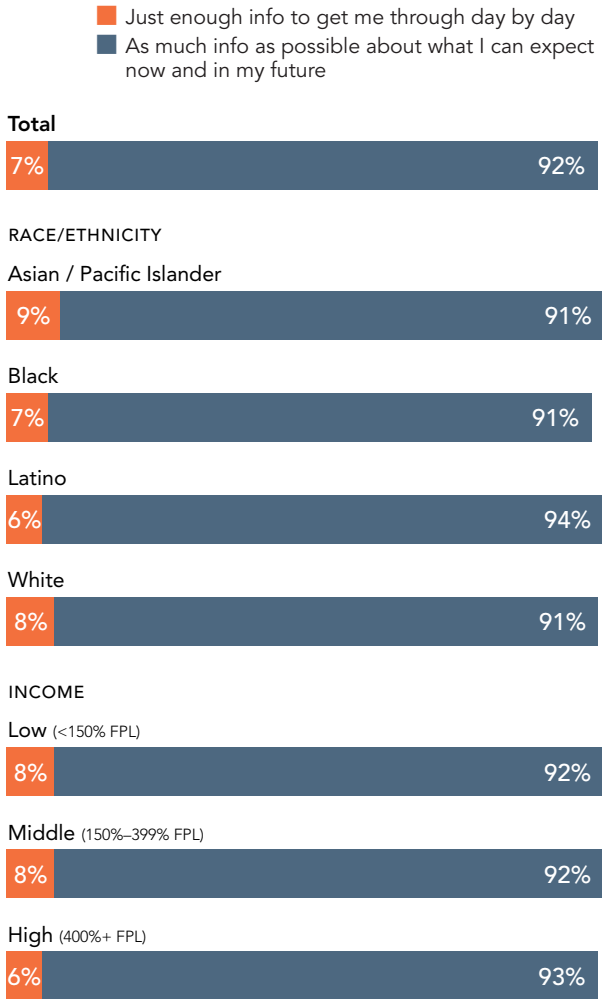
In a recent survey of Californians, 92% of respondents without a serious illness reported that if they had a serious illness they would want as much information as possible from their health care provider (Figure 1). This high desire for information was consistent across different racial/ethnic groups and income levels. These respondents also noted they would want their providers to talk to them about both the good and bad things that could happen with treatment (93%), what to expect if the illness gets worse (93%), and how to make their life better as they live with their illness (90%).

**Californians want to discuss wishes for medical treatment at the end of life.** Across all survey respondents, 82% reported that if they had a serious illness they would definitely (54%) or probably (28%) want to talk with their doctor about their wishes for medical treatment toward the end of life. This high level of interest persisted across races and ethnicities — more than three-quarters of each subgroup assessed in the survey said they would definitely or probably want these conversations. Black respondents were the most likely to say they would definitely want these conversations (61%).

Making sure that medical care at end of life aligns with one's own wishes matters greatly: When asked about the importance of various factors at the end of life, 89% of Californians reported that making sure their wishes for

medical care are followed at the end of life was important to them — with 60% weighing this as extremely important.

**Figure 1. Level of Information Wanted from Health Care Provider if Seriously Ill, by Demographic, 2019**



Notes: In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four. Segments may not total 100% due to non-response or rounding.

**Many Californians with serious illness are not having these important discussions with their providers.**

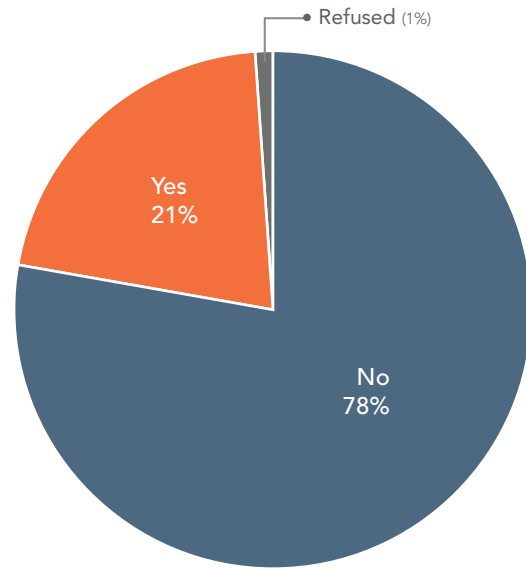
Many survey respondents with a serious illness reported that they had not discussed significant issues related to their illness and treatment with their providers. Between one-third and two-thirds of respondents with serious illness said “yes” when asked if any of their health care providers had ever talked about the following issues:

- ▶ **35%** Any fear, stress, or sadness you may be feeling
- ▶ **36%** What is most important for you as you live your life with your illness
- ▶ **49%** What to expect if your illness gets worse
- ▶ **58%** How to make your life better as you live with your illness
- ▶ **65%** Both the good and bad things that could happen with your treatment(s)

While an earlier survey<sup>1</sup> found that nearly all physicians (99%) consider it important that health care providers have conversations about advance care planning with their patients, only one in five Californians with a serious illness reported that their doctors had asked them about their wishes for medical treatment at the end of life (Figure 2).

**There is an unmet opportunity to educate and encourage providers to have these conversations.** Less than a third of physicians report having had formal training in talking with patients and their families about end-of-life care.<sup>2</sup> Given the gap between the kinds of conversations people want about serious illness and the frequency with which these conversations actually occur, education and support for providers are needed. A variety of communications resources for health care providers are available through [VitalTalk](#), Ariadne Labs’ [Serious Illness Care Program](#) and [Serious Illness Conversation Guide](#), the [Center to Advance Palliative Care](#), [The Conversation Project](#), the [California State University Shiley Institute for Palliative Care](#), and the [Coalition for Compassionate Care of California](#).

**Figure 2. Whether a Doctor Has Asked About Wishes for Medical Treatment at End of Life, Among Californians with Serious Illness**



**TAKEAWAY** While Californians want to have important discussions with their health care providers about their serious illnesses and wishes for medical treatment at the end of life, these conversations are only occurring with a minority of Californians with a serious illness. Resources exist to help providers learn these important skills and deliver these desired supports to patients and their families.

**Endnotes**

1. *Physicians’ Views Toward Advance Care Planning and End-of-Life Care Conversations*, PerryUndem, 2016, [www.johnhartford.org](http://www.johnhartford.org) (PDF).
2. Ibid.