



CANCER LEGAL CARE
LAWYERS ON YOUR CANCER CARE TEAM

**Cancer Legal Care 2023 Survey
Summary Report**

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Executive Summary

Background

Cancer is an extremely costly disease, with cancer costs projected to reach \$246 billion by 2030. Millions of Americans face this financial burden, often due to legal and insurance issues that could be improved with help from lawyers and legal services. These challenges relate to income, food, disability benefits, health insurance, and legal status.

Providing legal services to individuals with cancer is necessary during the challenges of cancer diagnoses, treatment, and survivorship. While medical legal partnerships exist in over half of U.S. states, many people still struggle with legal and financial challenges after diagnosis. Cancer Legal Care (CLC) is a nonprofit located in the Twin Cities area that provides free legal services to people with cancer and their families in hopes of easing the financial stress of cancer. In order to understand client experiences with CLC, understand the impact of a cancer diagnosis on individual's finances and gain additional insights into CLC's new Social Security Advocacy program, CLC staff and cancer survivorship researchers at the University of Minnesota (UMN) developed and conducted a survey of recent CLC clients in the summer of 2023.

Overview of Survey Design and Administration

Utilizing the key themes identified from CLC key informant interviews, the UMN and CLC collaboratively developed a brief survey to administer more broadly to current and past CLC clients to further understand barriers to (1) accessing legal services and (2) enrollment on Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) in this population as well as understand the impact of a cancer diagnosis on the finances of clients. Once developed, our team mailed 430 mailed surveys to clients working with CLC in the past 2 years. 120 (28%) surveys were completed, and, of these, 113 (26%) were included in analysis. Excluded surveys were from respondents who indicated they did not use CLC services (n=5) and respondents who submitted partial surveys (n=2).

Findings

Most respondents reported utilizing CLC services for themselves (75%) after receiving information from a medical clinic or personnel, and that CLC was able to resolve all (70%) or most (23%) of their legal concerns. Cancer's financial toxicity is evident, with 61% of respondents reporting a decrease in income after their diagnosis, with 34% indicating a moderate impact on finances and income and 44% indicating a profound impact. Respondents were excited about the new programming CLC is launching around a new Social Security Advocacy program. 40% of respondents indicated that they did not feel confident applying for Social Security Disability Insurance without professional help.

Further details can be found in the subsequent tables that present findings by individual survey question. Appendix A contains detailed information about survey design and administration methods. Appendix B contains excerpts from open ended survey questions. Appendices C & D include a copy of the interview guide and survey instrument respectively.

Conclusions

Cancer Legal Care provides a broad range of legal services that support individuals with cancer and their families. Clients experience great benefit from their interactions with CLC, which is critical given the tremendous financial impact reported by individuals after diagnosis. New programming, such as CLC's recently developed Social Security Advocacy services, provides additional critical opportunities to address financial concerns after diagnosis through legal advocacy for clients.



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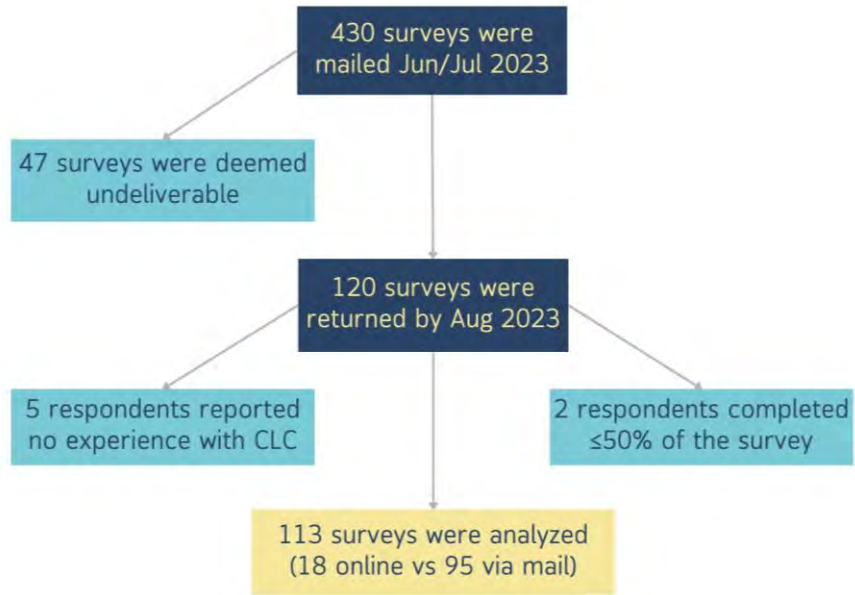
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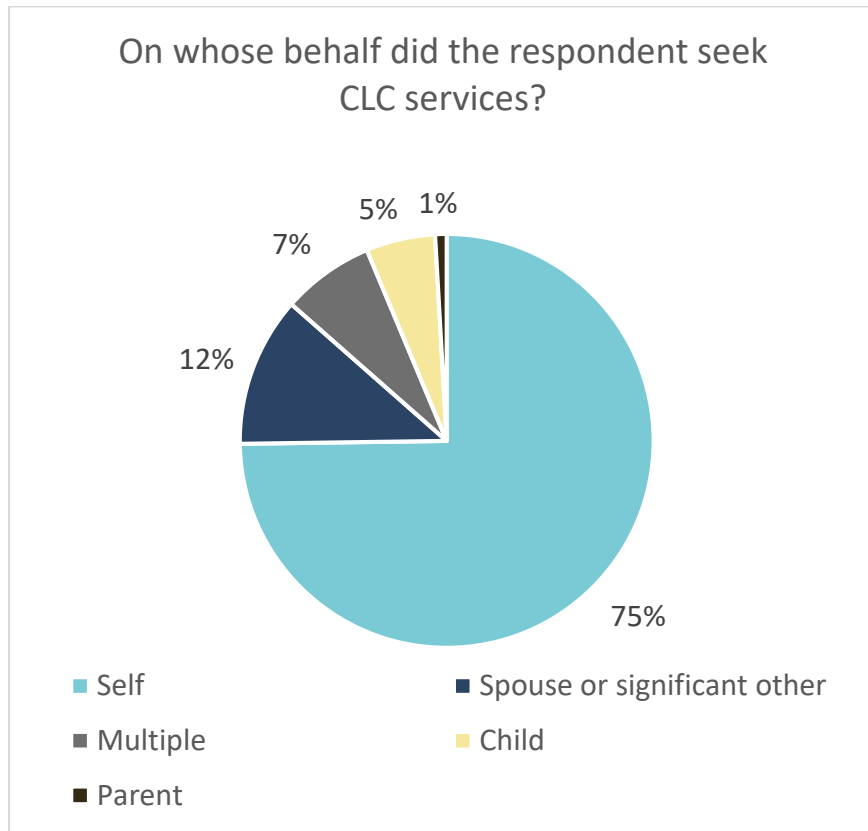


Cohort Development



Section 1: CLC Experience

Respondent Type



I worked with Cancer Legal Care for: Check all that apply.

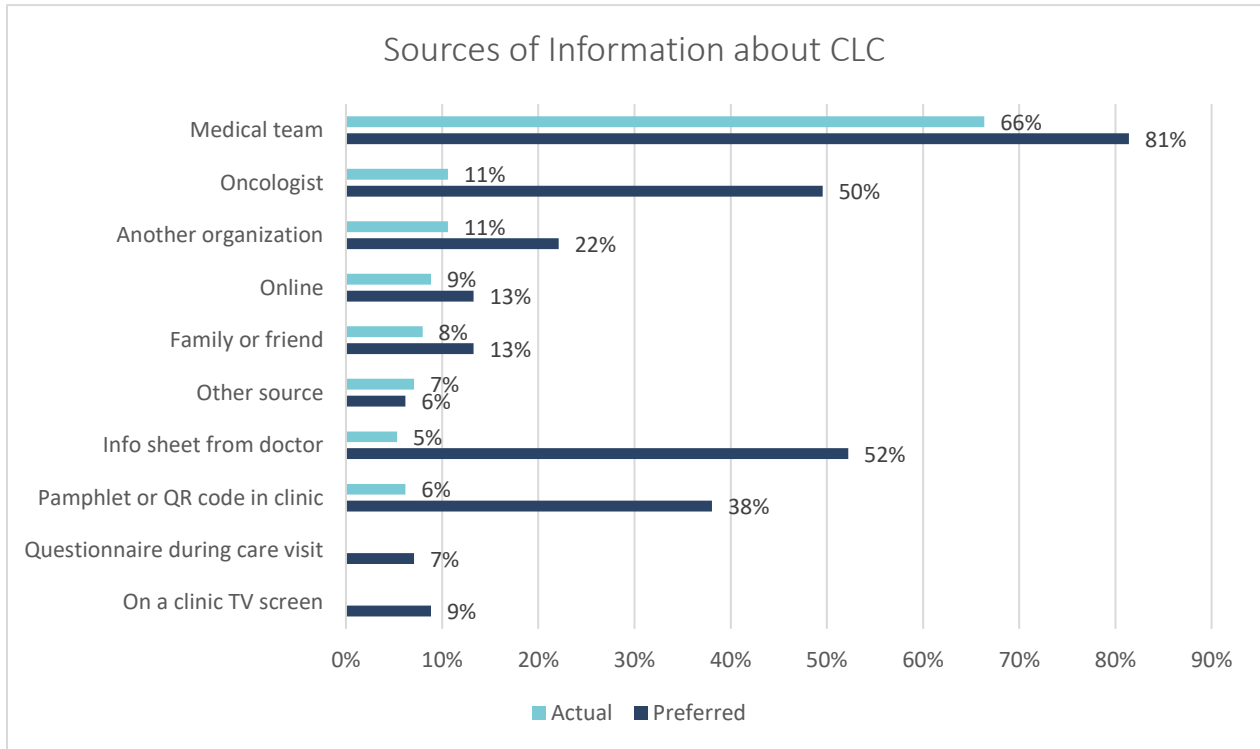
| Response | % | N |
|-------------------|-----|----|
| Self | 74% | 84 |
| Significant Other | 12% | 13 |
| Child | 6% | 7 |
| Parent | 1% | 1 |
| Multiple | 7% | 8 |

Participants could mark more than one option on this question, so a category of “Multiple” was created. 111 participants answered this question.

The vast majority (75%) of respondents had sought CLC services for themselves only.



Sources of Information



How did you find out about Cancer Legal Care? Check all that apply.

How would you like to find out about services like those offered by Cancer Legal Care? Check all that apply.

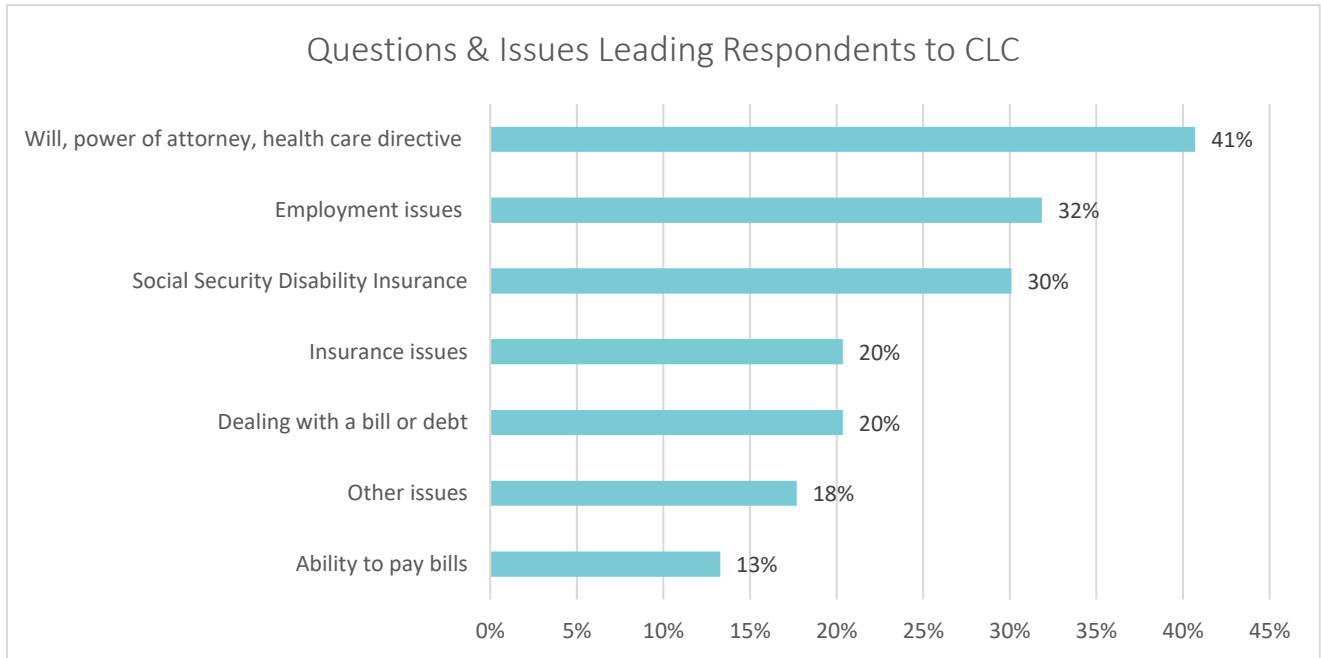
| Response | % | | N | |
|---------------------------------|-----------|--------|-----------|--------|
| | Preferred | Actual | Preferred | Actual |
| On a clinic TV screen | 9% | 0% | 10 | 0 |
| Questionnaire during care visit | 7% | 0% | 8 | 0 |
| Pamphlet or QR code in clinic | 38% | 6% | 43 | 7 |
| Info sheet from doctor | 52% | 5% | 59 | 6 |
| Other source | 6% | 7% | 7 | 8 |
| Family or friend | 13% | 8% | 15 | 9 |
| Online | 13% | 9% | 15 | 10 |
| Another organization | 22% | 11% | 25 | 12 |
| Oncologist | 50% | 11% | 56 | 12 |
| Medical team | 81% | 66% | 92 | 75 |

Participants could mark more than one option on these questions. 113 participants answered each of these two questions.

In comparing these questions, it seems that many more individuals would like to learn about CLC from their oncologist or through an informational handout than is currently the case.



Questions and Issues



What types of questions or issues did you have that led you to contact Cancer Legal Care? Check all that apply.

