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.
2022 Arkansas Caregiver Data Survey

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?

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

* 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)?

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

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

- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Very Good
- ☐ Excellent

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

Not a strain at all

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

Not stressful at all

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* 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.

- Taken on more debt (credit cards, loans, lines of credit)
- Missed or was late paying for a student loan
- Borrowed money from family or friends
- Filed for bankruptcy (medical or personal)
- Been unable to afford basic expenses like food
- Left your bills unpaid or paid them late
- Used up your personal short-term savings
- None of the above

- Used long-term savings like retirement to pay for things
- Stopped saving or stopped trying to save money
- Moved to a less expensive home, apartment or other living arrangement
- Was evicted or had a home foreclosed
- Delayed your retirement or decided to never retire
- Had to start working again, working more, or find a second job

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

- Made/Makes it Better
- Not Affected
- Made/Makes it Worse
- Unsure
- Prefer not to Answer
Now let's get some basic information about the care recipient.

* How old is/was the person you care/cared for?
  - Less than 12 months
  - 12 months to 4 years
  - 5 years to 13 years
  - 14 years to 18 years
  - 19 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

* 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?

- Alzheimer's/Dementia; Confusion; Forgetfulness
- Arthritis
- Blood Pressure/Hypertension
- Brain damage/Injury
- Broken Bones
- Cancer
- Developmental/Intellectual Disorder, Downs Syndrome
- Diabetes
- Feeble, Unsteady, Frequent Falls
- Hearing Loss, Deafness
- Heart Disease, Heart Attack
- 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?

- Getting in and out of beds/chairs
- Getting Dressed
- Getting to/from bathroom or toilet
- Bathing/Showering
- Incontinence or Diapers
- Feeding or Assistance Feeding
- Medication Assistance (giving medications, eye drops, injections)
- Managing Finances (paying bills or filling out insurance forms)
- Other (please specify)

- Grocery Shopping or Other Shopping
- Housework (doing dishes, laundry, dusting)
- Preparing Meals
- Transportation (driving or assisting in getting transportation services)
- Arranging outside services (nurses, home care aides, direct care support, meals on wheels)
- Advocating for the individual with healthcare providers, community services or government agencies
- Monitoring severity of their condition in order to adjust care when needed

- 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?

- None
- Once
- Twice
- 3 or More Times
- Unknown
- Unknown
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
     - Note: If answer YES, will skip to the list of programs question.
     - If any other answer, will continue to next question.
   - [ ] No
   - [ ] Unsure
   - [ ] Prefer not to answer
* 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
- Friends or Family
- Local Government Agencies (County Health Facilities or County Offices)
- Local Hospital or other care facility
- Online or Social Media
- 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
2022 Arkansas Caregiver Data Survey

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?

- I have not received respite care.
- A family member
- A friend
- 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?

- Spend time with spouse/significant other
- Spend time with other family/friends
- Run errands
- Complete household tasks
- Private time to relax, rest
- Other (please specify)
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.

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City/Town
State/Province
  -- select state --
ZIP/Postal Code
Email Address
Phone Number