

## **ARCHANGELS**

### **Rare Disease and Caregiving Survey**

#### **Overview**

This study was conducted by SSRS on its Opinion Panel Omnibus platform. The SSRS Opinion Panel Omnibus is a national, twice-per-month, probability-based survey. Data collection was conducted on two waves of the omnibus, from January 17 to January 21, 2025 and from February 7 to February 10, 2025, among a total sample of  $N = 2,012$  respondents. The survey was conducted via web ( $n = 1,952$ ) and telephone ( $n = 60$ ) and administered in English ( $n = 2,012$ ). More information about the SSRS Opinion Panel can be found at [www.ssrs.com](http://www.ssrs.com).

All SSRS Opinion Panel Omnibus data are weighted to represent the target population of U.S. adults ages 18 or older. The margin of error for total respondents is +/- 2.6 percentage points at the 95% confidence level. For results among the  $n = 728$  caregivers, the margin of sampling error is +/- 4.3 percentage points. And for results among the  $n = 180$  rare disease households, the margin of sampling error is +/- 8.9 percentage points.

#### **Notes About Results**

Because percentages are rounded, they may not total 100%. An asterisk (\*) indicates less than 0.5%.

Data collection was conducted via web and telephone. Verbiage in this topline reflects web wording. Telephone wording may differ slightly due to interviewer-administered data collection.

EMP1. Currently, are you yourself employed full time, part time, or not at all?

**(Not employed)**

EMP2. Would you say you are....?

Total		Caregivers
<b>62</b>	<b>Total employed</b>	<b>58</b>
46	Full-time	41
16	Part-time	17
<b>38</b>	<b>Total not employed</b>	<b>42</b>
20	Retired	21
5	A homemaker	5
1	A student	2
3	Temporarily unemployed	4
7	Disabled/Unable to work	8
1	Other not employed	1
(2012)		(728)

CARE1. At any time in the past 12 months have you provided unpaid care or assistance to a friend or family member who needs assistance due to aging, a disability, or a chronic health-related issue?

By care or assistance, we are referring to providing help with activities (like bathing/dressing, grocery shopping, housekeeping, meal preparation, providing transportation to medical appointments, managing medications, help with bill-paying or managing their finances, arranging for outside services, etc.) for someone who needs assistance due to aging, a chronic condition, or other health issues.

Total	
36	Yes
64	No
*	DK/Ref
(2012)	

**(Caregivers, n=728)**

CARE2. We would like to understand more about your experiences providing this care. How much do you agree or disagree with each of the following statements? **[ITEMS ASKED IN ORDER]**

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree	DK/ Ref	Total Agree	Total Dis-agree
a. The situation with the person I provide care for can be unpredictable or unstable								
Total Caregivers (n=728)	15	37	28	14	6	0	52	20
b. I have had to cut down on my own expenses because I am helping pay for things								
Total Caregivers	12	27	21	25	14	0	39	39
c. Our family has disagreements about people not doing enough to help								
Total Caregivers	11	29	25	23	11	*	40	35
d. I feel underprepared for most situations I encounter as a caregiver								
Total Caregivers	8	23	28	31	10	0	31	41
e. I have someone I can turn to for support when things are difficult								
Total Caregivers	22	48	16	10	4	0	70	14
f. I am confident in my ability to navigate my relative/friend's health insurance benefits								
Total Caregivers	12	35	26	19	7	0	48	26
g. I am confident in my ability to handle most things that I have to do as a caregiver								
Total Caregivers	20	54	18	6	1	0	75	7
h. I don't have as much personal freedom as I would like								
Total Caregivers	14	33	25	21	7	0	47	28

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree	DK/Ref	Total Agree	Total Dis-agree
i. I am stressed out								
Total Caregivers	19	32	21	21	7	0	51	27
j. I know how to manage my friend/relative's financial situation								
Total Caregivers	13	33	31	18	5	0	46	23
k. I feel that I am doing a good thing being a caregiver								
Total Caregivers	30	54	15	1	*	0	83	1
l. I resent what I have to do as a caregiver								
Total Caregivers	2	10	23	37	28	0	12	65
m. My caregiving responsibilities have caused me to miss more work than normal								
Caregivers employed FT or PT (n=437)	5	19	17	41	19	0	23	59
n. My employer provides support to help me in my job as a caregiver								
Caregivers employed FT or PT (n=437)	8	24	33	19	16	0	32	35

**(Caregivers, n=728)**

Caregiver Intensity Score Summary Table

Total	Intensity Score
8	Clear
68	Yellow
24	Red
(n = 728)	

CARE3. Now thinking about your own healthcare, in the past 12 months, how many times, if any, have you...?