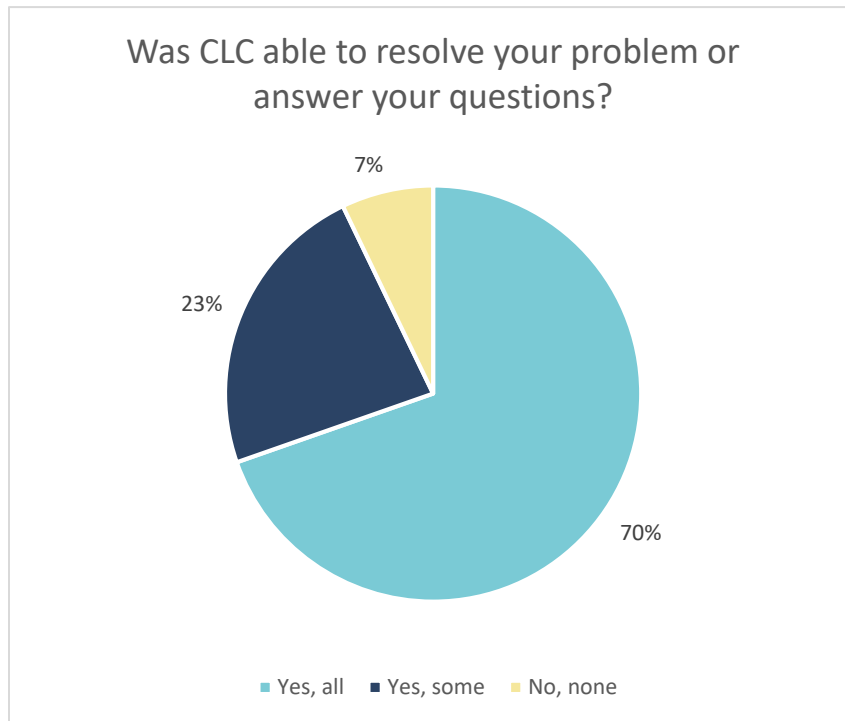
| Response | % | N |
|--|-----|----|
| Ability to pay bills | 13% | 15 |
| *Other issues | 18% | 20 |
| Dealing with a bill or debt | 20% | 23 |
| Insurance issues | 20% | 23 |
| Social Security Disability Insurance | 30% | 34 |
| Employment issues | 32% | 36 |
| Will, power of attorney, health care directive | 41% | 46 |

*Other issues included ability to stay in home, taxes, family issues, and write-in responses.

Participants could mark more than one option on this question. 113 participants answered this question.



Resolution



Was Cancer Legal Care able to help you resolve your legal problem or answer your questions?

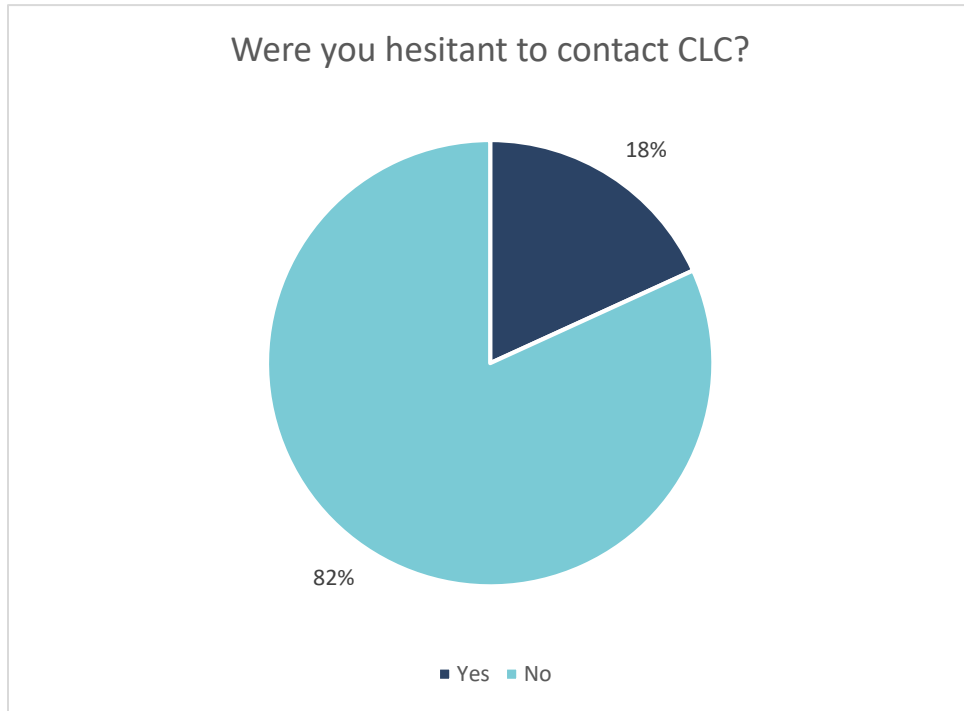
| Response | % | N |
|-----------|-----|----|
| Yes, all | 70% | 78 |
| Yes, some | 23% | 26 |
| No, none | 7% | 8 |

112 participants answered this question.

For 93% of respondents, CLC was able to resolve some or all of their issues and questions.



Hesitancy



Were you hesitant for any reason to contact Cancer Legal Care?

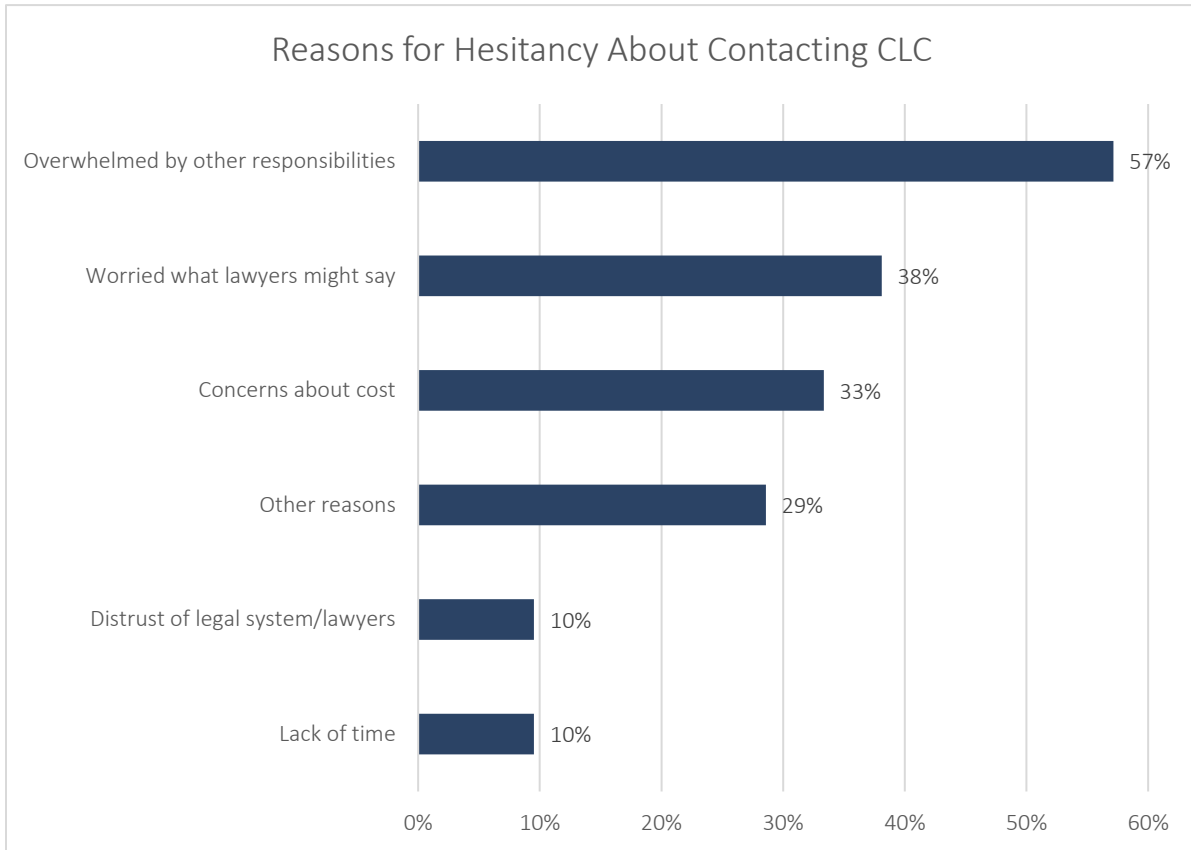
| Response | % | N |
|----------|-----|----|
| Yes | 18% | 20 |
| No | 82% | 90 |

110 participants answered this question.

Only 18% of respondents reported they were hesitant to contact CLC. Their reasons for hesitancy were solicited in the next, follow-up question.



Hesitancy- Reasons

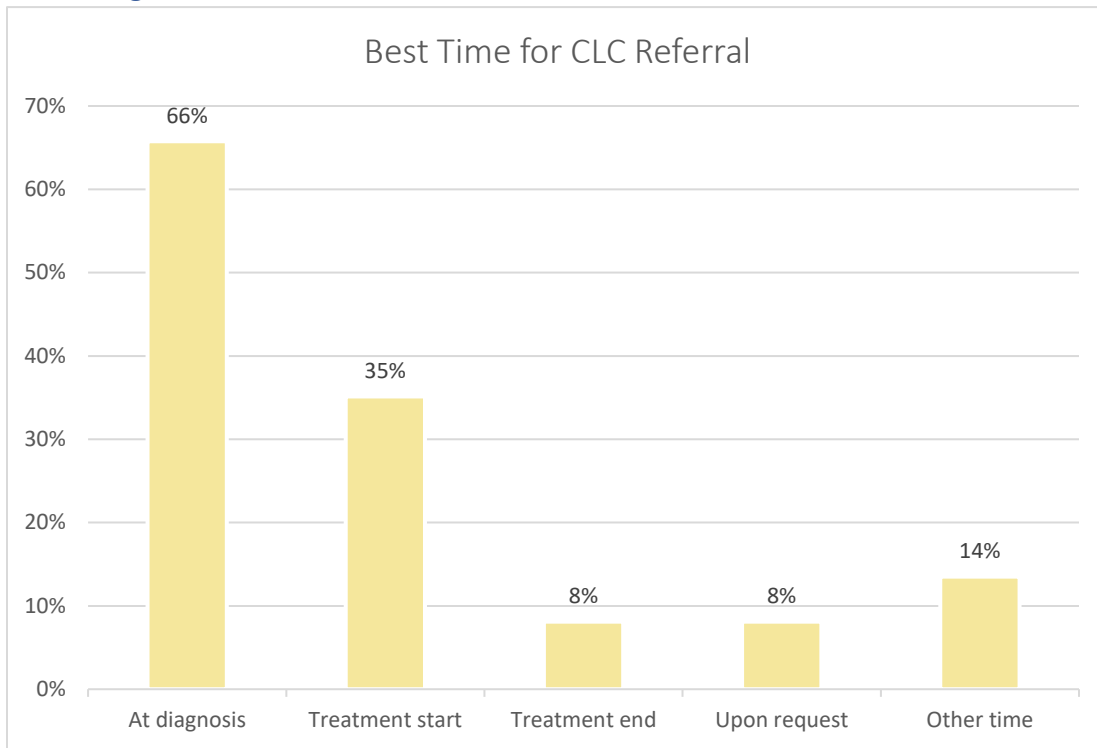


What reasons made you hesitant? Check all that apply.

| Response | % | N |
|---------------------------------------|-----|----|
| Lack of time | 10% | 2 |
| Distrust of legal system/lawyers | 10% | 2 |
| Other reasons | 29% | 6 |
| Concerns about cost | 33% | 7 |
| Worried what lawyers might say | 38% | 8 |
| Overwhelmed by other responsibilities | 57% | 12 |

Participants could mark more than one option on this question. 21 participants answered this question. Other reasons for hesitancy that were written-in included feeling overwhelmed by treatment, scheduling issues, and feeling undeserving of CLC’s services. See appendix B for all write-in responses to this question.

Referral Timing



When would it have been most useful to learn about Cancer Legal Care’s services? Check all that apply.

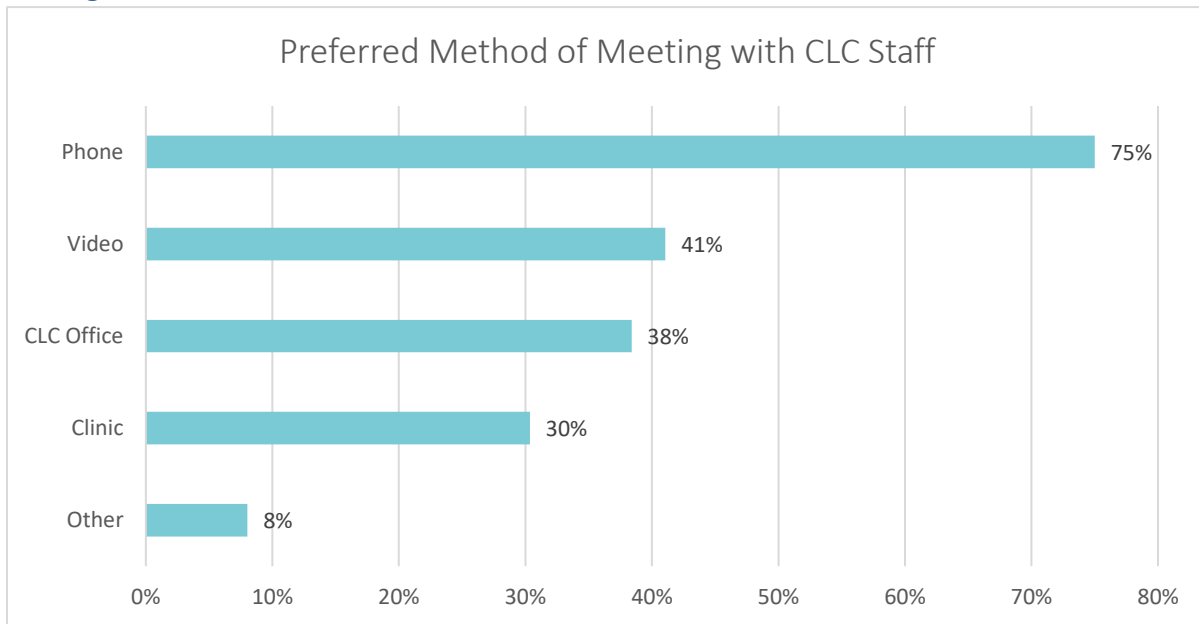
| Response | % | N |
|-----------------|-----|----|
| At diagnosis | 66% | 73 |
| Treatment start | 35% | 39 |
| Treatment end | 8% | 9 |
| Upon request | 8% | 9 |
| Other time | 14% | 15 |

Participants could mark more than one option on this question. 111 participants answered this question.

Responses indicate that earlier is better when it comes to connecting with CLC. Those who wrote in responses suggesting an “other time” often conveyed the need for flexibility depending on patients’ needs, or that anytime would be good.

Individuals answered this question similarly, regardless of who they sought CLC services for (themselves or another).

Meeting Method



If you were to meet with Cancer Legal Care again, how would you like to meet their staff? Check all that apply.

| Response | % | N |
|------------|-----|----|
| Other | 8% | 9 |
| Clinic | 30% | 34 |
| CLC Office | 38% | 43 |
| Video | 41% | 46 |
| Phone | 75% | 84 |

Participants could mark more than one option on this question. 112 participants answered this question.

Digital means of meeting were preferred over in-person methods. This be a result of convenience and flexibility or changes in norms since the COVID-19 pandemic.

