



ARKANSAS LIFESPAN RESPITE

2022 Arkansas Caregiver Data Survey

This survey is being conducted by the Arkansas Lifespan Respite Program to gather data and feedback from unpaid caregivers across the state on their caregiver experiences and needs. This data is critical in helping the state of Arkansas better understand where our caregivers are struggling and what we can do to provide better supports and services. We appreciate you taking the time to complete this survey. Approximate time to complete the full survey is 15 minutes.

* Have you ever provided unpaid care to a relative or a friend 18 years of age or older in order to help them take care of themselves OR a child (minor, less than 18) because of a medical, behavioral, or other condition or disability (more than required normal care)? This person must have lived in the household at the time.

- Yes
- No

Note: If an individual selects NO, they will automatically be disqualified from completing the survey.



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This is an important study and we have divided it into pages based on information about you, the caregiver, and information about the one you are caring or did care for, the "care recipient."

* How old were you (the caregiver) on your last birthday?

- 18 years to 24 years
- 25 years to 34 years
- 35 years to 44 years
- 45 years to 54 years
- 55 years to 64 years
- 65 years or older

* Which ethnicity do you identify as?

- Spanish/Hispanic/Latino
- Black/African American
- White/Caucasian
- American Indian/Alaska Native
- Asian
- Marshellese
- Native Hawaiian/Pacific Islander
- 2 or more
- Don't Know
- Prefer not to answer

* What gender do you identify as?

- Male
- Female
- Non-Binary
- Don't Know
- Prefer not to answer

* Which county in Arkansas do you (the caregiver) reside in?

Note: All Arkansas counties listed in alphabetical order

* Are you (the caregiver) or have you served in the US Armed Forces? This includes Army, Navy, Air Force, Marines, Coast Guard, Women's Armed Forces, National Guard or Reserves.

- Yes, Currently Serving
- Yes, Have Served but not currently
- No, I have not served
- Prefer not to answer

* Are you (the caregiver) or were you in the past, WHILE PROVIDING CARE, a student- either full time or part time?

- Yes, I am currently a student
- Yes, I used to be a student
- No
- Prefer not to answer

* Last year, what was your total annual household income from all sources, before taxes?

- Under \$30,000
- Between \$30,000 and \$49,999
- Between \$50,000 and \$74,999
- Between \$75,000 and \$99,999
- Between \$100,000 and \$150,000
- Over \$150,000

* Are you currently employed or have you been employed during the time you were a caregiver?

- Yes, I am currently employed
- No, I am not currently employed but was during some point of my caregiver time
- No, I have not been employed during my caregiver time
- Prefer not to answer *Note: If individual answers No, I have not been employed or Prefer not to Answer, survey will skip the remaining employment questions.*

* Approximately how many hours per week did/do you work?

- 1-10
- 11-20
- 21-30
- 31-40
- More than 40

* Does/Did your supervisor know that you are an unpaid caregiver?

- Yes
- No
- Unsure
- Prefer not to answer

* As a result of caregiving, have you/did you experience any of these at your place of employment?

- | | |
|--|---|
| <input type="checkbox"/> Tardiness, left early or took time off during the day to provide care | <input type="checkbox"/> Resigned from work entirely |
| <input type="checkbox"/> Took a leave of absence | <input type="checkbox"/> Retired early |
| <input type="checkbox"/> Reduced working hours | <input type="checkbox"/> Received a warning or disciplinary action about your performance or attendance at work |
| <input type="checkbox"/> Turned down a promotion or additional responsibilities | <input type="checkbox"/> None of the above |
| <input type="checkbox"/> Lost job benefits | |

* Have you/Did you ever feel/felt that your responsibilities as a caregiver led you to be penalized or discriminated against at your place of employment?

- Yes
- No
- Unsure/Prefer not to answer

* Please select any or all below that relates to you (the caregiver)?

