Help Wanted:
Californians’ Views and Experiences of Serious Illness and End-of-Life Care
Introduction

Most people will experience serious illness at some point in their lives — as a patient, a caregiver, a family member, or a friend. In 2019, the California Health Care Foundation commissioned a statewide survey to better understand the type of medical care and services Californians would prefer to receive if they had a serious illness or if they were approaching the end of life, and to explore the experiences of those actually dealing with these issues themselves or with loved ones. Help Wanted: Californians’ Views and Experiences of Serious Illness and End-of-Life Care reports selected findings from this survey and highlights key differences by race/ethnicity and income level.

KEY FINDINGS INCLUDE:

- When palliative care was described to them, 9 in 10 Californians without a serious illness said they would want this type of care if they had a serious illness. Four in 10 of those with a serious illness said they receive this type of help.

- Among respondents with a serious illness, Californians with low incomes reported the highest level of interest in getting supports beyond disease treatment, compared to those with higher incomes.

- Over 9 in 10 respondents of all races/ethnicities and income levels said they would want “as much information as possible” if faced with a serious illness.

- Only 7% of Californians with low incomes who also have a serious illness said they were “very prepared” to deal with their illness if it got worse.

- Survey respondents reported that at the end of life, it would be extremely important to them that their families are not burdened — by treatment costs (70%), by making tough decisions about their care (60%), or by needing to take care of them (59%).

- A majority of respondents said they would prefer to die a natural death (63%) rather than have doctors attempt everything to prolong life (9%). More than 1 in 4 (28%) were not sure.

- More than two-thirds (71%) of respondents said they would want to die at home. However, just over a third of Californians who died in 2017 died at home (36%).
Interest in and Receipt of Palliative Care Services
California, 2019

Some people with a serious illness get extra help. This type of help is on top of regular medical care. It could be help with things like dealing with side effects or pain, dealing with stress and other hard feelings, figuring out how to live better with your illness, or finding out what services you might qualify for. Base: respondents with a serious illness (n = 588)

Would you want this type of help to deal with your illness(es)?

- Definitely Yes: 38%
- Probably Yes: 40%
- Probably Not: 19%
- Definitely Not: 4%
- I’m Not Sure: 13%
- No Response: 1%

Do you already get this type of help?

- Yes: 41%
- No: 44%
- I’m Not Sure: 13%
- No Response: 1%

Note: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. Segments may not total 100% due to rounding.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Helpfulness of Supportive Services
California, 2019

*How helpful would this be for you as you deal with your illness(es)? Base: respondents with a serious illness (n = 588)*

<table>
<thead>
<tr>
<th>Service</th>
<th>Somewhat Helpful</th>
<th>Very Helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help with pain or other side effects</td>
<td>22%</td>
<td>41%</td>
</tr>
<tr>
<td>Pills or medication sent to your home</td>
<td>20%</td>
<td>39%</td>
</tr>
<tr>
<td>Financial help to pay bills and make ends meet</td>
<td>18%</td>
<td>34%</td>
</tr>
<tr>
<td>Help with sadness, stress, or other hard feelings</td>
<td>23%</td>
<td>27%</td>
</tr>
<tr>
<td>Help paying for healthy food</td>
<td>17%</td>
<td>28%</td>
</tr>
<tr>
<td>Mental health care from a therapist or doctor</td>
<td>20%</td>
<td>22%</td>
</tr>
<tr>
<td>Help around the house with chores</td>
<td>15%</td>
<td>27%</td>
</tr>
<tr>
<td>Help with transportation</td>
<td>17%</td>
<td>22%</td>
</tr>
<tr>
<td>Spiritual support or counseling</td>
<td>20%</td>
<td>18%</td>
</tr>
<tr>
<td>Having better or more affordable housing</td>
<td>11%</td>
<td>27%</td>
</tr>
</tbody>
</table>

Note: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness.