Individuals answered this question similarly, regardless of who they sought CLC services for (themselves or another).

Section 2: Cancer and Finances

Financial wellbeing before vs. after cancer diagnosis.



Which one of these comes closest to your current feelings about your household income?

Before the cancer diagnosis, how would you describe your feelings about your household income?

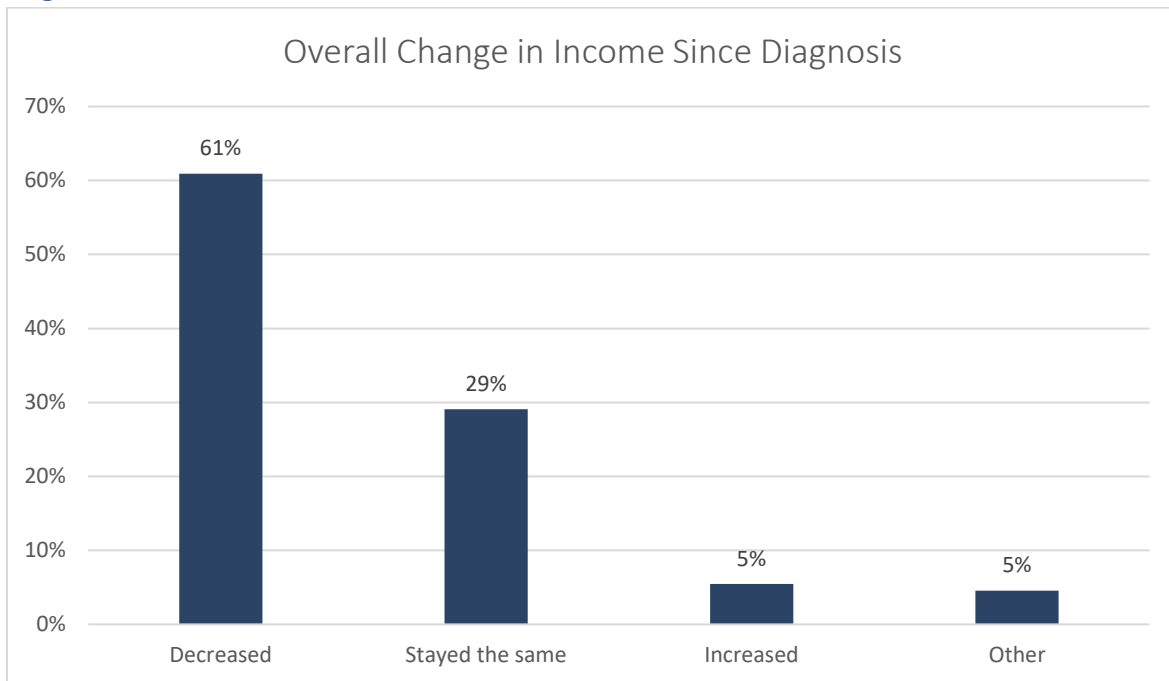
| | Missing (After) | Living comfortably (After) | Getting by (After) | Difficult to get by (After) | Very difficult to get by (After) |
|---|-----------------|----------------------------|--------------------|-----------------------------|----------------------------------|
| Missing (Before) | 2 | 0 | 0 | 0 | 0 |
| Living Comfortably (Before) | 0 | 27 | 31 | 10 | 1 |
| Getting by (Before) | 0 | 0 | 21 | 11 | 4 |
| Finding it difficult to get by (Before) | 0 | 2 | 1 | 3 | 0 |

111 participants answered each of these two questions.

This figure shows that respondents tended to be worse off financially after cancer diagnosis. Prior to cancer, no respondents found it very difficult to get by, compared with 5% who did after diagnosis. Only 3% of respondents were better off financially after diagnosis, while 55% had their financial situation stay the same, and 42% felt their situation worsen. Of the 3% of surveys that indicated an improved financial situation, two were completed by individuals whose family members had passed away due to cancer, and one was completed by an individual who had been connected to SSDI by CLC.



Change in Income



Overall, how has your income changed since diagnosis?

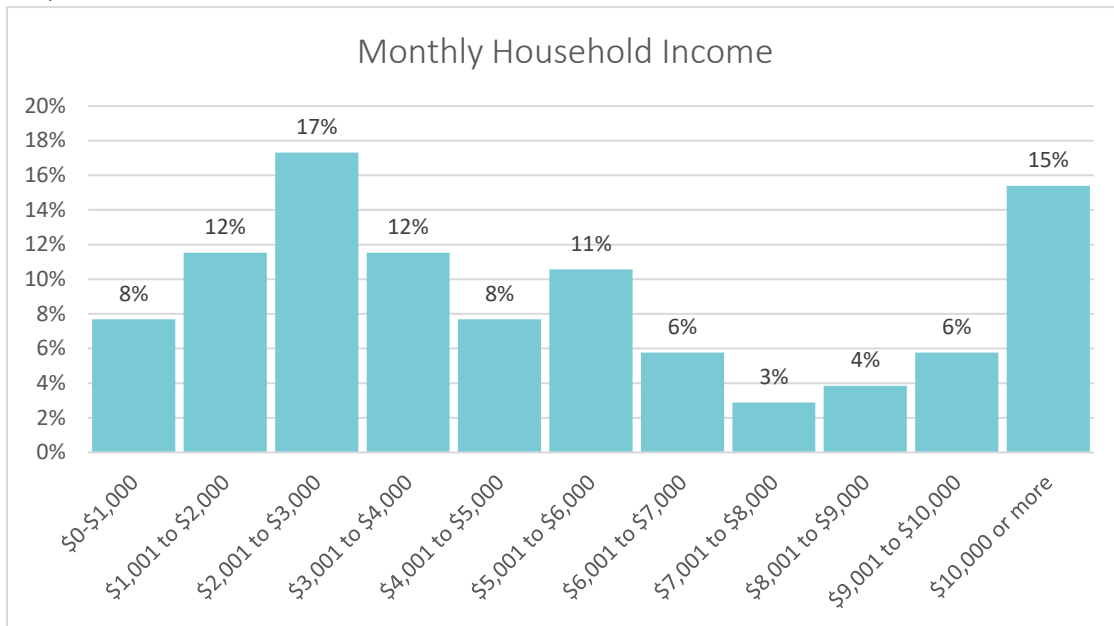
| Income Change | % | N |
|-----------------|-----|----|
| Decreased | 61% | 67 |
| Stayed the same | 29% | 32 |
| Increased | 5% | 6 |
| Other | 5% | 5 |

110 respondents answered this question.

These findings cohere with the previous figure, showing a negative impact of cancer on income. However, this question asked about income objectively, whereas the previous figure reports subjective feelings *about* income.



Monthly Household Income



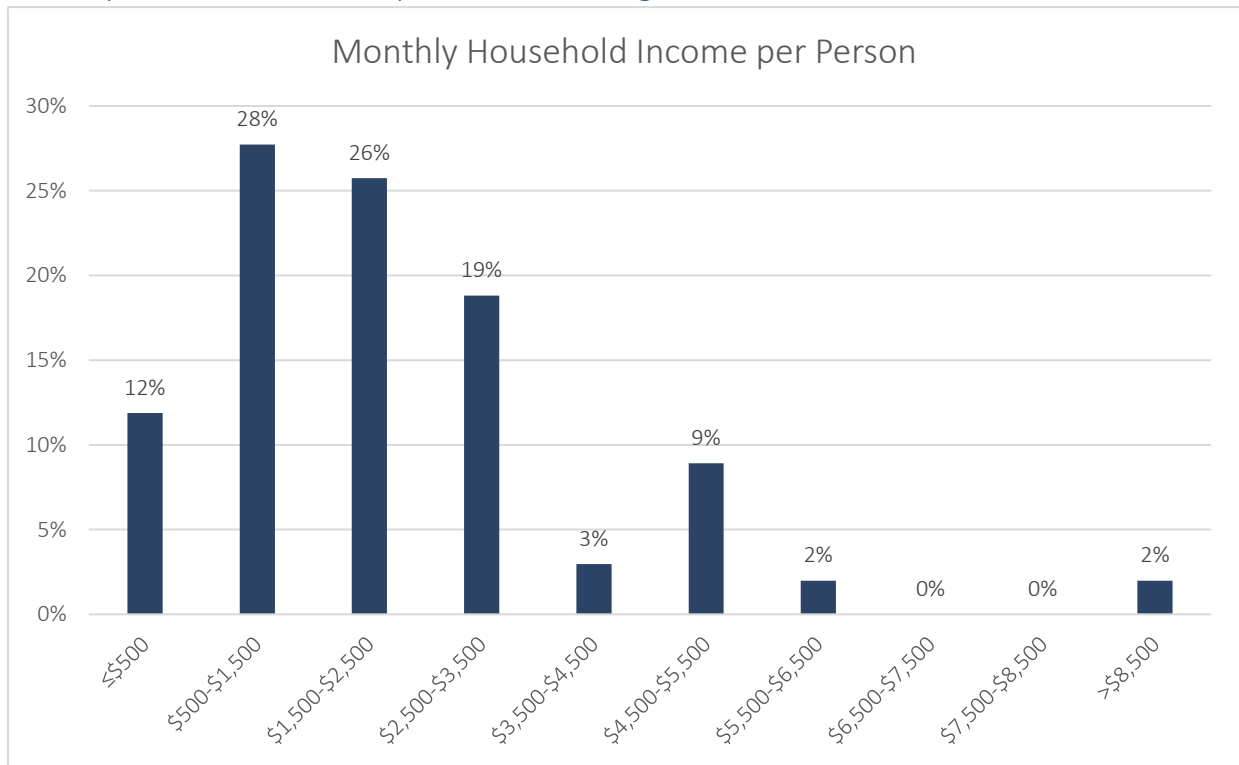
What is your current MONTHLY household income? Please respond from the perspective of the person who received services from Cancer Legal Care. This is the total MONTHLY pre-tax income from all sources earned. Please include all members of your family living in your household.

| Response | % | N |
|---------------------|-----|----|
| \$0-\$1,000 | 8% | 8 |
| \$1,001 to \$2,000 | 12% | 12 |
| \$2,001 to \$3,000 | 17% | 18 |
| \$3,001 to \$4,000 | 12% | 12 |
| \$4,001 to \$5,000 | 8% | 8 |
| \$5,001 to \$6,000 | 11% | 11 |
| \$6,001 to \$7,000 | 6% | 6 |
| \$7,001 to \$8,000 | 3% | 3 |
| \$8,001 to \$9,000 | 4% | 4 |
| \$9,001 to \$10,000 | 6% | 6 |
| \$10,000 or more | 15% | 16 |

Based on 104 respondents who answered this question with a numeric answer (those who didn't know their income or wrote in context with no number were removed).



Monthly Household Income per Person- Histogram



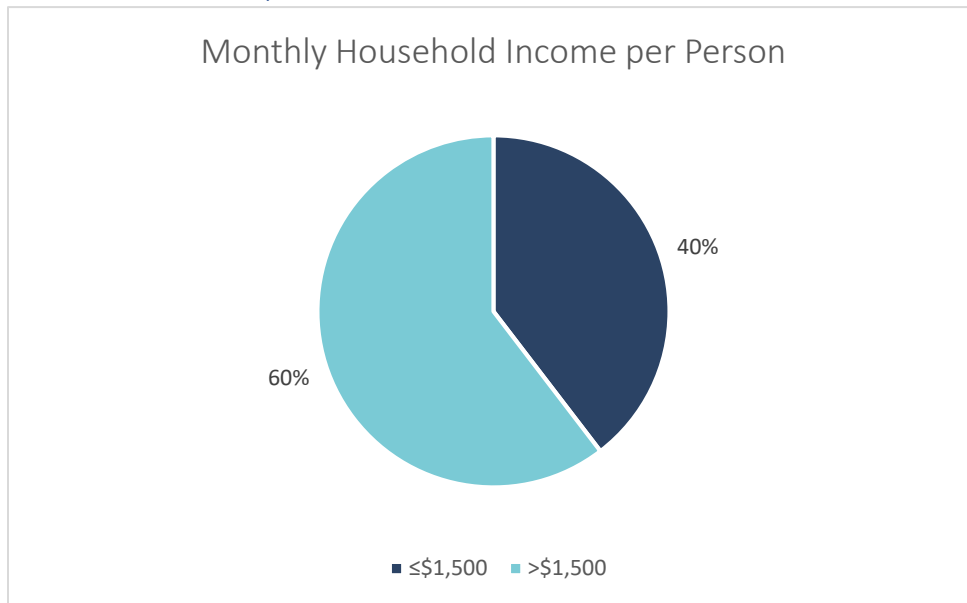
| Response | % | N |
|-----------------|-----|----|
| ≤\$500 | 12% | 12 |
| \$500-\$1,500 | 28% | 28 |
| \$1,500-\$2,500 | 26% | 26 |
| \$2,500-\$3,500 | 19% | 19 |
| \$3,500-\$4,500 | 3% | 3 |
| \$4,500-\$5,500 | 9% | 9 |
| \$5,500-\$6,500 | 2% | 2 |
| \$6,500-\$7,500 | 0% | 0 |
| \$7,500-\$8,500 | 0% | 0 |
| >\$8,500 | 2% | 2 |

This figure is based on 101 respondents who provided numeric answers to questions about both income and household size (those who didn't know or wrote in context with no number were removed).

Individuals reporting monthly household incomes between \$0 and \$10,000 were assigned the value in the middle of their reported range. Individuals reporting monthly household incomes over \$10,000 were conservatively assigned a value of \$10,500. These estimated incomes were then divided by the reported number of individuals living in the respondents' household.