- | | |
|---|--|
| <input type="checkbox"/> My role as a caregiver gives/gave me a sense of purpose or meaning in my own life. | <input type="checkbox"/> I do not/ did not feel I have/had a choice in taking on the responsibility of providing care for this person. |
| <input type="checkbox"/> I find/found it difficult to take care of my own health while caring for another. | <input type="checkbox"/> None of the above |
| <input type="checkbox"/> I feel/felt alone or lonely as a caregiver. | |

* How would you describe your own overall health (when you were caregiving)?

- | | |
|----------------------------|---------------------------------|
| <input type="radio"/> Poor | <input type="radio"/> Very Good |
| <input type="radio"/> Fair | <input type="radio"/> Excellent |
| <input type="radio"/> Good | |

* On a scale of 1 to 5, how much physical strain would you say caregiving has/had on you?

Not a strain at all

Very much a strain



* On a scale of 1-5, how emotionally stressful would you say caregiving is/has been?

Not stressful at all

Very stressful



* On a scale of 1-5, how much of a financial strain would you say caregiving is/has been?

Not a strain at all

Very much a strain



* Below is a list of financial impacts that some caregivers have experienced. Select any and all that apply to you.

- | | |
|--|--|
| <input type="checkbox"/> Taken on more debt (credit cards, loans, lines of credit) | <input type="checkbox"/> Used long-term savings like retirement to pay for things |
| <input type="checkbox"/> Missed or Was late paying for a student loan | <input type="checkbox"/> Stopped saving or stopped trying to save money |
| <input type="checkbox"/> Borrowed money from family or friends | <input type="checkbox"/> Moved to a less expensive home, apartment or other living arrangement |
| <input type="checkbox"/> Filed for bankruptcy (medical or personal) | <input type="checkbox"/> Was evicted or had a home foreclosed |
| <input type="checkbox"/> Been unable to afford basic expenses like food | <input type="checkbox"/> Delayed your retirement or decided to never retire |
| <input type="checkbox"/> Left your bills unpaid or paid them late | <input type="checkbox"/> Had to start working again, working more, or find a second job |
| <input type="checkbox"/> Used up your personal short-term savings | |
| <input type="checkbox"/> None of the above | |

* How would you say being a caregiver plays/played a role in your overall health?

- | | |
|--|--|
| <input type="radio"/> Made/Makes it Better | <input type="radio"/> Unsure |
| <input type="radio"/> Not Affected | <input type="radio"/> Prefer not to Answer |
| <input type="radio"/> Made/Makes it Worse | |



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Now let's get some basic information about the care recipient.

* How old is/was the person you care/cared for?

- | | |
|--|--|
| <input type="radio"/> Less than 12 months | <input type="radio"/> 25 years to 34 years |
| <input type="radio"/> 12 months to 4 years | <input type="radio"/> 35 years to 44 years |
| <input type="radio"/> 5 years to 13 years | <input type="radio"/> 45 years to 54 years |
| <input type="radio"/> 14 years to 18 years | <input type="radio"/> 55 years to 64 years |
| <input type="radio"/> 19 years to 24 years | <input type="radio"/> 65 years or older |

* Is/Was the person you care/cared for, or do/did they identify as....

- Male
- Female
- Non-Binary
- Prefer not to answer

* What is your relationship with this person?

Note: Dropdown contains all common family relations, friend, partner/companion,, neighbor, and an OTHER field to free type if relation is not listed

* What is the primary diagnosis or illness the care recipient has/had, for which they need/needed your care?