Source: *Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

Help Wanted
Palliative Care Preferences

Californians with a serious illness report that various physical, emotional, logistical, and financial supportive services would be helpful. Nearly two-thirds of respondents said that getting help with pain or side effects would be very (41%) or somewhat (22%) helpful. About 6 in 10 said that getting medications sent to their home would be very (39%) or somewhat (20%) helpful.
Helpfulness of Supportive Services, by Income Level
California, 2019

**PERCENTAGE RESPONDING “VERY HELPFUL” OR “SOMewhat HELPFUL”**

*How helpful would this be for you as you deal with your illness(es)? Base: respondents with a serious illness (n = 588)*

<table>
<thead>
<tr>
<th>Service</th>
<th>&lt;150% FPL</th>
<th>150%–399% FPL</th>
<th>400%+ FPL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial help to pay bills and make ends meet</td>
<td>29%</td>
<td>59%</td>
<td>78%</td>
</tr>
<tr>
<td>Help with pain or other side effects</td>
<td>51%</td>
<td>68%</td>
<td>75%</td>
</tr>
<tr>
<td>Pills or medication sent to your home</td>
<td>54%</td>
<td>56%</td>
<td>74%</td>
</tr>
<tr>
<td>Help paying for healthy food</td>
<td>25%</td>
<td>51%</td>
<td>71%</td>
</tr>
<tr>
<td>Help with sadness, stress, or other hard feelings</td>
<td>41%</td>
<td>50%</td>
<td>65%</td>
</tr>
<tr>
<td>Having better or more affordable housing</td>
<td>39%</td>
<td>39%</td>
<td>65%</td>
</tr>
<tr>
<td>Help with transportation</td>
<td>25%</td>
<td>43%</td>
<td>58%</td>
</tr>
</tbody>
</table>

Notes: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was $12,490 for a single person and $25,750 for a household of four.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

* For more details see fact sheet Extra Support Most Helpful to Low-Income Californians with Serious Illness available at www.chcf.org/helpwanted.
Interest in Palliative Care Services
California, 2019

Do you think you would want this type of help if you had a serious illness, like cancer?
Some people with a serious illness get extra help. This type of help is on top of regular medical care. It could be help with things like dealing with side effects or pain, dealing with stress and other hard feelings, figuring out how to live better with your illness, or finding out what services you might qualify for. Do you think you would want this type of help if you had a serious illness, like cancer? Base: respondents without a serious illness (n = 2,000)

Notes: Respondents without a serious illness are those who do not report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. 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 rounding.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Interest in Aspects of Palliative Care
California, 2019

PERCENTAGE RESPONDING YES

If you had a serious illness, would you want any of your doctors or health care providers to . . . Base: respondents without a serious illness (n = 2,000)

- Talk about both the good and bad things that could happen with your treatment(s)? 93%
- Talk about what to expect if your illness gets worse? 93%
- Do everything they can to help with pain or side effects? 92%
- Talk about how to make your life better as you live with your illness? 90%
- Talk about any fear, stress, or sadness you may be feeling? 89%
- Ask what is most important for you as you live your life with your illness? 88%

The vast majority of respondents without a serious illness expressed interest in receiving the kinds of services that are typically provided as part of palliative care. Nine in 10 would want to discuss what to expect if their illness got worse, good and bad impacts of treatment, and how to live better with their illness. This high level of interest contrasts with experiences reported by respondents with serious illness (see page 8).

Note: Respondents without a serious illness are those who do not report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness.
Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
# Experiences with Aspects of Palliative Care

California, 2019

**PERCENTAGE RESPONDING YES**

*Have any of your health care providers... Base: respondents with a serious illness (n = 588)*

<table>
<thead>
<tr>
<th>Question</th>
<th>% Responding Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talked about both the good and bad things that could happen with your treatment(s)?</td>
<td>65%</td>
</tr>
<tr>
<td>Talked about how to make your life better as you live with your illness?</td>
<td>58%</td>
</tr>
<tr>
<td>Talked about what to expect if your illness gets worse?</td>
<td>49%</td>
</tr>
<tr>
<td>Done everything they can to help with pain or side effects?</td>
<td>45%</td>
</tr>
<tr>
<td>Asked what is most important for you as you live your life with your illness?</td>
<td>36%</td>
</tr>
<tr>
<td>Talked about any fear, stress, or sadness you may be feeling?</td>
<td>35%</td>
</tr>
</tbody>
</table>