Monthly Household Income per Person – Pie Chart



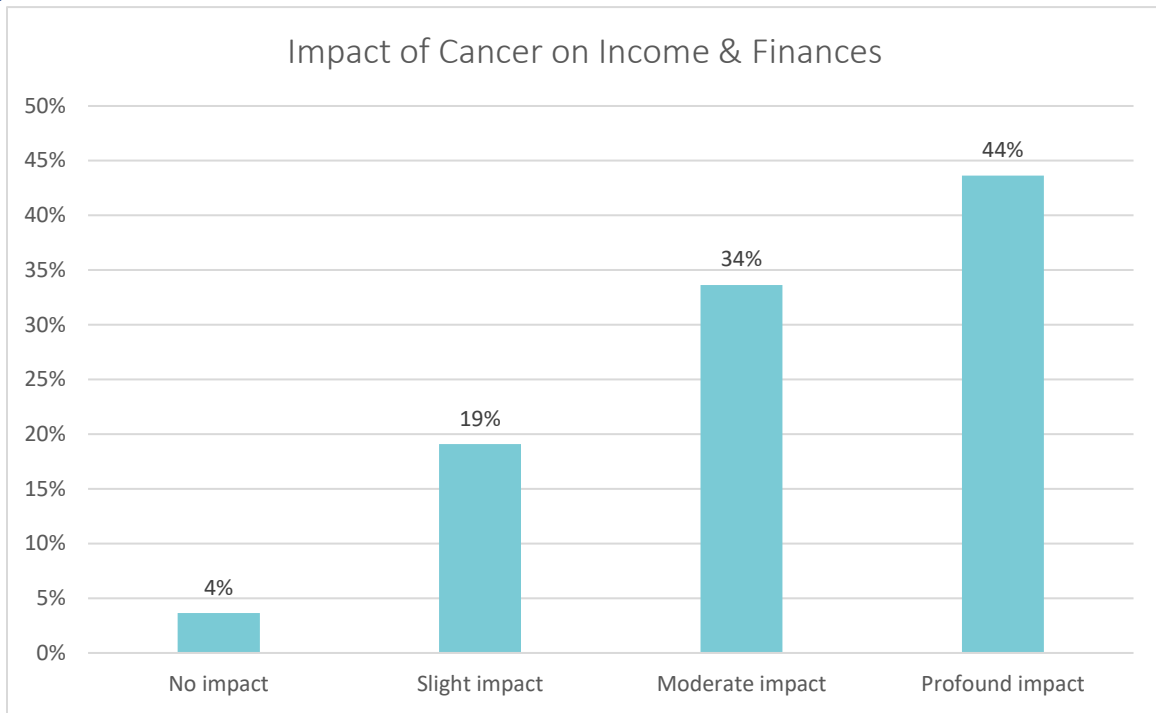
| Response | % | N |
|----------|-----|----|
| ≤\$1,500 | 40% | 40 |
| >\$1,500 | 60% | 61 |

This figure is based on 101 respondents who provided numeric answers to questions about both income and household size (those who didn't know or provided context but no number were removed).

Individuals reporting monthly household incomes between \$0 and \$10,000 were assigned the value in the middle of their reported range. Individuals reporting monthly household incomes over \$10,000 were conservatively assigned a value of \$10,500. These estimated incomes were then divided by the reported number of individuals living in the respondents' household.



Impact of Cancer on Finances



How would you describe the impact cancer has had on your household income and finances? Please respond from the perspective of the person who received services from Cancer Legal Care.

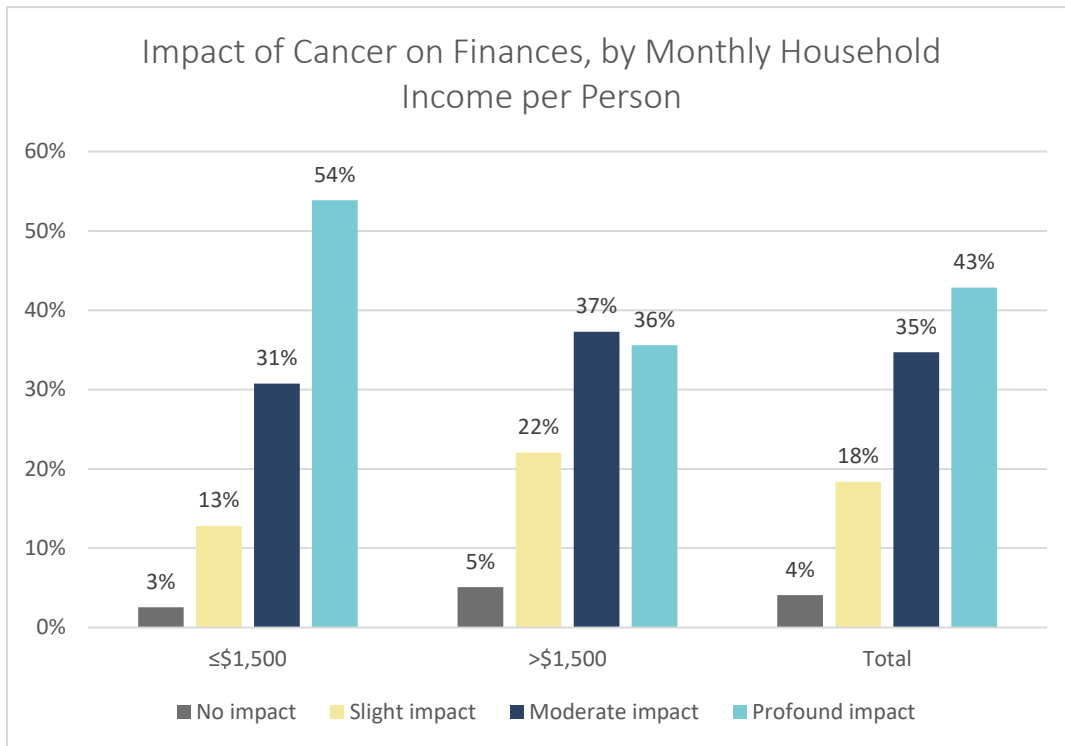
| Response | % | N |
|-----------------|-----|----|
| No impact | 4% | 4 |
| Slight impact | 19% | 21 |
| Moderate impact | 34% | 37 |
| Profound impact | 44% | 48 |

110 respondents answered this question.

This figure establishes that for most respondents (78%), cancer had a moderate or profound impact on their finances.



Impact of Cancer on Finances- Stratified



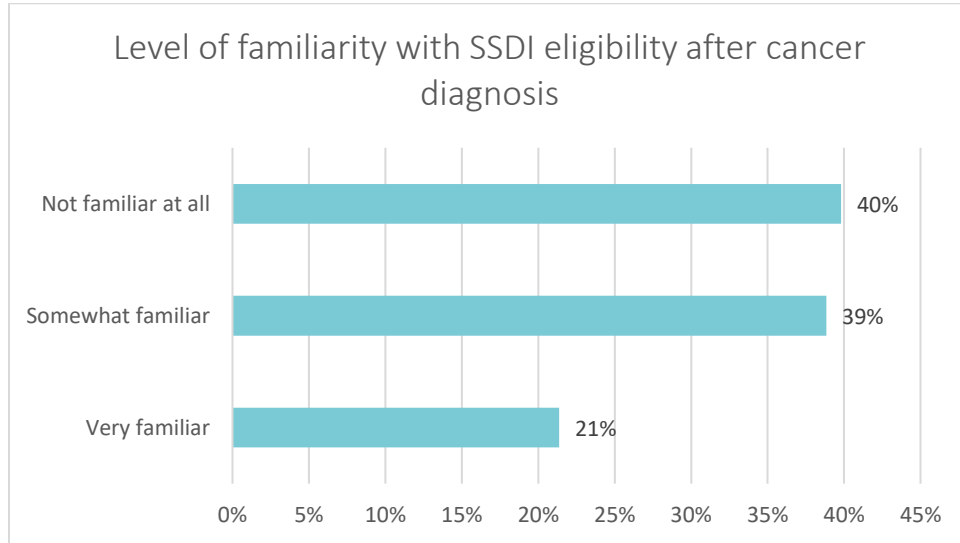
| | % | | | N | | |
|-----------------|----------|----------|-------|----------|----------|-------|
| | ≤\$1,500 | >\$1,500 | Total | ≤\$1,500 | >\$1,500 | Total |
| No impact | 3% | 5% | 4% | 1 | 3 | 4 |
| Slight impact | 13% | 22% | 18% | 5 | 13 | 18 |
| Moderate impact | 31% | 37% | 35% | 12 | 22 | 34 |
| Profound impact | 54% | 36% | 43% | 21 | 21 | 42 |

Based on 98 respondents who provided numeric answers to questions about both income and household size then also responded with information about the impact of cancer on their finances.

This figure takes the information from the previous question and stratifies the results by income level. It shows that individuals with lower incomes had their finances more profoundly impacted by cancer.

Section 3: Social Security Disability Insurance (SSDI)

Familiarity with SSDI



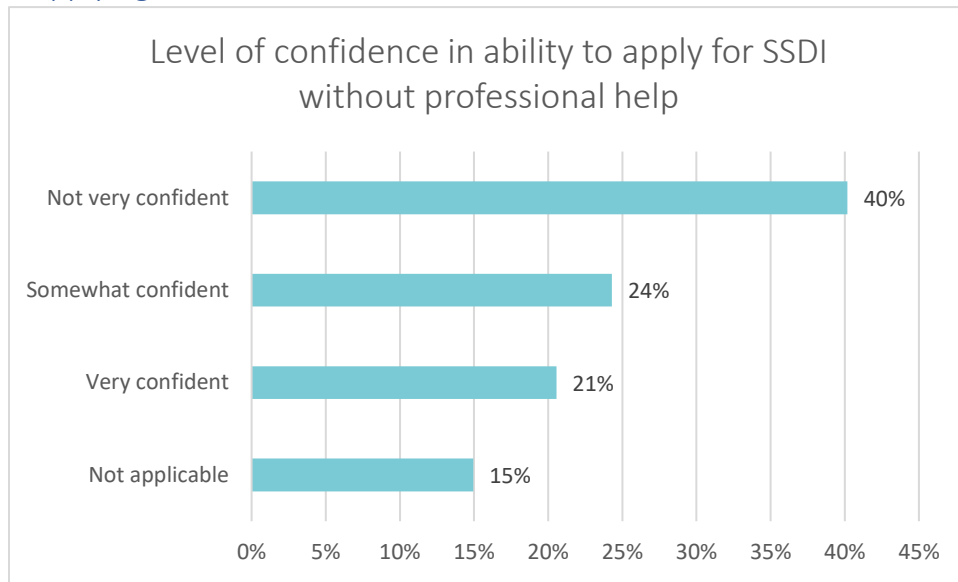
What is your level of familiarity with the availability of Social Security disability benefits for people who have been diagnosed with cancer?

| Response | % | N |
|---------------------|-----|----|
| Very familiar | 20% | 22 |
| Somewhat familiar | 35% | 40 |
| Not familiar at all | 37% | 41 |

103 participants answered this question using one of the above categories. Write-ins were re-coded or removed for this question.



Confidence Applying for SSDI



What is your level of confidence in being able to apply for Social Security disability benefits without professional assistance?

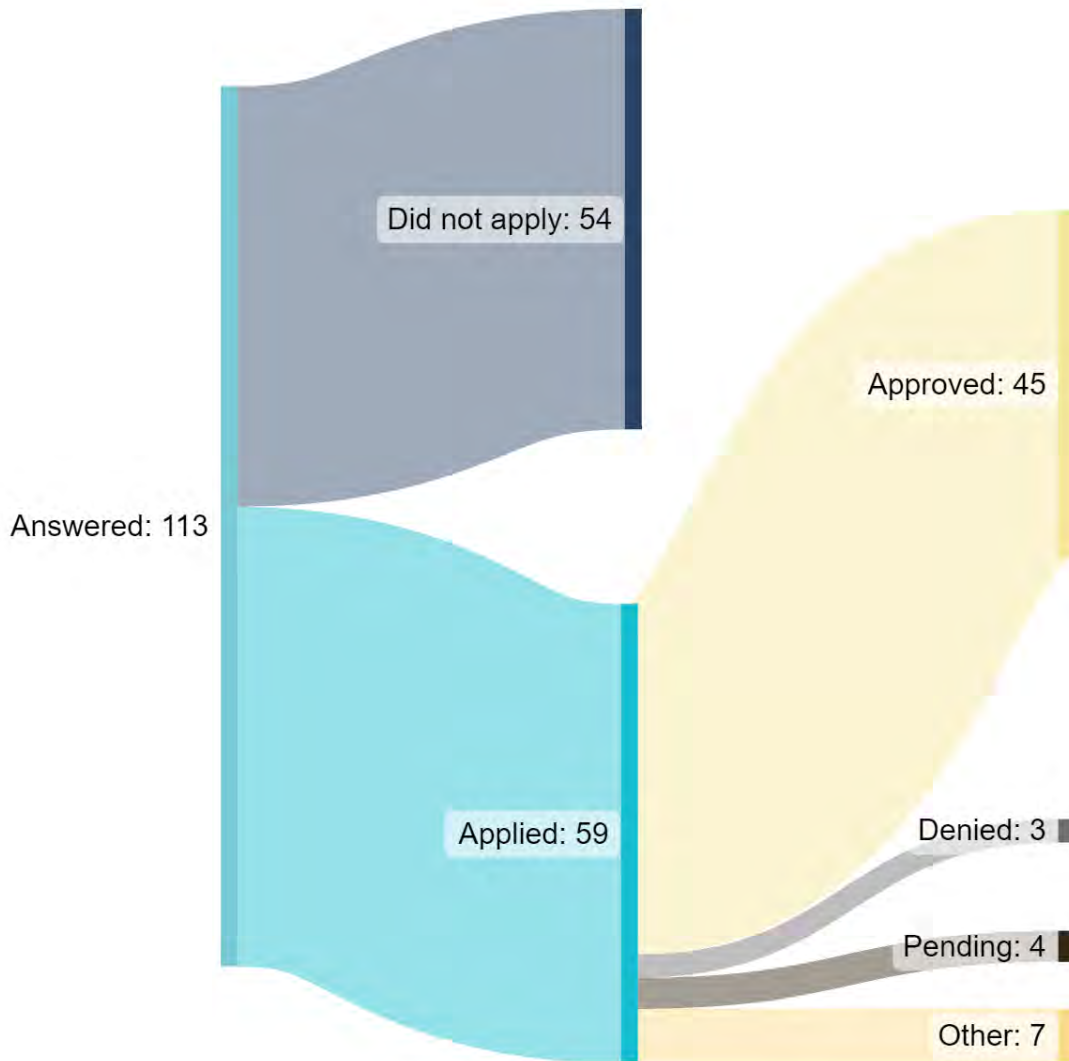
| Response | % | N |
|--------------------|-----|----|
| Not applicable | 15% | 16 |
| Very confident | 21% | 22 |
| Somewhat confident | 24% | 26 |
| Not very confident | 40% | 43 |

107 participants answered this question

Of respondents who indicated that the issue was applicable to them, almost half (40%) said that they were not very confident in their ability to apply for Social Security disability benefits.



Rate of SSDI Application and Subsequent Outcomes



Have you ever applied for Social Security disability benefits (either SSDI or SSI)? Please respond from the perspective of the person who received services from Cancer Legal Care.

