Illinois Department on Aging

Resources for the Family Caregiver

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Recording Link 11/23/26:
Resources for Family Caregivers-20261123 1847-1

The **MISSION** of the Illinois Department on Aging is to serve and advocate for older Illinoisans and their caregivers by administering quality and culturally appropriate programs that promote partnerships and encourage independence, dignity, and quality of life.



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New & Trending



- **Governor's Proclamation of November 23rd being #ThanksCaregiving Day**
  - This week Governor Pritzker approved a proclamation marking this day and the state Senate passed a resolution acknowledging November 2026 as Family Caregiver Month in Illinois.
  - We hope you and your organizations will join us in celebrating this day by thanking caregivers and offering support. **Please post on your social media channels AND/OR share IDoA's post w/ comment on Monday (today)** Social media content for Monday is here.

- EngAging Illinois: Illinois' Multi-Sector Plan on Aging
  - Caregiver Goals: Investing in Caregivers

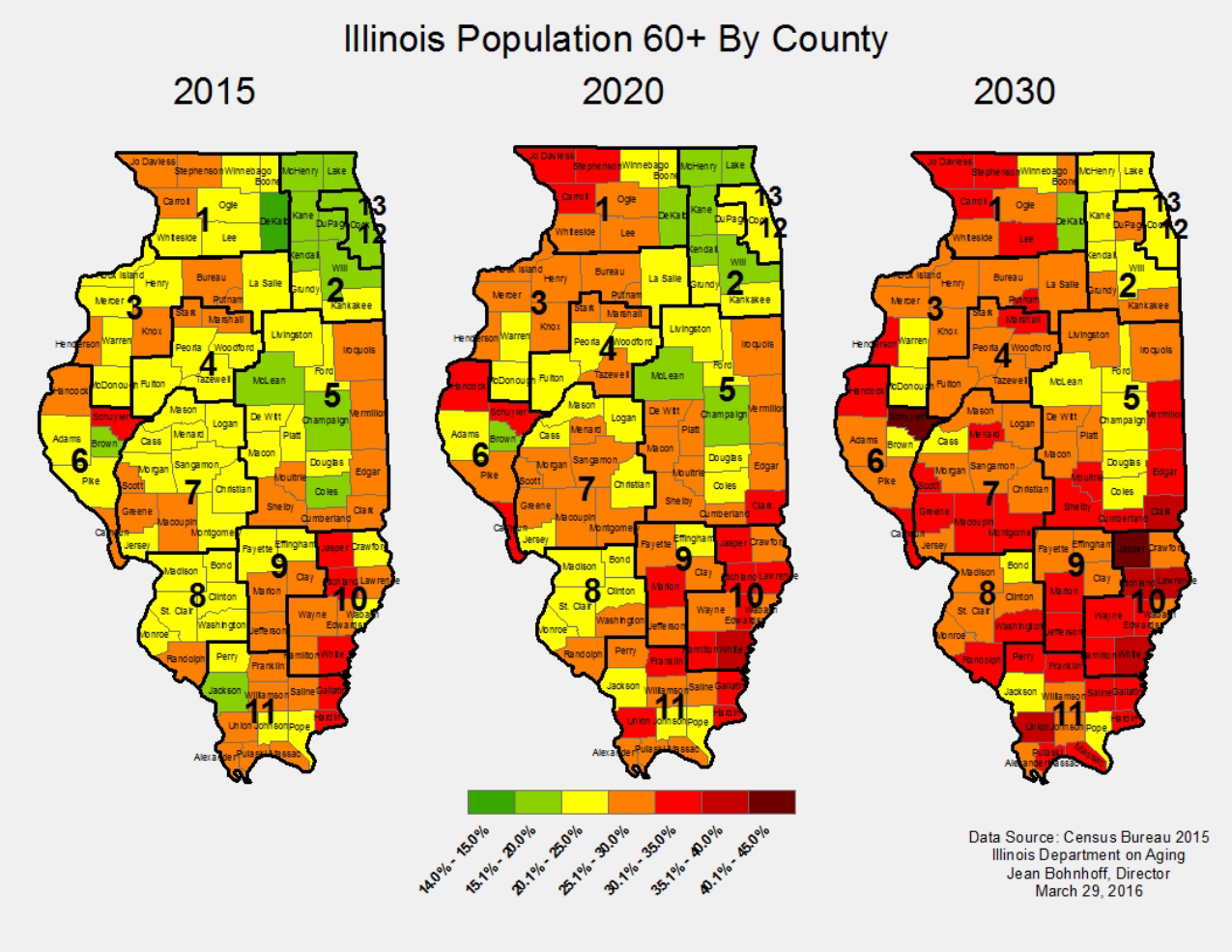
- Illinois Caregiver Assistance and Resource Portal Act (2024): Support for Caregivers (current website)
  - Oct. 2026: IL awarded grant from ACL to build the portal