**Note:** Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness.

Most Important Factors at End of Life
California, 2019

PERCENTAGE RESPONDING “EXTREMELY IMPORTANT”

How important is each of the following to you at the end of your life? Base: all respondents (n = 2,588)

- Making sure family is not burdened financially by my care: 70%
- Being able to pay for the care I need: 62%
- Making sure family isn’t burdened by making tough decisions about my care: 60%
- Making sure my wishes for medical care are followed: 60%
- Making sure family is not burdened by taking care of me: 59%
- Being comfortable and without pain: 58%
- Having loved ones around me: 57%
- Being at peace spiritually: 55%
- Not feeling alone: 51%
- Having providers who respect my cultural beliefs and values: 44%
- Living as long as possible: 41%
- Being at home: 40%

Notes: Question is based on a 1-to-7 scale, from 1 being “not at all important” to 7 being “extremely important.” Data reflect the percentage of respondents who rated each response a 7. Additional responses included “A close relationship with my doctor” (32%), “Seeing friends or family I have not seen in a long time” (25%), and “Going back to my hometown or country where I’m from” (19%).

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

Help Wanted
End-of-Life Preferences

Californians are most likely to say a top preference at the end of life is that their family members are not burdened by health care costs and decisions. Survey respondents also noted that being able to pay for the care they need and making sure their wishes are followed were extremely important.
Variation in End-of-Life Preferences, by Race/Ethnicity
California, 2019

PERCENTAGE RESPONDING “EXTREMELY IMPORTANT”
How important is each of the following to you at the end of your life? Base: all respondents (n = 2,588)

Living as long as possible
- White: 59%
- Black: 53%
- Asian / Pacific Islander: 35%
- Latino: 24%

Having doctors and nurses who will respect my cultural beliefs and values
- White: 62%
- Black: 51%
- Asian / Pacific Islander: 40%
- Latino: 37%

Being at peace spiritually
- White: 70%
- Black: 69%
- Asian / Pacific Islander: 48%
- Latino: 40%

Being at home
- White: 49%
- Black: 48%
- Asian / Pacific Islander: 35%
- Latino: 29%

Notes: Question is based on a 1-to-7 scale, from 1 being “not at all important” to 7 being “extremely important.” Data reflect the percentage of respondents who rated each a 7.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Preferences Around Prolonging Life, by Race/Ethnicity and Income Level, California, 2019

*If you had an advanced illness, which would you prefer? Base: all respondents (n = 2,588)*

<table>
<thead>
<tr>
<th></th>
<th>Dying a natural death</th>
<th>Doctors and nurses using everything available to attempt to prolong my life</th>
<th>I’m not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian / Pacific Islander</td>
<td>61%</td>
<td>13%</td>
<td>26%</td>
</tr>
<tr>
<td>Black</td>
<td>53%</td>
<td>22%</td>
<td>25%</td>
</tr>
<tr>
<td>Latino</td>
<td>60%</td>
<td>8%</td>
<td>31%</td>
</tr>
<tr>
<td>White</td>
<td>67%</td>
<td>6%</td>
<td>25%</td>
</tr>
<tr>
<td>&lt;150% FPL</td>
<td>53%</td>
<td>12%</td>
<td>33%</td>
</tr>
<tr>
<td>150%–399% FPL</td>
<td>61%</td>
<td>9%</td>
<td>30%</td>
</tr>
<tr>
<td>400%+ FPL</td>
<td>68%</td>
<td>8%</td>
<td>23%</td>
</tr>
<tr>
<td>Overall</td>
<td>63%</td>
<td>9%</td>
<td>28%</td>
</tr>
</tbody>
</table>

More than 6 in 10 Californians surveyed prefer dying a natural death, compared to about 1 in 10 who would want to receive all possible care to prolong life. Black respondents (22%) were more likely to prefer prolonging life than other racial/ethnic groups. Across all racial/ethnic groups, at least 1 in 4 were not sure.

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

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Preferred Location of Death
California, 2019

If given a choice at the end of your life, where would you want to be when you die? Base: all respondents (n = 2,588)

A large majority of Californians would prefer to die at home rather than in a health care facility. The proportion wanting to die at home is consistent with CHCF’s 2011 survey findings (70%). *

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

Location of Death
California, 2005, 2011, and 2017

Despite the survey finding that 71% of Californians would prefer to die at home, only 36% of Californians who died in 2017 did so at home. The proportion of Californians dying at home has increased since 2005, while the proportion who died in the hospital decreased from 45% in 2005 to 37% in 2017.