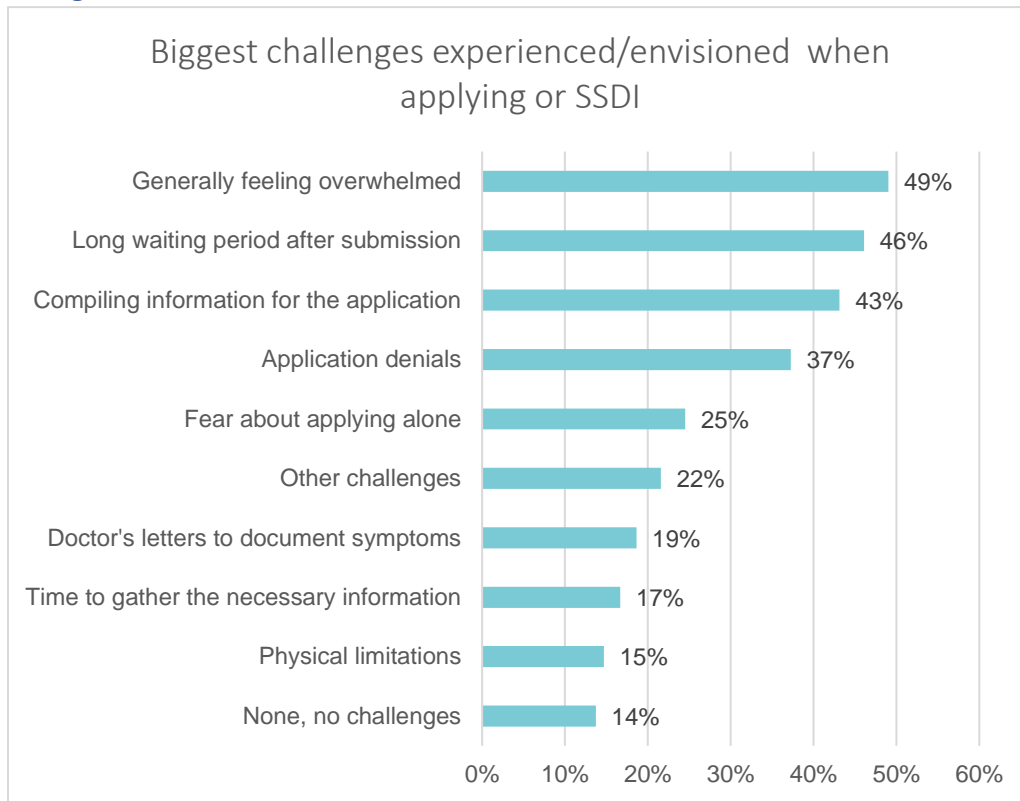
What was the outcome? If you applied multiple times, please mark the outcome for the most recent application.

113 individuals indicated whether they applied or not. All 59 individuals who said they applied also provided information about the outcome.

Just over half of respondents had applied for SSDI (52%), of which most had received approval (76%).



SSDI Challenges



What are the biggest challenges you have experienced or envision you may experience when applying for Social Security disability benefits? Check all that apply.

| Response | % | N |
|---|-----|----|
| None, no challenges | 14% | 14 |
| Physical limitations | 15% | 15 |
| Time to gather the necessary information | 17% | 17 |
| Doctor's letters to document symptoms | 19% | 19 |
| Other challenges | 22% | 22 |
| Fear about applying alone | 25% | 25 |
| Application denials | 37% | 38 |
| Compiling information for the application | 43% | 44 |
| Long waiting period after submission | 46% | 47 |
| Generally feeling overwhelmed | 49% | 50 |

Participants could mark more than one option on this question. 102 participants answered this question.

SSDI presented respondents with many different challenges. Only 14% indicated that they faced no challenges at all. Other challenges that respondents wrote in included issues navigating the SSDI system, a lack of understanding about the process and eligibility requirements, concerns

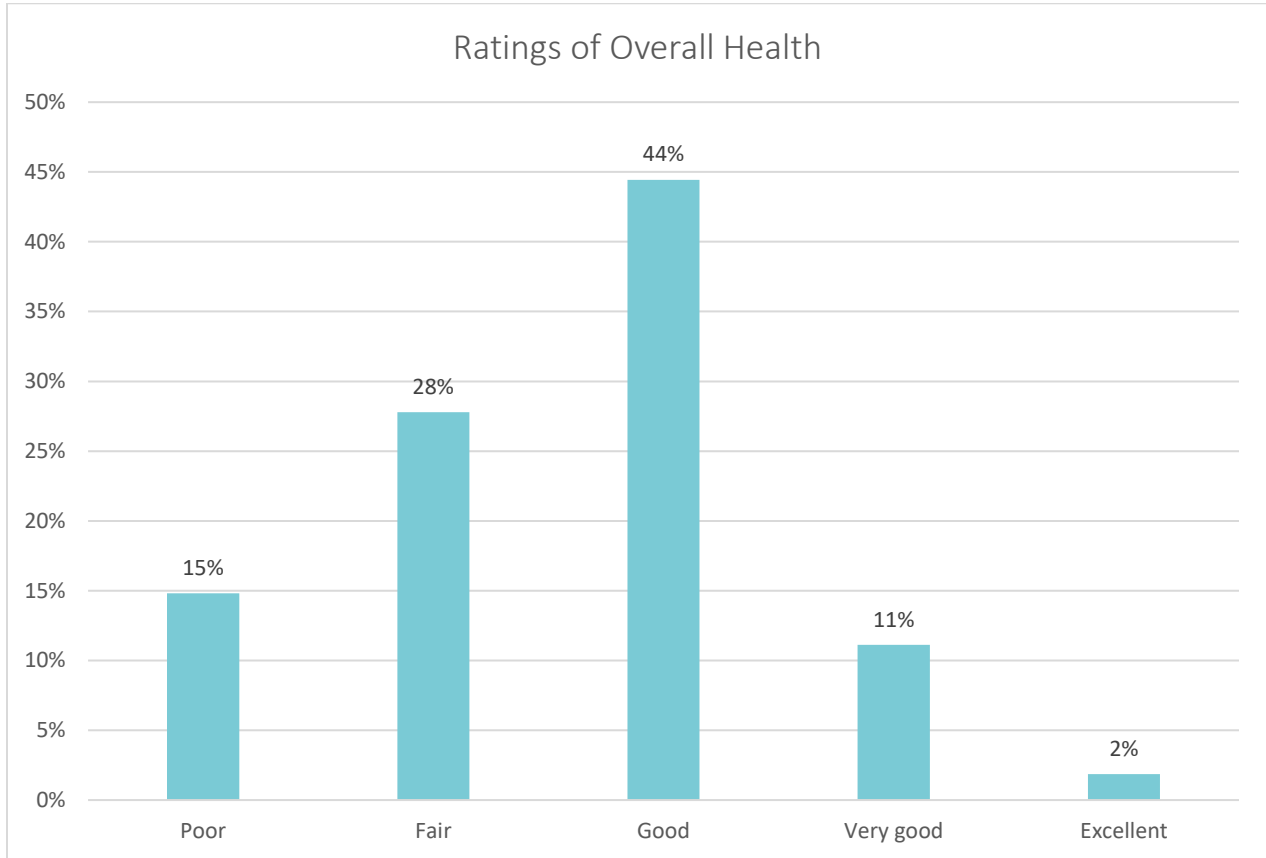


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about losing other insurance or retirement benefits, advanced age, and knowing they did not qualify. See appendix B for all write-in responses to this question.

Section 4: Demographics

Overall Health



In general, how would you rate your overall health? Please respond from the perspective of the person who received services from Cancer Legal Care.

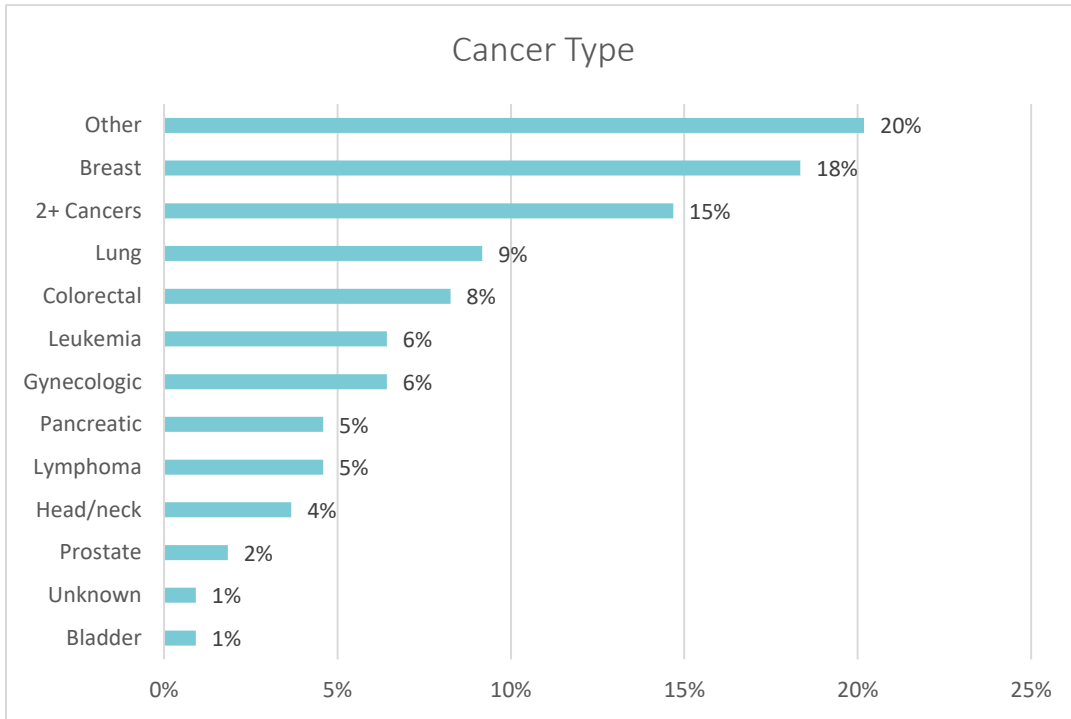
| Response | % | N |
|-----------|-----|----|
| Poor | 15% | 16 |
| Fair | 28% | 30 |
| Good | 44% | 48 |
| Very good | 11% | 12 |
| Excellent | 2% | 2 |

108 respondents answered this question.

A plurality of respondents rated their current health status as good (44%), however almost as many rated their health as fair or poor (43%).



Cancer Type



Which of the following types of cancer diagnoses led you to contact Cancer Legal Care? Please respond from the perspective of the person who received services from Cancer Legal Care. Check all that apply. Please mark primary sites only. Exclude metastatic locations.

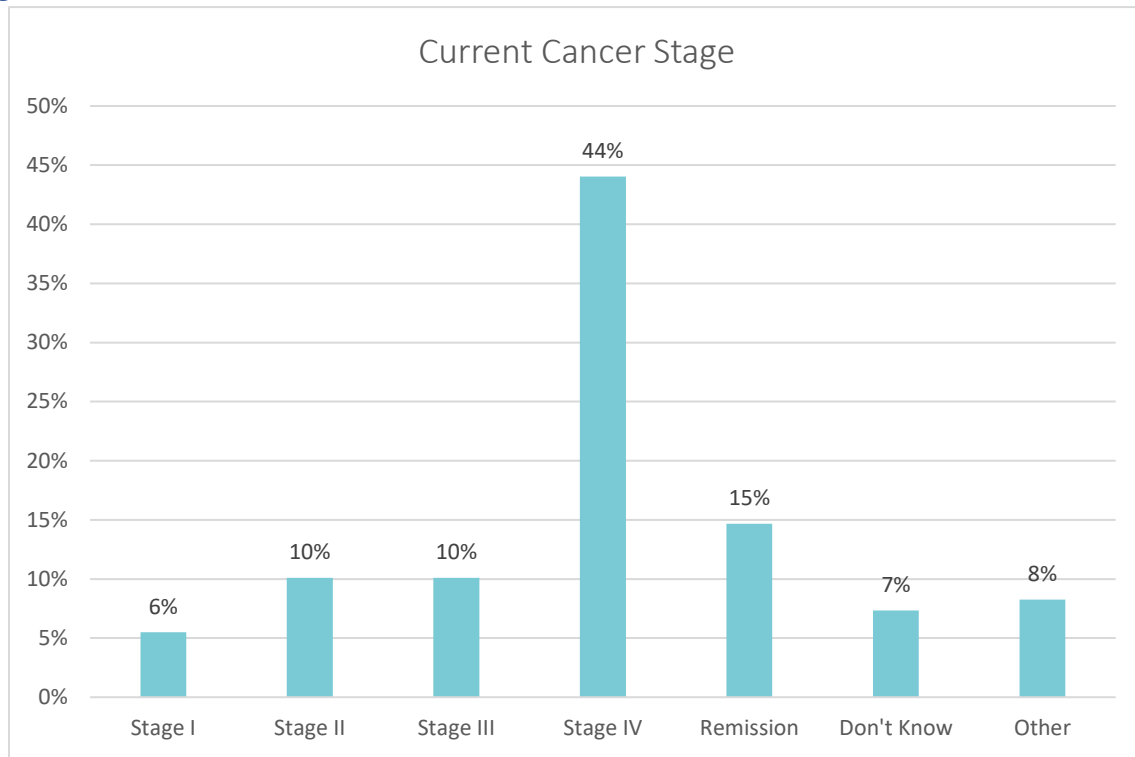
| Response | % | N |
|-------------|-----|----|
| Bladder | 1% | 1 |
| Unknown | 1% | 1 |
| Prostate | 2% | 2 |
| Head/neck | 4% | 4 |
| Lymphoma | 5% | 5 |
| Pancreatic | 5% | 5 |
| Gynecologic | 6% | 7 |
| Leukemia | 6% | 7 |
| Colorectal | 8% | 9 |
| Lung | 9% | 10 |
| 2+ Cancers | 15% | 16 |
| Breast | 18% | 20 |
| Other | 20% | 22 |

109 respondents answered this question. More than one answer could be provided.

Other cancers written in included multiple myeloma, gastric, liver, brain, testicular, blood, and bone cancers.



Stage



What is the current stage of your cancer? Please respond from the perspective of the person who received services from Cancer Legal Care. If multiple cancers with different stages, please mark the highest stage.