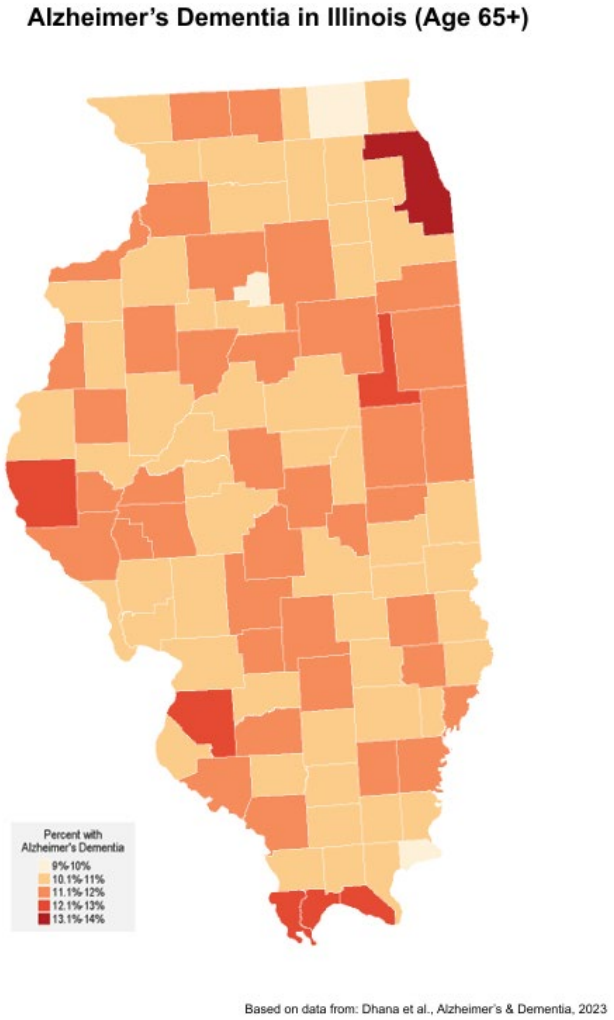
- SNL "Sister" Skit 11/14/2026: Bing Videos

"There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver."

-Rosalyn Carter

Projected Growth of Aging Population in IL





[Illinois Map and Spreadsheet - Alzheimer's Prevalence]