Notes: Hospital includes inpatient, outpatient, emergency room, or dead on arrival at hospital. Other and place of death unknown are not shown.

Views of the End of Life Option Act, by Race/Ethnicity and Income Level, California, 2019

In June 2016, the End of Life Option Act became law in California. This state law gives some terminally ill adults the option to take life-ending medication prescribed by a doctor. Do you support or oppose people having this option? Base: all respondents (n = 2,588)

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Support</th>
<th>Oppose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian / Pacific Islander</td>
<td>76%</td>
<td>20%</td>
</tr>
<tr>
<td>Black</td>
<td>70%</td>
<td>28%</td>
</tr>
<tr>
<td>Latino</td>
<td>68%</td>
<td>29%</td>
</tr>
<tr>
<td>White</td>
<td>82%</td>
<td>16%</td>
</tr>
<tr>
<td>&lt;150% FPL</td>
<td>65%</td>
<td>31%</td>
</tr>
<tr>
<td>150%–399% FPL</td>
<td>71%</td>
<td>27%</td>
</tr>
<tr>
<td>400%+ FPL</td>
<td>83%</td>
<td>14%</td>
</tr>
<tr>
<td>Overall</td>
<td>75%</td>
<td>22%</td>
</tr>
</tbody>
</table>

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

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
In 2019, a higher percentage of Californians surveyed indicated they were familiar with terms related to serious illness and end-of-life care than in 2011.* While four in five survey respondents had heard of hospice care in 2019, less than two in five respondents had heard of palliative care, and about one in five had heard of POLST (Physician Orders for Life-Sustaining Treatment).

Awareness of Serious Illness and End-of-Life Terms, by Income Level, California, 2019

PERCENTAGE RESPONDING YES

*Have you ever heard of any of the following terms? Base: all respondents (n = 2,588)*

<table>
<thead>
<tr>
<th>Term</th>
<th>&lt;150% FPL</th>
<th>150%–399% FPL</th>
<th>400%+ FPL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice Care</td>
<td>64%</td>
<td>76%</td>
<td>90%</td>
</tr>
<tr>
<td>Do-Not-Resuscitate (DNR) Order</td>
<td>48%</td>
<td>67%</td>
<td>85%</td>
</tr>
<tr>
<td>Advance Directive</td>
<td>33%</td>
<td>45%</td>
<td>60%</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>22%</td>
<td>30%</td>
<td>49%</td>
</tr>
<tr>
<td>POLST (Physician Orders for Life-Sustaining Treatment)</td>
<td>18%</td>
<td>22%</td>
<td>23%</td>
</tr>
</tbody>
</table>

Note: In 2019, the federal poverty level (FPL) was $12,490 for a single person and $25,750 for a household of four.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
End-of-Life Wishes in Writing, by Demographic Groups
California, 2019

Do you have any of your wishes regarding the medical treatment you would want in a written document? Base: all respondents (n = 2,588)

No Response 1%
Yes 34%
No 66%

MOST LIKELY TO SAY YES
- 65+ 61%
- White 42%
- Has Serious Illness 40%
- 400%+ FPL 40%

MOST LIKELY TO SAY NO
- Latino 76%
- <150% FPL 74%
- 150%–399% FPL 69%
- Black 68%

Note: In 2019, the federal poverty level (FPL) was $12,490 for a single person and $25,750 for a household of four. Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. Segments may not total 100% due to rounding.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Barriers to Documenting End-of-Life Wishes
California, 2019

PERCENTAGE RESPONDING YES
Are any of these a reason you do not have your wishes in writing? Base: respondents who do not have their wishes in writing (n = 1,633)

- I trust my family to make decisions for me: 47%
- I’m too busy right now with other things: 42%
- I don’t want to think about death or dying: 41%
- I don’t know how to put wishes in a legal document: 34%
- A legal document is too permanent: 16%
- Doctors might not give me care that could help: 15%
- I don’t know why I would need this: 14%

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

Among survey respondents who had not put their end-of-life wishes in writing, the main reasons for not doing so included having trust in family members to make decisions, feeling too busy, and not wanting to think about death or dying.
Nearly all Californians surveyed would want family members to make decisions about their care near the end of life, if they were unable to make decisions for themselves. Half reported wanting their spouse or partner to make those decisions.