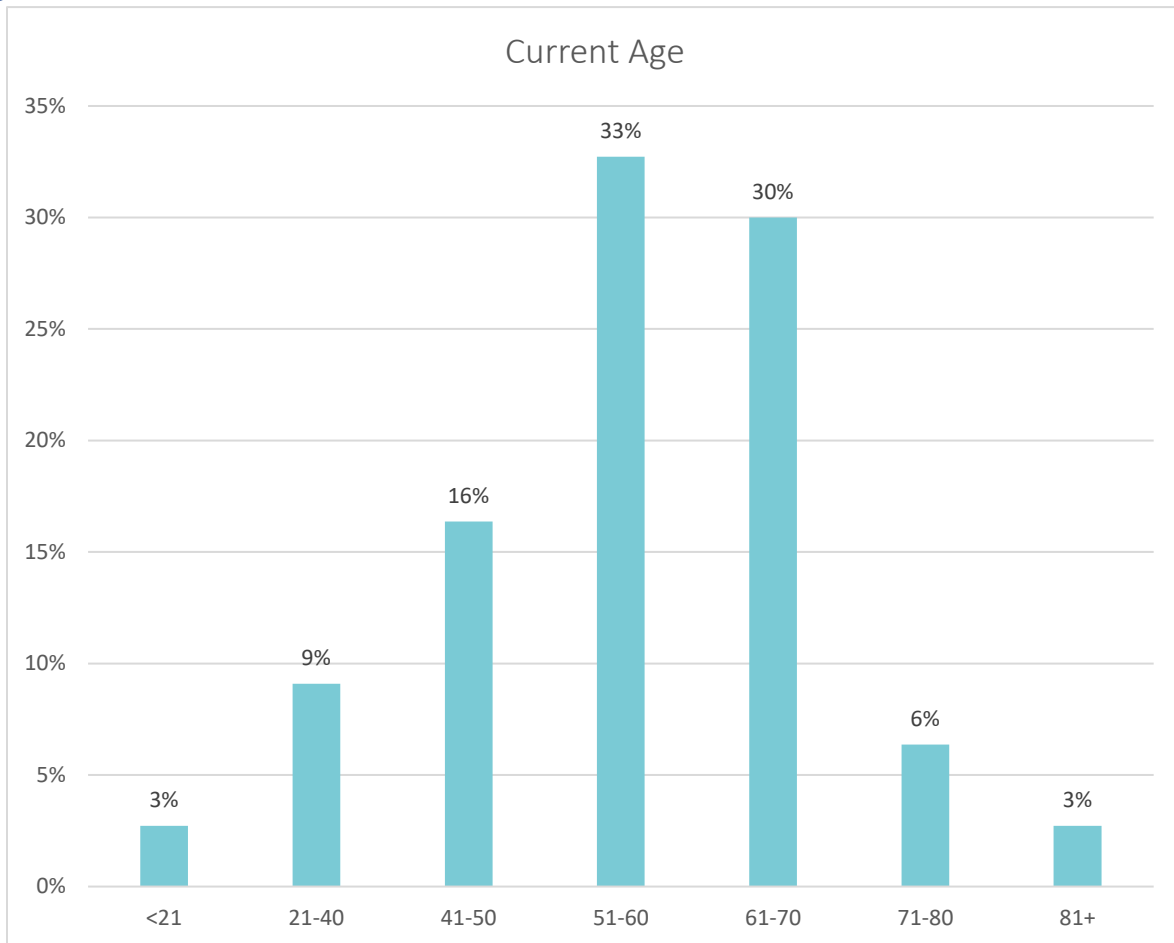
| Response | % | N |
|------------|-----|----|
| Stage I | 6% | 6 |
| Stage II | 10% | 11 |
| Stage III | 10% | 11 |
| Stage IV | 44% | 48 |
| Remission | 15% | 16 |
| Don't Know | 7% | 8 |
| Other | 8% | 9 |

109 respondents answered this question.

A plurality of respondents (44%) indicated they had stage IV cancer. This may indicate the legal challenges are most urgent for those at later stages of cancer.



Age



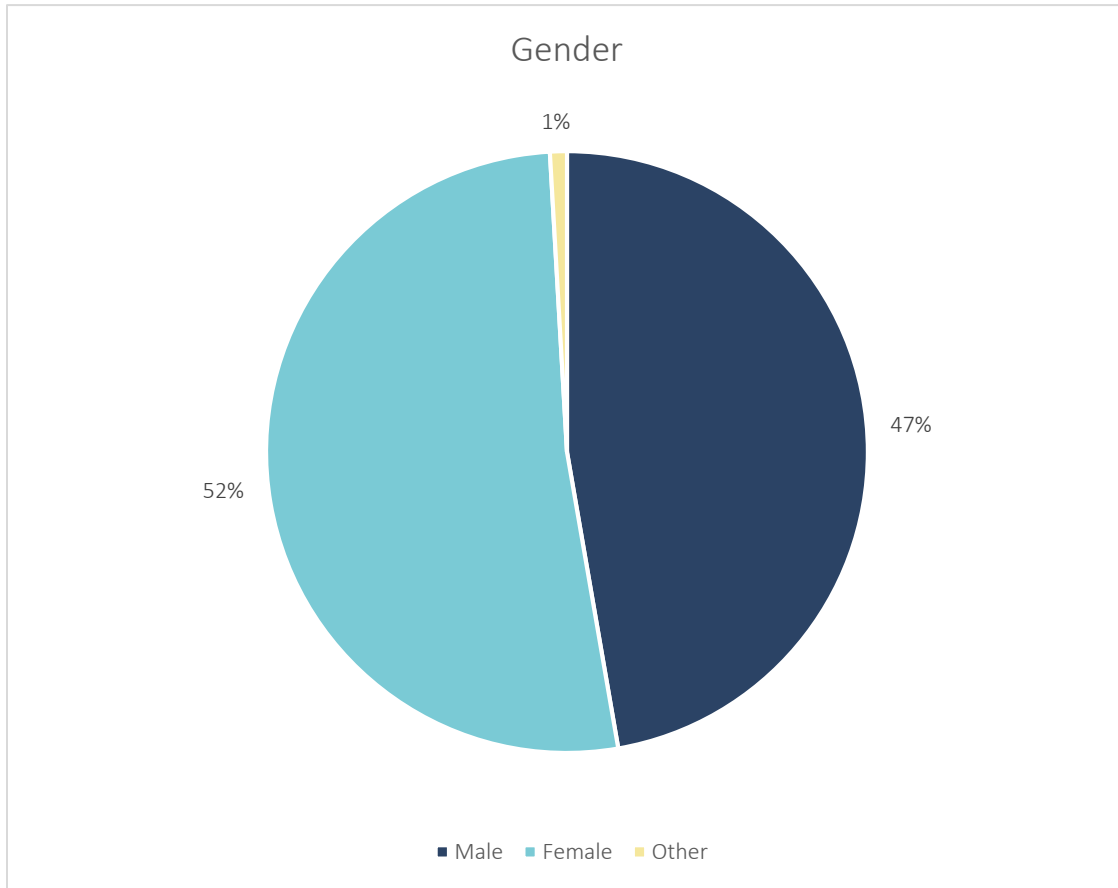
What is your age? Please respond from the perspective of the person who received services from Cancer Legal Care.

| Response | % | N |
|----------|-----|----|
| <21 | 3% | 3 |
| 21-40 | 9% | 10 |
| 41-50 | 16% | 18 |
| 51-60 | 33% | 36 |
| 61-70 | 30% | 33 |
| 71-80 | 6% | 7 |
| 81+ | 3% | 3 |

110 respondents answered this question.



Gender



What is your gender? Please respond from the perspective of the person in your household who received services from Cancer Legal Care.

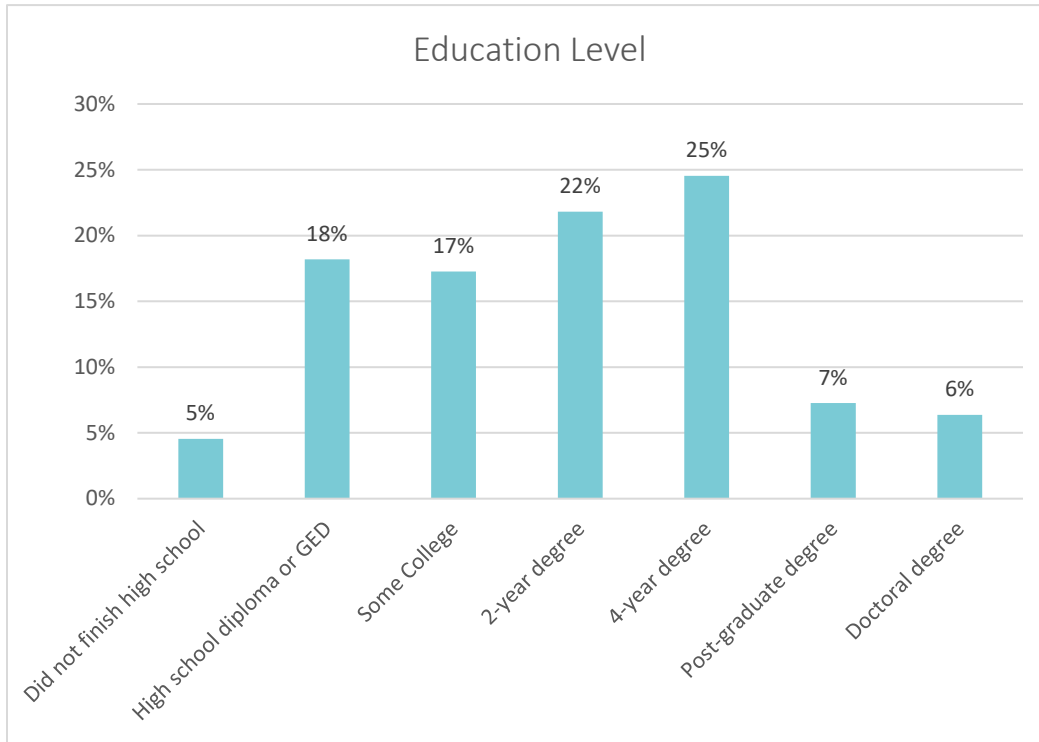
| Response | % | N |
|----------|-----|----|
| Male | 47% | 52 |
| Female | 52% | 57 |
| Other | 1% | 1 |

110 respondents answered this question.

The gendered division of the sample was roughly equal, with slightly fewer males (47%). Only one respondent wrote in a gender other than male or female.



Education



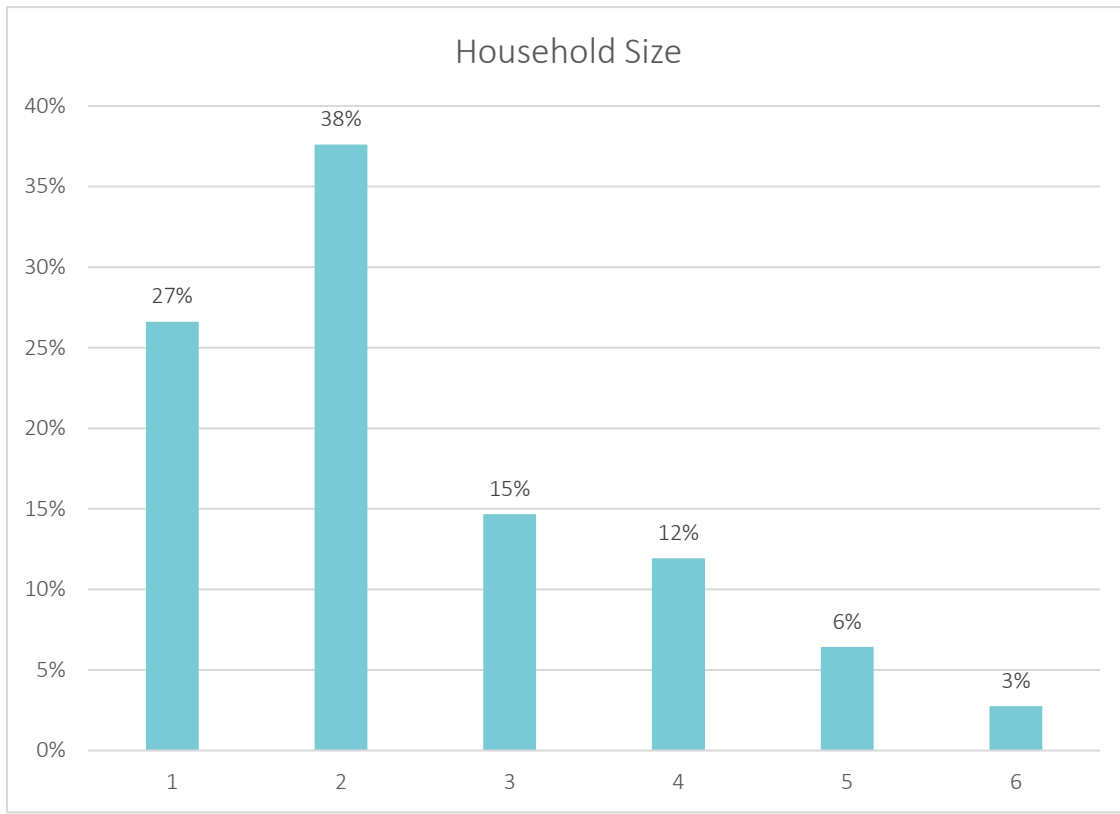
What is the highest level of education you completed? Please respond from the perspective of the person who received services from Cancer Legal Care.

| Response | % | N |
|----------------------------|-----|----|
| Did not finish high school | 5% | 5 |
| High school diploma or GED | 18% | 20 |
| Some College | 17% | 19 |
| 2-year degree | 22% | 24 |
| 4-year degree | 25% | 27 |
| Post-graduate degree | 7% | 8 |
| Doctoral degree | 6% | 7 |

110 respondents answered this question.



Household Size



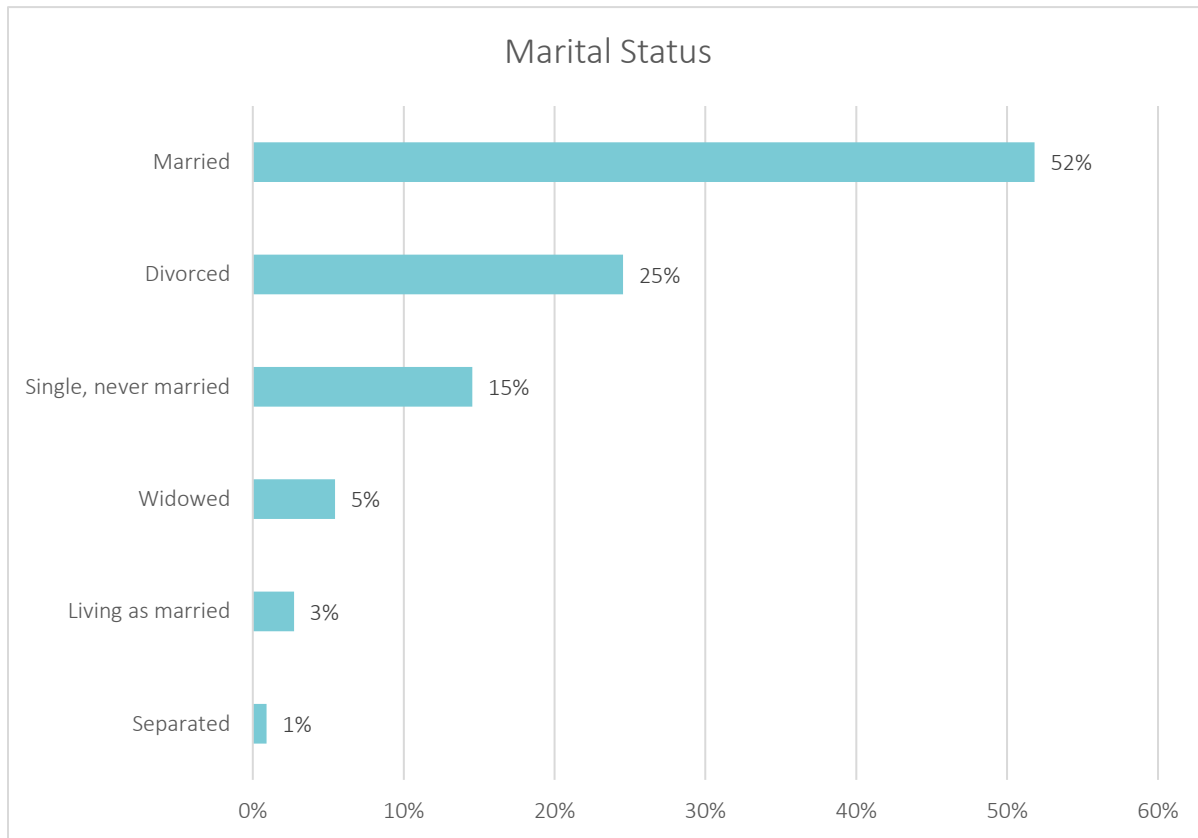
How many people live in your household, including yourself? Please respond from the perspective of the person who received services from Cancer Legal Care.

| Response | % | N |
|----------|-----|----|
| 1 | 27% | 29 |
| 2 | 38% | 41 |
| 3 | 15% | 16 |
| 4 | 12% | 13 |
| 5 | 6% | 7 |
| 6 | 3% | 3 |

109 respondents answered this question.