- | | |
|---|---|
| <input type="radio"/> Alzheimer's/Dementia; Confusion; Forgetfulness | <input type="radio"/> Lung Disease, Emphysema, COPD |
| <input type="radio"/> Arthritis | <input type="radio"/> Mental Illness, Emotional Illness, Depression |
| <input type="radio"/> Blood Pressure/Hypertension | <input type="radio"/> Mobility Issues |
| <input type="radio"/> Brain damage/Injury | <input type="radio"/> Old Age, Aging |
| <input type="radio"/> Broken Bones | <input type="radio"/> Parkinson's |
| <input type="radio"/> Cancer | <input type="radio"/> Stroke |
| <input type="radio"/> Developmental/Intellectual Disorder, Downs Syndrome | <input type="radio"/> Substance Abuse |
| <input type="radio"/> Diabetes | <input type="radio"/> Surgery, Wounds |
| <input type="radio"/> Feeble, Unsteady, Frequent Falls | <input type="radio"/> Vision Loss, Blindness |
| <input type="radio"/> Hearing Loss, Deafness | <input type="radio"/> Unsure |
| <input type="radio"/> Heart Disease, Heart Attack | <input type="radio"/> Prefer not to answer |
| <input type="radio"/> Other (please specify) | |

* Has the care recipient been diagnosed with Alzheimer's or any other dementia?

- Yes
 No

* Has the care recipient served in the US Armed Forces? This includes Army, Navy, Air Force, Marines, Coast Guard, Women's Armed Forces, National Guard or Reserves.

- Yes, Currently Serving
 Yes, Have Served but not currently
 No, Have Not Served
 Unsure/ Prefer not to answer

* How long have you been or did you provide care to this person?

- Less than 1 year
 1 year to 5 years
 5 years to 10 years
 10+ Years

* Which of the best describes how much care or assistance you give/have given to this person because of their condition within a normal week?

- All the time; 24/7
- Almost all the time, only small breaks here and there
- Almost all the time, only break is to sleep
- Off and On around the clock
- Other (please specify)

* Which of these tasks do you/did you assist the person with?

- | | |
|--|---|
| <input type="checkbox"/> Getting in and out of beds/chairs | <input type="checkbox"/> Grocery Shopping or Other Shopping |
| <input type="checkbox"/> Getting Dressed | <input type="checkbox"/> Housework (doing dishes, laundry, dusting) |
| <input type="checkbox"/> Getting to/from bathroom or toilet | <input type="checkbox"/> Preparing Meals |
| <input type="checkbox"/> Bathing/Showering | <input type="checkbox"/> Transportation (driving or assisting in getting transportation services) |
| <input type="checkbox"/> Incontinence or Diapers | <input type="checkbox"/> Arranging outside services (nurses, home care aides, direct care support, meals on wheels) |
| <input type="checkbox"/> Feeding or Assistance Feeding | <input type="checkbox"/> Advocating for the individual with healthcare providers, community services or government agencies |
| <input type="checkbox"/> Medication Assistance (giving medications, eye drops, injections) | <input type="checkbox"/> Monitoring severity of their condition in order to adjust care when needed |
| <input type="checkbox"/> Managing Finances (paying bills or filling out insurance forms) | |
| <input type="checkbox"/> Other (please specify) | |

None of the above

* In the last 12 months (or the last year of previous caregiving duties), how many times has/had the care recipient been hospitalized overnight?

- | | |
|-----------------------------|---------------------------------------|
| <input type="radio"/> None | <input type="radio"/> 3 or More Times |
| <input type="radio"/> Once | <input type="radio"/> Unknown |
| <input type="radio"/> Twice | |



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Now let's talk about any assistance you receive as a caregiver, or that the care recipient receives, and where you look for caregiver information.

*

Has anyone else provided **UNPAID** help for the care recipient during your time as a caregiver?

- Yes
- No
- Unsure
- Prefer not to answer

* Has the care recipient received **PAID** help from any aides, housekeepers, or other people who were paid for their work/assistance during your time as a caregiver?

- Yes
- No
- Unsure
- Prefer not to answer

* Is/Was the care recipient on any Medicaid Waiver or Arkansas State Plan Waiver program offered by the Arkansas Department of Human Services?

- Yes
- No
- Unsure
- Prefer not to answer

*Note: If answer YES, will skip to the list of programs question.
If any other answer, will continue to next question.*

* Is/Was the care recipient on any waitlist for services or programs offered by the Arkansas Department of Human Services?