Let’s say you were not able to make decisions about your care near the end of your life. Who would you want to make decisions about your care? Base: all respondents (n = 2,588)

Notes: The full question asked was, “Let’s say you were not able to make decisions about your care near the end of your life. Your doctor says there are different options. Someone has to decide for you. Who would you want to make decisions about your care?” Segments may not total 100% due to rounding.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Discussed End-of-Life Wishes, by Demographic Groups
California, 2019

Have you talked with this person (preferred decisionmaker) about the kind of medical care you would want near the end of your life? Base: all respondents (n = 2,588)

Notes: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was $12,490 for a single person and $25,750 for a household of four.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Doctor Has Asked About End-of-Life Wishes
California, 2019

Have you ever had a doctor ask you about your wishes for medical treatment at the end of your life?

Among Those with a Serious Illness
Base: respondents with a serious illness (n = 588)

- Yes: 21%
- No: 78%

Among Those Age 65 and Older
Base: respondents age 65+ (n = 553)

- Yes: 20%
- No: 79%

Notes: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Would Like to Talk to Doctor About End-of-Life Wishes
California, 2019

If you were seriously ill, would you like to talk with your doctor about your wishes for medical treatment towards the end of your life? Base: all respondents (n = 2,588)

- Definitely Yes: 54%
- Probably Yes: 28%
- Maybe: 13%
- Definitely or Probably Not: 5%
- No Response: 1%

Most likely to say "Definitely Yes"
- 65+: 61%
- Black: 61%
- Women: 59%
- White: 59%

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019. Segments may not total 100% due to rounding.
Information Preferences Around Serious Illness, by Race/Ethnicity and Income Level, California, 2019

If you had a serious illness, how much information would you want from your health care provider? Base: respondents without a serious illness (n = 2,000)

Notes: Respondents without a serious illness are those who do not report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was $12,490 for a single person and $25,750 for a household of four.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Feeling Prepared If Illness Gets Worse, by Income Level
California, 2019

How prepared do you feel to deal with your illness(es) if it gets worse in the future? By prepared, we mean you know what is going on, you can plan for what is coming, and you feel ready. Base: respondents with a serious illness (n = 588)

One in 6 survey respondents with a serious illness felt very prepared to deal with their illness(es) if it worsens. Adults with the lowest incomes are the least likely to feel prepared, with 1 in 14 reporting that they felt very prepared.

Notes: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was $12,490 for a single person and $25,750 for a household of four. Nonresponders not shown. Segments may not total 100% due to nonresponse or rounding.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
**Overall Rating of End-of-Life Care of Loved One, by Insurance Type, California, 2019**

*Overall, how would you rate the care your loved one received at the end of life — that is, in the last few months of their life? Base: respondents who lost a close loved one within the past two years (n = 1,276)*

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**Notes:**
- *Public insurance* includes respondents who said their loved one’s source of coverage was either Medicare only, Medi-Cal only, Medicare and Medi-Cal, or VA benefits / Tri-Care.
- *Private insurance* includes respondents who said their loved one’s source of coverage was through an employer or a private plan they purchased on their own. Segments may not total 100% due to rounding.

*Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.*

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**Help Wanted**

**End-of-Life Care**

Among survey respondents who lost a loved one in the past two years, 4 in 10 rated the care their loved one received as either excellent (14%) or very good (28%). One in 14 (7%) rated their loved one’s care as poor. Respondents whose loved one had private insurance were more likely than those with public insurance to rate care as excellent (24% vs. 15%).
Provider Communication at End of Life, by Insurance Type
California, 2019

Overall, how would you rate the doctors in terms of how well they communicated with your loved one and family members about treatment options? Base: respondents who lost a close loved one within the past two years (n = 1,276)

Among survey respondents who lost a loved one in the past two years, 1 in 3 reported that doctors’ communication about treatment options was either excellent (12%) or very good (21%). One in 14 (7%) rated the doctors’ communication as poor. Respondents whose loved one had private insurance were twice as likely as those with public coverage to rate communication as excellent (29% vs. 14%).