Marital Status



What is your current marital status? Please respond from the perspective of the person who received services from Cancer Legal Care.

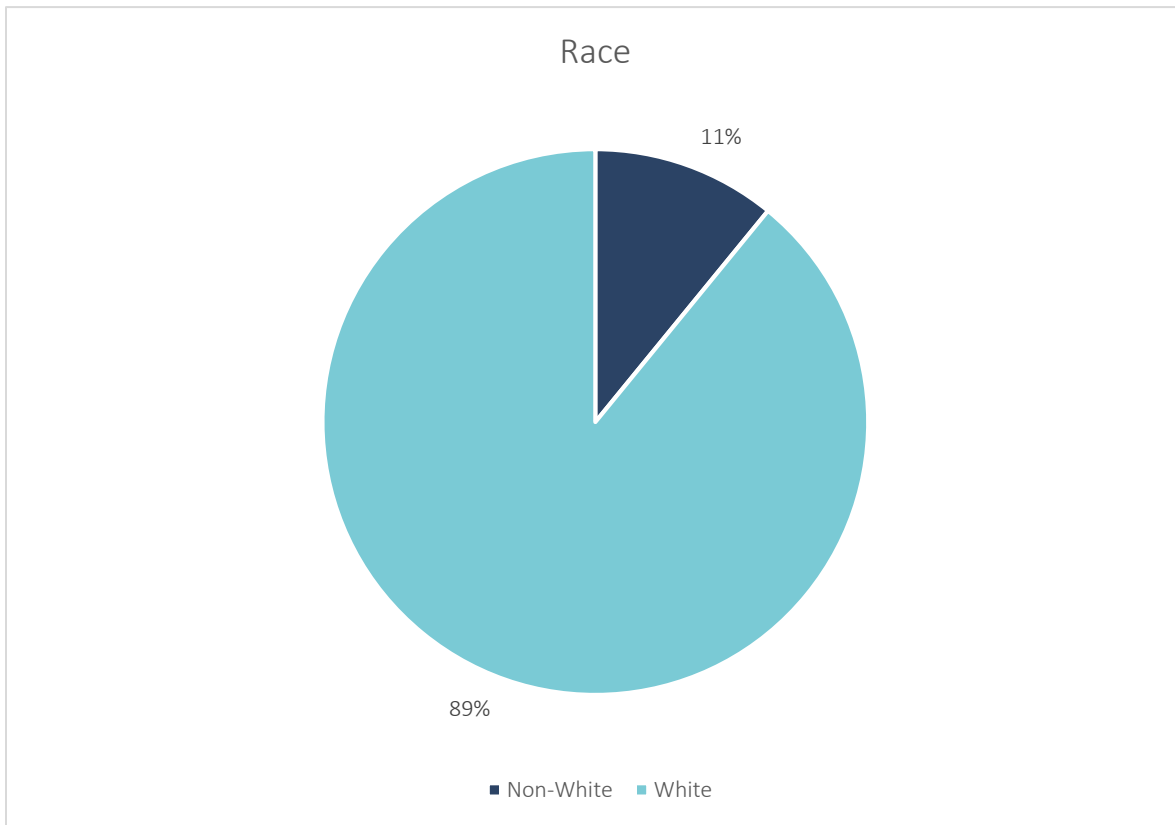
| Marital Status | % | N |
|-----------------------|-----|----|
| Separated | 1% | 1 |
| Living as married | 3% | 3 |
| Widowed | 5% | 6 |
| Single, never married | 15% | 16 |
| Divorced | 25% | 27 |
| Married | 52% | 57 |

110 respondents answered this question.

More than half of respondents were married at the time of the survey (52%).



Race



What race(s) do you identify with? Check all that apply. Please respond from the perspective of the person who received services from Cancer Legal Care.

Are you Hispanic, Latino/a, or of Spanish origin? Please respond from the perspective of the person who received services from Cancer Legal Care.

Answers to race and ethnicity questions were combined using the Hispanic trumps method. If individuals responded that they were Hispanic, they were then counted as non-white. If individuals responded they were not Hispanic, then their race was determined based their answer to the question about race.

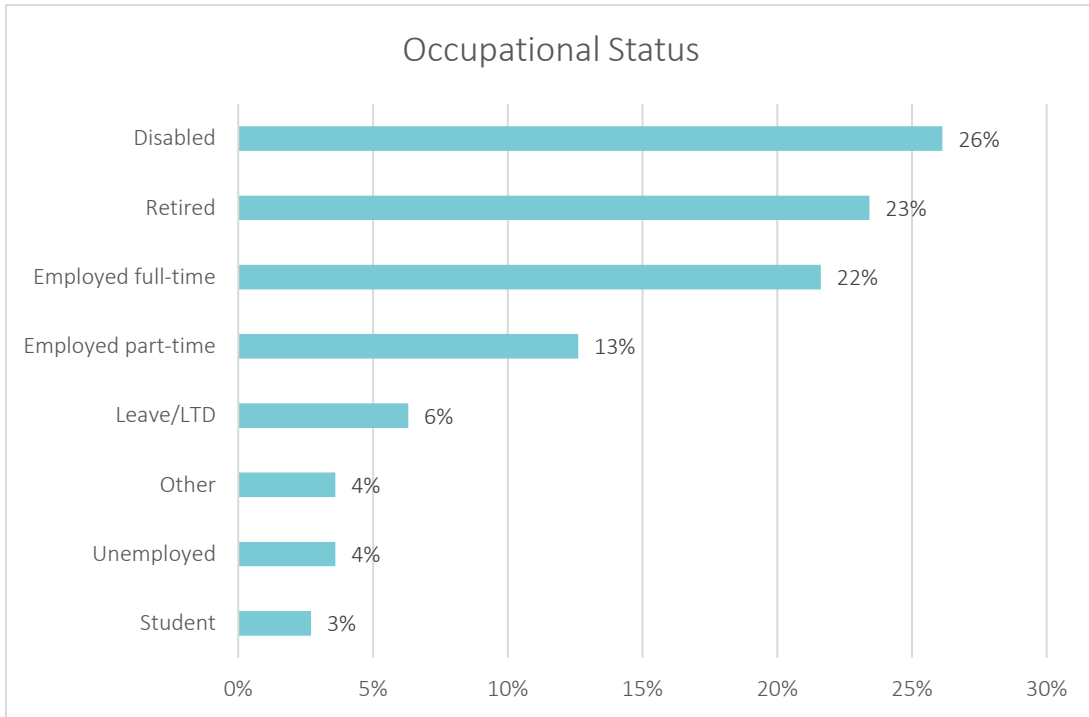
| Response | % | N |
|-----------|-----|-----|
| Non-White | 11% | 12 |
| White | 89% | 98 |
| Total | | 110 |

110 respondents answered both questions.

The majority of respondents were white (89%).



Occupational Status



What is your current occupational status? Please respond from the perspective of the person who received services from Cancer Legal Care.

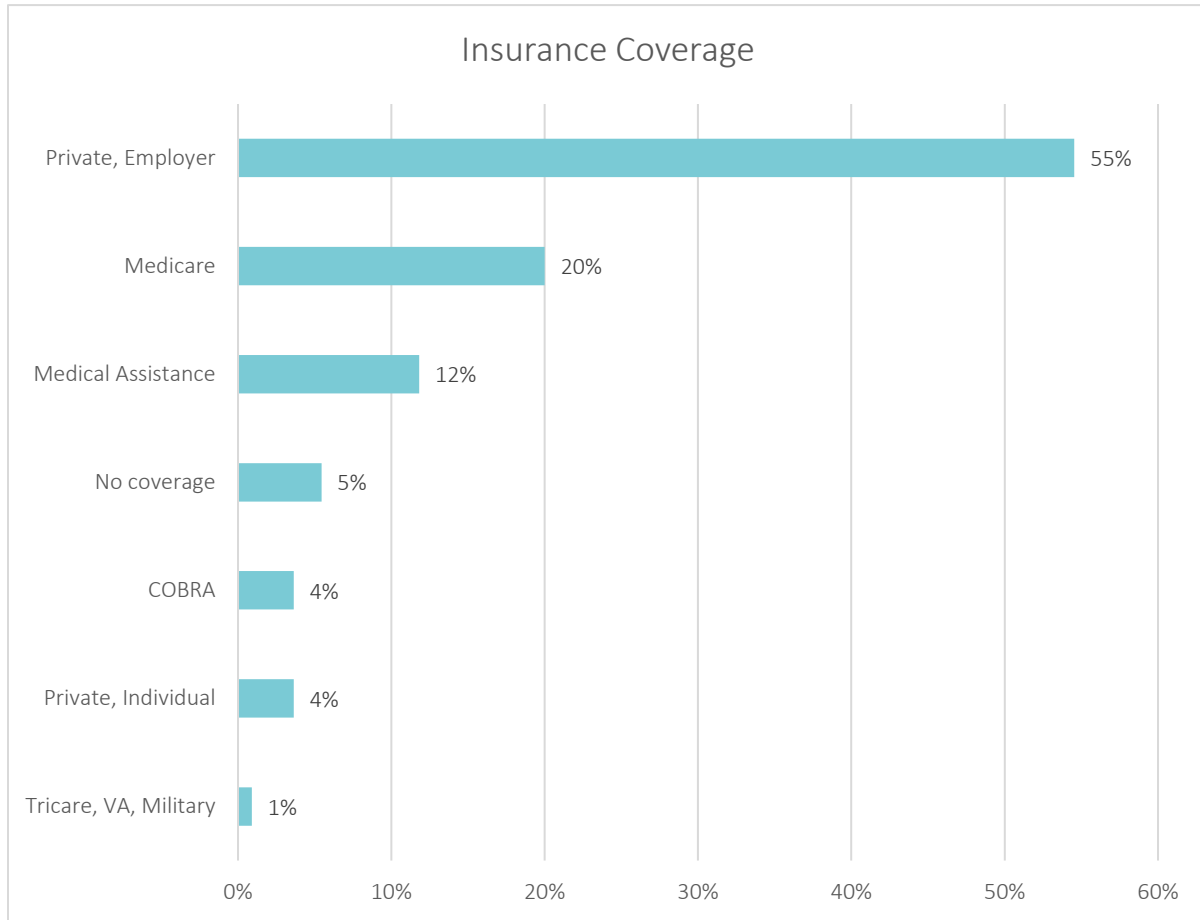
| Response | % | N |
|--------------------|-----|----|
| Student | 3% | 3 |
| Unemployed | 4% | 4 |
| Other | 4% | 4 |
| Leave/LTD | 6% | 7 |
| Employed part-time | 13% | 14 |
| Employed full-time | 22% | 24 |
| Retired | 23% | 26 |
| Disabled | 26% | 29 |

111 respondents answered this question.

Leave/LTD was not initially offered as an option on the survey, but has been added due to the number of individuals who wrote it in.



Insurance Coverage



Do you have any kind of health care coverage? Please respond from the perspective of the person who received services from cancer legal care.

What is the primary source of your health care insurance coverage? Please respond from the perspective of the person who received services from Cancer LegalCare.

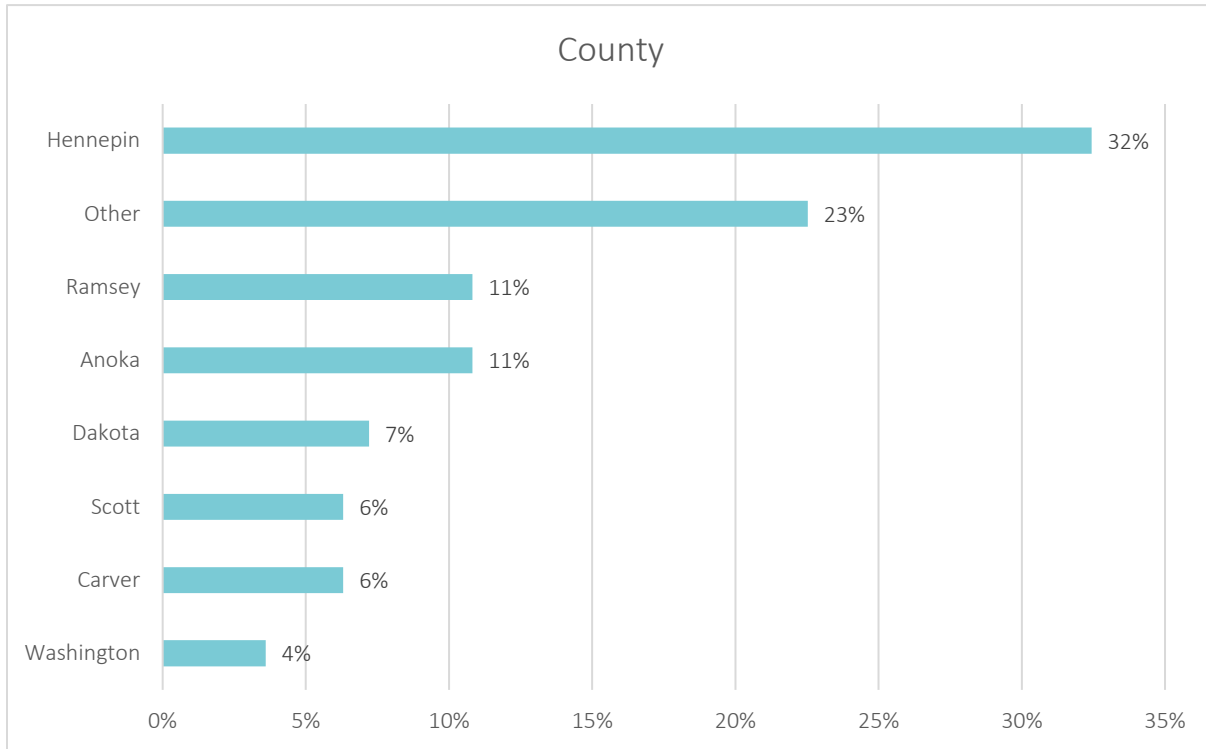
These questions were combined into one figure.

| Response | % | N |
|-----------------------|-----|----|
| Tricare, VA, Military | 1% | 1 |
| Private, Individual | 4% | 4 |
| COBRA | 4% | 4 |
| No coverage | 5% | 6 |
| Medical Assistance | 12% | 13 |
| Medicare | 20% | 22 |
| Private, Employer | 55% | 60 |

110 respondents answered these questions. COBRA was not initially offered as an option on the survey, but has been added due to the number of individuals who wrote it in.