**[ITEMS ASKED IN RANDOM ORDER]**

	Have not done this in the past 12 months	1-2 times	3-6 times	7 or more times	DK/Ref	Total have done this in past 12 months
a. Seen a doctor or other health care provider, such as a specialist, in their office or health care clinic						
Total (n=2012)	<b>22</b>	40	29	10	0	<b>78</b>
Caregivers (n=728)	<b>22</b>	42	26	10	0	<b>78</b>
Rare Disease HH (n=180)	<b>21</b>	32	28	19	0	<b>79</b>
b. Seen a mental health professional or therapist in their office or health care clinic						
Total	<b>80</b>	10	6	4	*	<b>20</b>
Caregivers	<b>79</b>	12	5	3	0	<b>21</b>
Rare Disease HH	<b>72</b>	16	7	4	0	<b>28</b>
c. Seen a doctor or other health care provider, such as a specialist, online or via a telehealth appointment						
Total	<b>54</b>	31	11	4	*	<b>46</b>
Caregivers	<b>50</b>	33	12	4	0	<b>50</b>
Rare Disease HH	<b>37</b>	41	15	7	0	<b>63</b>
d. Seen a mental health professional or therapist online or via a telehealth appointment						
Total	<b>81</b>	9	5	4	0	<b>19</b>
Caregivers	<b>78</b>	11	6	4	0	<b>22</b>
Rare Disease HH	<b>71</b>	14	8	7	0	<b>29</b>
e. Used an AI tool such as ChatGPT or Gemini to learn about a health condition or treatment options						
Total	<b>77</b>	14	5	4	*	<b>23</b>
Caregivers	<b>78</b>	13	4	5	0	<b>22</b>
Rare Disease HH	<b>62</b>	24	7	7	0	<b>38</b>
f. Gone online to find other people who might have health concerns similar to yours						
Total	<b>62</b>	22	11	6	0	<b>38</b>
Caregivers	<b>61</b>	23	11	5	0	<b>39</b>
Rare Disease HH	<b>50</b>	24	18	9	0	<b>50</b>

**(People who went online to find others with similar health concerns, n=770)**

CARE4. Were you successful in finding people online with health concerns similar to yours?

Total		Caregivers	Rare Disease HH
83	Yes	80	80
17	No	20	20
0	Dk/Ref	0	0
(770)		(283)	(90)

CARE3f/CARE4 COMBO TABLE

Total		Caregivers	Rare Disease HH
<b>38</b>	<b>Total looked online for someone with similar health concerns in past 12 months</b>	<b>39</b>	<b>50</b>
32	Successful	31	40
7	Not successful	8	11
<b>62</b>	<b>Total did not look online for someone with similar health concerns</b>	<b>61</b>	<b>50</b>
0	Dk/Ref	0	0
(2012)		(728)	(180)

CARE5. Have you, or has anyone in your household, ever been told by a doctor or other health professional that you (or they) have a rare disease? A rare disease is one that affects fewer than 200,000 people in the U.S..

Total		Caregivers
8	Yes	13
92	No	87
*	Dk/Ref	0
(2012)		(728)

**(No one in HH diagnosed with rare disease, n=1832)**

CARE6. Are you, or is anyone in your household, currently experiencing an illness that doctors or other health care professionals have not been able to diagnose?

Total		Caregivers
8	Yes	10
92	No	90
0	Dk/Ref	0
(1832)		(728)

CARE5/CARE6 COMBO TABLE

Total		Caregivers
15	Total rare disease or undiagnosed HH	22
85	Total not rare disease or undiagnosed HH	78
(2012)		(728)