Notes: Public insurance includes respondents who said their loved one’s source of coverage was either Medicare only, Medi-Cal only, Medicare and Medi-Cal, or VA benefits / Tri-Care. Private insurance includes respondents who said their loved one’s source of coverage was through an employer or a private plan they purchased on their own. Segments may not total 100% due to rounding.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Loved One’s Experience with Aspects of Palliative Care
California, 2019

As far as you know, did your loved one’s doctors or health care providers . . . Base: respondents who helped make health care decisions for a loved one who died from a serious or chronic health problem in the past two years (n = 238)

<table>
<thead>
<tr>
<th>Question</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do everything they could to help with your loved one’s pain or side effects from their illness or treatment?</td>
<td>74%</td>
</tr>
<tr>
<td>Talk with you or your loved one about how to make your loved one’s life better as they lived with their illness?</td>
<td>74%</td>
</tr>
<tr>
<td>Talk with you or your loved one about what to expect if their illness got worse?</td>
<td>73%</td>
</tr>
<tr>
<td>Talk with you or your loved one about both the good and bad things that could happen with their treatment?</td>
<td>72%</td>
</tr>
<tr>
<td>Ask what was most important for your loved one as they lived their life with their illness?</td>
<td>64%</td>
</tr>
<tr>
<td>Talk with you or your loved one about any fear, stress, or sadness you or they were feeling?</td>
<td>53%</td>
</tr>
</tbody>
</table>

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Loved One Feeling Prepared as Illness Got Worse
California, 2019

How prepared was your loved one to deal with their illness as it got worse? Base: respondents who helped make health care decisions for a loved one who died from a serious or chronic health problem in the past two years (n = 238)

- Very Prepared: 21%
- Somewhat Prepared: 42%
- Not Too Prepared: 14%
- Not at All Prepared: 17%
- Not Sure: 6%

Note: This question defined prepared as “your loved one knew what was going on, they could plan for what was coming, and they felt ready.”

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
**Preferred Versus Actual Location of Death**

*California, 2019*

As far as you know, where do you think your loved one would have wanted to die if given the choice? Where did your loved one die? Base: respondents who lost a close loved one within the past two years (n = 1,276)

<table>
<thead>
<tr>
<th>Location of Death</th>
<th>Preferred Location of Death</th>
<th>Actual Location of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>65%</td>
<td>39%</td>
</tr>
<tr>
<td>Hospital</td>
<td>8%</td>
<td>38%</td>
</tr>
<tr>
<td>Nursing Home/Facility, Hospice Facility, or Assisted Living Facility</td>
<td>2%</td>
<td>10%</td>
</tr>
<tr>
<td>Somewhere Else</td>
<td>1%</td>
<td>5%</td>
</tr>
<tr>
<td>I’m Not Sure</td>
<td>6%</td>
<td>22%</td>
</tr>
</tbody>
</table>

Notes: Nonresponders not shown. Segments may not total 100% due to nonresponse or rounding.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

Many survey respondents reported that their loved ones did not pass away in their preferred location. Nearly 2 in 3 respondents reported that their loved ones would have preferred to die at home, while only 4 in 10 were able to do so. In contrast, nearly 4 in 10 died in the hospital, which was the preferred location for less than 1 in 10 loved ones.
Loved One’s Experience at End of Life
California, 2019

Think about the very end of your loved one’s life. Do you think the end went the way your loved one wanted it to go? Base: respondents who had a loved one die from a serious or chronic health problem in the past two years (n = 889)

- Yes: 33%
- No: 34%
- I’m Not Sure: 32%
- No Response: 2%

Note: Segments may not total 100% due to rounding.
Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Loved One’s End-of-Life Wishes Followed
California, 2019

To what extent do you feel your loved one’s end-of-life wishes were followed and honored by the doctors, nurses, and other health care providers who cared for them? Base: respondents who lost a close loved one within past two years (n = 1,276)

- Completely: 29%
- For the Most Part: 27%
- I’m Not Sure: 33%
- In Some Ways But Not Others: 6%
- Not at All: 3%
- No Response: 2%

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Influencing Factors

Factors That May Impact Health and Access to Care, by Race/Ethnicity and Income Level, California, 2019

Social isolation, housing insecurity, and food insecurity can all negatively impact a person’s health and ability to access care when needed. Survey respondents of color and those with the lowest incomes were disproportionately likely to report a lack of social networks and an insecurity with basic needs.