County



What is your current primary county of residence? Please respond from the perspective of the person who received services from cancer legal care.

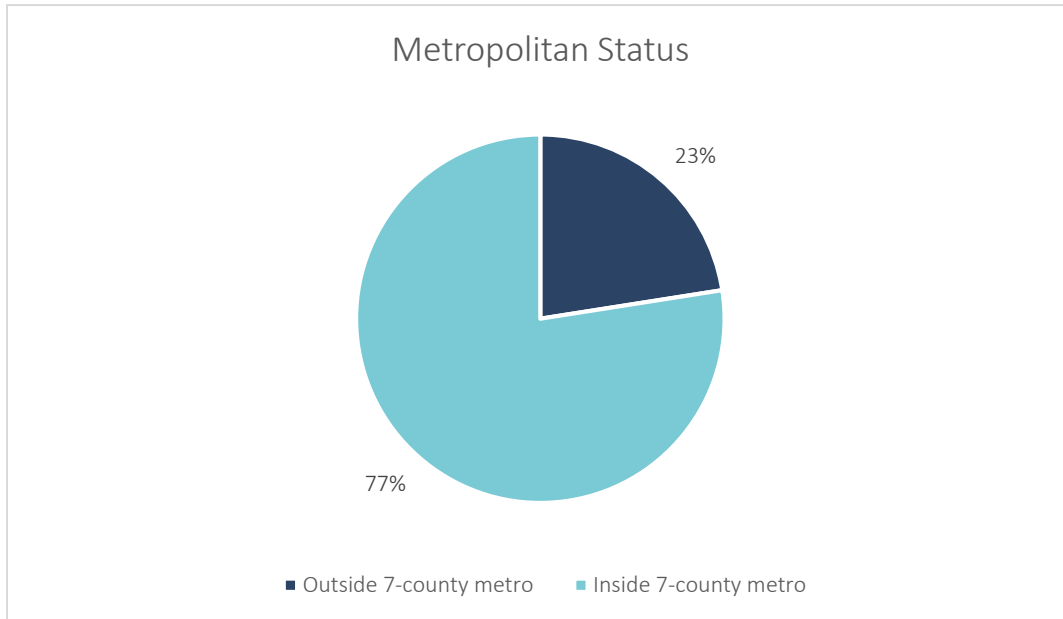
| Response | % | N |
|------------|-----|----|
| Washington | 4% | 4 |
| Carver | 6% | 7 |
| Scott | 6% | 7 |
| Dakota | 7% | 8 |
| Anoka | 11% | 12 |
| Ramsey | 11% | 12 |
| Other | 23% | 25 |
| Hennepin | 32% | 36 |

111 respondents answered this question.

The most frequent “Other” counties included Wright (3 respondents), Crow Wing (2), and Winona (2). The remaining 18 counties had only one respondent each.



Metropolitan Status



What is your current primary county of residence? Please respond from the perspective of the person who received services from cancer legal care.

Answers to this question were re-categorized to reflect metropolitan status based on county.

| Response | % | N |
|------------------------|-----|----|
| Outside 7-county metro | 23% | 25 |
| Inside 7-county metro | 77% | 86 |

111 respondents answered this question.

APPENDIX A: Methodology

Prior to study initiation, the University of Minnesota (UMN) Institutional Review Board determined this research to be non-human subject research in December 2023.

Key Informant Interviews

In February 2023, CLC and UMN collaborated in the development of a Key Informant Interview Guide. During March 2023, CLC conducted key informant interviews with five CLC clients, including those from diverse racial/ethnic and socio-economic backgrounds and may have experience applying for SSDI or SSI benefits. Participants received \$25 directly from CLC as a token of appreciation. Appendix C includes a copy of the Key Information Interview Guide.

CLC provided UMN with de-identified qualitative data from the key informant interviews. The interviews were transcribed verbatim. Themes, consistencies, and differences across participants were examined. Two coders read the interview transcripts and applied the constant comparative method to analyze and code data. This approach required coders to be constantly alert to the similarities and differences which existed between instances, cases and concepts, and ensured that the full diversity and complexity of the data was explored.

Survey Development and Administration

In April 2023, utilizing the key themes identified from the key informant interviews, the UMN and CLC collaboratively developed a brief survey to administer more broadly to recent (back to 2022) CLC clients **to further understand barriers to (1) accessing legal services and (2) enrolling on Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) in this population as well as understand the impact of a cancer diagnosis on the finances of clients.** The choice to extend inclusion only back to 2022 was due to the need for current contact information. Once a draft of the survey was developed, the instrument was pilot tested among five users without prior experience with CLC to gain feedback on comprehension, wording and logic of the survey online via a RedCAP survey as well as a paper survey. We then developed a revised version incorporating all clarifications and wording edits from the pilot testing.

UMN printed advance notification postcards, hard copies of the survey, invitation letters, outgoing envelopes, and return envelopes. The cover letter noted the option to complete the survey via the mailed paper survey or online via a secure and confidential RedCAP survey tool. Using randomly generated 5-digit numbers, the surveys and outgoing envelopes were labeled with unique survey IDs. The UMN compiled all of the mailed materials, including applying postage to the advance postcards, outgoing, and return envelopes. These supplies were provided to CLC to affix mailing labels and \$5 incentives for mailing to 430 of their recent clients. The advance postcards mailed approximately one week prior to survey mailing (mid-June 2023)..

Between June and July 2023, CLC mailed surveys to 430 of their clients. The mailing included an option for people to complete the survey online if they preferred, using the survey ID from their mailing as the identifier. The survey was created in REDCap and the link was provided in the



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LAWYERS ON YOUR CANCER CARE TEAM

invitation letter. The confidential paper surveys were returned to the University of Minnesota for data entry into this REDCap project. One study member from UMN entered the data and a second member checked for data entry accuracy.

Two weeks after the initial survey was sent, CLC sent reminder emails to non-responders. With some early undeliverable mail, CLC selected another 30 people to receive the survey. Of the surveys mailed, 47 were returned and/or been deemed undeliverable. The potential respondent pool totaled 383. As of August 19th, 2023, 120 surveys were completed.

APPENDIX B: Select Open-Ended Comments

Survey Question #6b: What other reasons made you hesitant [to contact Cancer Legal Care]?

- Felt some guilt that perhaps other cancer patients deserved /needed this service more than me (financially)
- Fighting the cancer, my financial & employment legal issues were the least of my concerns
- Treatment
- Concerned about contentious relationship with my employer
- The best time for me to call was on Friday.
- Figured they wouldn't even return call/waste of time

Survey Question #7: What would you tell someone about your experience with Cancer Legal Care?

- The Cancer Care Legal team was able to advocate on my behalf with my employer when they made unreasonable requests for the release of medical information. At that time, I was completely overwhelmed and could barely function. The help you provided was priceless to me. Thank you from the bottom of my heart.
- Cancer Legal Care does wonderful work and is much needed.
- Thank you for the services you provide and doing so in a professional and compassionate manner!
- You folks are amazing. You helped us with questions about employment right after my diagnosis and are currently helping with a large insurance claim that has been denied. We really appreciate everything you have and are doing for us.
- Again, you will never know how much peace of mind having this done has given me. I did feel guilty not paying for it, but if it hadn't been gifted to me I couldn't have afforded to have it done. You are providing a huge service and safety net for those of us who are fighting this terrible disease.
- We definitely appreciated the services offered, especially for free. Thank you.
- We are so grateful for CLC and the invaluable service they provide. The fact that they are doing this survey shows their dedication to providing the best assistance they can to their clients. Thank you!
- Cancer legal care was most generous with their time. They were a tremendous help solving our financial woes with the insurance company. We are very grateful!
- Keep up the great work! Your help is phenomenal!! Don't know what I would have done without your help. Going through cancer treatment and a stem cell transplant was very stressful. It was very comforting to know Cancer Legal Care was willing to help with the many issues that arose. Your staff is very helpful and caring.
- The assistance I received saved me hundreds of dollars. It got me to do a will. I no longer have worries about getting this done. My assigned attorney was wonderful. I am so thankful to cancer legal care for the help I received at a very stressful time.
- I just wish I had known about you sooner. I didn't know what questions I had but it would have been a great help to just sit down with you and figure out what I needed to know/do. My employer, even though a large hospital system, did not know a lot about disability, health insurance extension, etc.

Survey Question #15: Please feel free to share your thoughts and provide more information about cancer's impact on our household income and finances.

- Cancer's impact on my life along with my household income has been devastating. Unable to get life insurance because of my cancer. I had always been healthy with no health issues. Unable to work now related to cancer treatment side effects. Chronic pain - neuropathy. Living day to day unable to save now for retirement.
- Costs of treatment add up-many things are not covered (wigs, supplements)-as a mother with cancer it's even more expensive--i.e., childcare and household help for 4 children because you can't take care of them is very, very costly
- I have no income since I was diagnosed. I exhausted all my savings, and my children are supporting me until I can get back to work.
- I am a widow and only have my income to rely on. My out-of-pocket cancer expense has been \$10,000 to date with another \$3,000 expected this year. I do receive social security, but that is not enough for me to live on, so I work a part time job and also work as a realtor. I was unable to do extra work during cancer treatment and that made the financial end very stressful.
- My husband was terminated and lost income and health insurance at diagnosis and beginning treatment.
- Impact my finance I can't pay all what I owe. Family needs my help, but I have limited power to help.
- It has extremely limited our saving time for kids' college and retirement for my spouse.
- Terminal cancer is beyond terrifying. Having to worry about finances above and beyond a terminal diagnosis is cruel and unfair. Cancer legal care helped me plan and prepare regarding my disability options, so things feel much less precarious.
- You find yourself spending thousands up front trying to cover costs of funerals and expenses you don't want your loved ones dealing with. Medical bills-even with good insurance come in at steep costs.

Survey Question #19a: What were 'other' challenges [you have experienced or envision you may experience when applying for Social Security disability benefits]?

- Fearing cancellation
- Challenge regarding medical insurance
- Understanding all aspects
- My LTD filed for me. It was a messy, long process.
- Making sure when talking to someone over the phone they know what they're doing. We had to wait over 1 hour before talking to someone. (Called a few times).
- Amount of \$ is not enough.
- My employer hired a law firm to navigate process
- Lack of understanding what information is needed.
- N/A as 83 years old and not employable
- I'm on SS
- What would it do for me? Do I make too much money?
- Would not qualify. Not enough credits.
- Lack of documentation to the oncologist. He told her he had neuropathy, pain, not documented. Daughter was denied attending hearing with judge. She wasn't a true legal representative

- Waiting for back pay so I can catch up on my bills
- My only challenge is that I do not know what social security retirement benefits I would lose, if any at all.
- Age
- I went through this when my late husband became disabled, so I know what it feels like.
- Too late to apply now?
- I don't have a computer/laptop/iPad or Wi-Fi at home. I only have my cell phone. not a computer genius.
- Waiting to be approved for PCA grant so I can get paid to care for my daughter since was forced to take a leave from teaching.
- I don't even know if I qualify please.

Survey Question #19b: How could Cancer Legal Care address these concerns [challenges you have experienced or envision you may experience when applying for Social Security disability benefits]?

- Have a checklist for documents and info needed, then meet in person to fill out the forms.
- Provide "How To's" guidance and possibly have someone review the application before submitting application to check for missing data and holes that need to be filled.
- They could help patients with the application process and any issues once filing that arise with it. They also could direct on what should all be gathered prior to filing.
- Help to ensure completion of application. Helping to walk through eligibility.
- Some kind of help getting started from someone who knows what's going on.
- Having stuff dedicated to help with questions. Website resources for common questions. I had a service that was provided by my group policy to guide me.
- Having a step-by-step guide to help.
- Assuring people that you will get an answer and that it takes time. you may have to go to a SS doctor.
- Need more info about requirements
- I think it was overwhelming- too much work to gather what SSA needs. When you have cancer, you have no energy to fill out paperwork. Cancer diagnosis is all that is needed for SSA.
- I was helped by my insurance company, and it was very easy. I imagine CLC could do the same.
- I guess we'd like to know if this is an option for us in the future and if we qualify?!
- Help with the questions so you get the answers in a more timely fashion. So information can be gathered.
- Coming up w/ list of what is needed.
- CLC can help by taking the lead throughout the application process and hanging in with Pt from beginning to end.
- Being able to give step-by-step instructions is helpful and information on what to expect would help too.
- Back to - "You don't know what you don't know" the hardest part was getting started due to not knowing. Any information up front would have helped. Cancer Legal Care was great to work with.
- Know that self-application is denied to know that they would help with the appeal in a timely manner.
- Verify all paperwork is complete and everything needed is submitted the 1st time and on time.

- Reach out to their current or former clients and ask if they'd need help contacting the SSDI office.
- Assistance filling out the application. Explanation of information I need to provide. Help with follow-up needed.
- By offering emotional and legal support. Sometimes just knowing someone cares and you are not alone makes a huge difference.
- Maybe by helping explain the process and "handholding" through the process. Perhaps even helping fill out the forms.
- Communication on how the process is going. Explaining what may be needed yet.
- Provide info on who is eligible
- Guidance from the get-go. Drs. [must] write properly worded letters for documentation; they did not record his limitations. Confusing to upload CD as required by social security computers did not [accept] CD roms.
- We were applying for on who was young, we had lawyer, but still got denied. We had lawyers, but still got denied. We just didn't know the process; some guidance or tips would help.
- Cancer Legal Care team could help me fill out the application or explained parts of application that can be tricky or hard to understand.
- Holding our hand to some extent while we apply.
- If there is an option for a one-on-one meeting to start the process and maybe one in the middle as a check..
- I would benefit simply from having someone tell me exactly what to do
- We did have someone walk us through the process when we applied for my late husband's SS disability, and it gave us great peace of mind. It would help many people to have a navigation through the process.
- Have a phone conversation with someone who listens to me and answers my question and gives me helpful information I haven't asked for or was unaware I should know of.
- Having legal representation in one's own corner for your "best interests" vs Employer HR.
- Assist with completing the SSDI application or w/ appointment to meet SS rep. This income will change my lifestyle.

Survey Question #20: Is there anything else you would like to add [about Social Security disability benefits]?

- SSI benefits were easy to apply for but the 5-month waiting period before benefits are paid is a bit lengthy and could be a challenge to some.
- Didn't realize had to pay for Medicare out of SSDI check. It's been a challenge - we just go without necessities. No furniture, drive old cars.
- I was able to get SSI disability but was told I have to wait 2 years to get Medicare. This has been a high financial burden on us. I had to pay for cobra (600 a month) to have insurance
- I feel once you get diagnosis and have to go through chemo and radiation you should automatically be approved for SSDI. But no, you jump through hoops, just to get denied.
- There is a lot of need for people who are eligible for SSDI - and a lot of confusion about the process.
- Been struggling with SSI for 7 years and still nowhere..