- Yes
- No
- Unsure
- Prefer not to answer

*Note: If answer YES, will skip to the list of programs question.
If any other answer, will continue to next question.*

* Is/Was the care recipient denied for any services or programs offered by the Arkansas Department of Human Services?

- Yes
- No
- Unsure
- Prefer not to answer

* Do you know which service program the care recipient has applied/had applied for or is currently receiving?

- ARChoices
- IndependentChoices (self-directed personal care)
- Autism Waiver
- PASSE
- Community and Employment Supports (CES)
- TEFRA
- PACE
- LivingChoices
- Other (please specify)

- None of the above

* Select below any and all places you use/used to learn more or gather information to better help you as a caregiver?

Doctor or Health Care Professional

Local Hospital or other care facility

Friends or Family

Online or Social Media

Local Government Agencies (County Health Facilities or County Offices)

Non-Profit or Advocacy Organizations for aging, caregiving, or specific conditions

State Government Agencies like the Arkansas Department of Human Services, Arkansas Department of Health

None of the above



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Caregiver respite is simply a temporary or short break from your caregiving duties while someone else provides that care in your place. Respite is a great way to relax and recharge your batteries as a caregiver so that you can provide the best quality care to those you are caring for. Respite can be provided in the home, in the community, or a facility including a day center or long-term care setting, depending on what is the best fit for you and the care recipient.

Let's talk a little about respite and what you would do if given caregiver respite opportunities.

* Have you ever heard of caregiver respite before this survey?

- Yes
- No
- Unsure/Prefer not to answer

* Do you know where to find respite care in the state of Arkansas?

- Yes
- No/Unsure
- Prefer not to answer

* If you have received respite care within the last 12 months, how easy was it for you to find?

- I have not received respite care in the last 12 months
- Easy
- Not easy at all
- Pretty easy
- Somewhat easy
- Very easy

Note: If individual answers HAVE NOT RECEIVED RESPITE CARE, survey will skip the next two questions.

* If you received respite care, who provided that care for you?

- | | |
|--|---|
| <input type="checkbox"/> I have not received respite care. | <input type="checkbox"/> A faith-based organization/church group or event |
| <input type="checkbox"/> A family member | <input type="checkbox"/> Community Group or Event |
| <input type="checkbox"/> A friend | <input type="checkbox"/> A service provider |
| <input type="checkbox"/> Other (please specify) | |

* Did you pay out of pocket for the respite care?

- Yes
- No
- Unsure
- I did not receive respite care/ Prefer not to answer

* If you were to receive some free time or a break from your caregiving duties, what do you think you would do with that time?

- | | |
|---|--|
| <input type="checkbox"/> Spend time with spouse/significant other | <input type="checkbox"/> Pursue hobbies/interests |
| <input type="checkbox"/> Spend time with other family/friends | <input type="checkbox"/> Participate in physical activities or exercise |
| <input type="checkbox"/> Run errands | <input type="checkbox"/> Attend or participate in caregiver workshops/training or support groups |
| <input type="checkbox"/> Complete household tasks | <input type="checkbox"/> Participate in social/recreational activities, including church |
| <input type="checkbox"/> Private time to relax, rest | |
| <input type="checkbox"/> Other (please specify) | |



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And finally to wrap up the survey, a few follow-up questions.

* If the situation arises, would you be interested in participating in future research on caregivers?

- Yes
 No

* Your information and answers provided in this survey are totally confidential. However, if a reporter writing a story about the results of the overall survey wanted to interview caregivers who participated, would you be willing to provide your information? (This is completely optional)

- Yes
 No

Thank you for assisting us in this data collection and providing your feedback. We look forward to gathering this data and providing it to the public as a better overall view of caregiver stresses, needs and respite opportunities for the state. If you would like to be provided with the overall results of this research once its completed, please provide your contact information.

Name

Address

Address 2

City/Town

State/Province

ZIP/Postal Code

Email Address

Phone Number