Notes:
Social isolation includes respondents who disagree with the statement "When I feel lonely there are several people I can talk to." Housing insecurity includes respondents who say it is hard to pay their rent or mortgage every month. Food insecurity includes respondents who say they often or sometimes "don't have enough to eat" or "have enough to eat but not always the kinds of food we want." In 2019, the federal poverty level (FPL) was $12,490 for a single person and $25,750 for a household of four.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
One in three survey respondents said they have faced barriers to getting the health care services they need. The most common barriers cited were insurance status or type and income.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
About 4 in 10 Black, Latino, and low-income respondents said they reported feeling like they could not get needed health care services because of their race/ethnicity, language, insurance status or type, and/or income level. Black respondents were much more likely to cite race/ethnicity as a barrier (14%) than Latino (6%), Asian / Pacific Islander (2%), and white (2%) respondents (not shown).
Felt Judgment or Discrimination from Provider
California, 2019

<table>
<thead>
<tr>
<th>PERCENTAGE RESPONDING YES</th>
<th>Have you ever felt judged or treated differently by a health care provider because of . . . Base: all respondents (n = 2,588)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes to Any</td>
<td>19%</td>
</tr>
<tr>
<td>Type of Insurance</td>
<td>12%</td>
</tr>
<tr>
<td>Being Uninsured</td>
<td>9%</td>
</tr>
<tr>
<td>Your Income</td>
<td>8%</td>
</tr>
<tr>
<td>Your Race/Ethnicity</td>
<td>7%</td>
</tr>
<tr>
<td>Your Language</td>
<td>5%</td>
</tr>
</tbody>
</table>

Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

One in five survey respondents said they felt judged or treated differently by a health care provider. The most common reasons for feeling judged or treated differently were the respondent’s type of insurance or being uninsured.
Felt Judgment or Discrimination from Provider, by Race/Ethnicity and Income Level, California, 2019

PERCENTAGE RESPONDING YES TO ANY

Have you ever felt judged or treated differently by a health care provider because of your race/ethnicity, your language, being uninsured, your income or your type of insurance? Base: all respondents (n = 2,588)

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian / Pacific Islander</td>
<td>15%</td>
</tr>
<tr>
<td>Black</td>
<td>37%</td>
</tr>
<tr>
<td>Latino</td>
<td>22%</td>
</tr>
<tr>
<td>White</td>
<td>14%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Income Level</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;150% FPL</td>
<td>32%</td>
</tr>
<tr>
<td>150%–399% FPL</td>
<td>22%</td>
</tr>
<tr>
<td>400%+ FPL</td>
<td>11%</td>
</tr>
<tr>
<td>Overall</td>
<td>19%</td>
</tr>
</tbody>
</table>

Note: In 2019, the federal poverty level (FPL) was $12,490 for a single person and $25,750 for a household of four.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
In general, how much do you trust your health care providers to act in your best interest? Base: all respondents (n = 2,588)

Overall, 40% of survey respondents expressed a lot of trust in their health care providers to act in their best interest; white and high-income respondents were most likely to report a lot of trust in their providers. Only 12% of respondents had not much or no trust in their providers to act in their best interests.

Note: 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 rounding.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Methodology

The survey was conducted June 6 through July 2, 2019, among a representative sample of 2,588 Californians age 18 and older, including 1,276 respondents who have lost a loved one in the past two years. The margin of error is +/- 3.1 percentage points for the total results.

The survey was administered using Ipsos’s KnowledgePanel, which is the first online research panel that is representative of the US population. Panel members are randomly recruited through address-based sampling methods, and households are provided with hardware and access to the Internet if needed.

For additional information on methodology and demographics of respondents, visit www.chcf.org/helpwanted.