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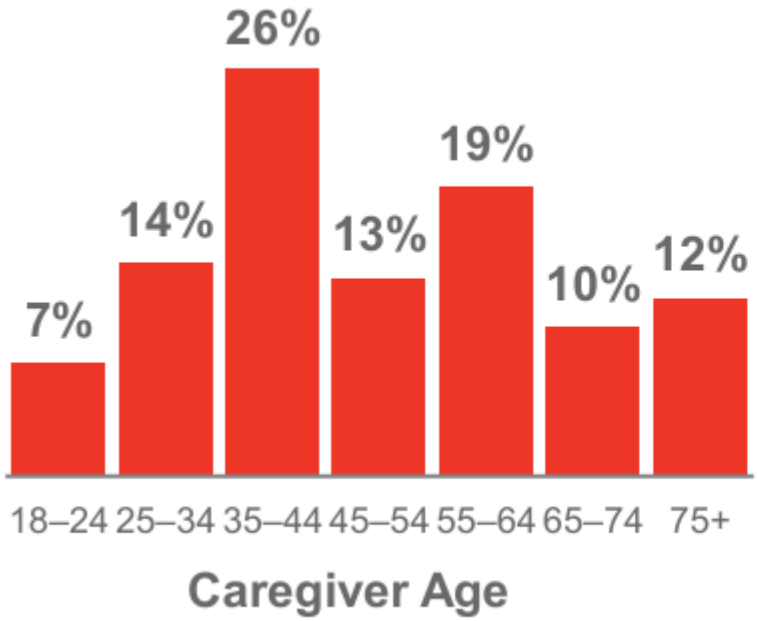
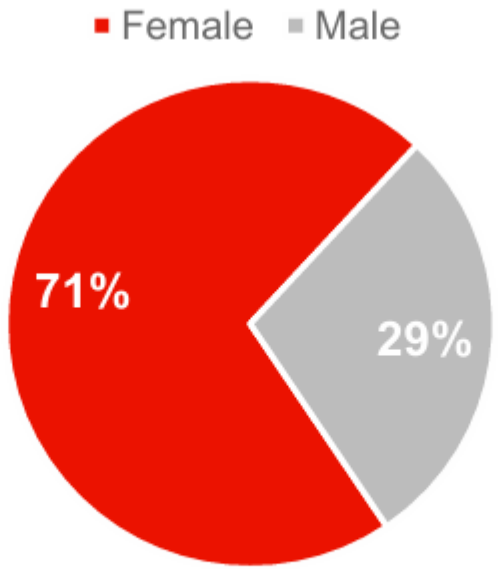
Demographics of Family Caregivers

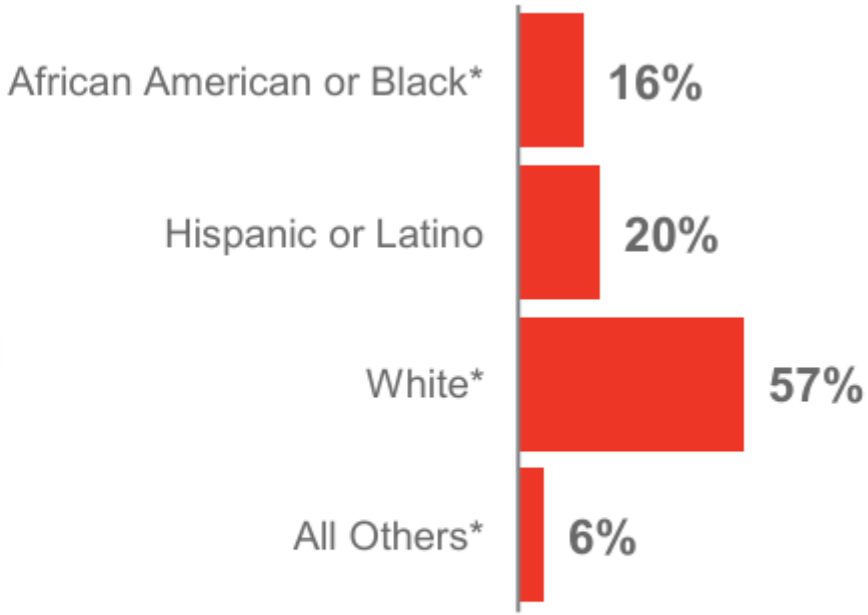
23% of Illinois adults (2,224,000) are caregivers for older family members or friends



Caregiver Age



Caregiver Gender



Caregiver Race and Ethnicity

*Non-Hispanic

[AARP & NAC: Caregiving in the U.S. 2025: Illinois]

Family Caregivers

- Six in ten family caregivers work while also caregiving (62%).
- 20% of caregivers spend more than 40 hours a week providing care
- Over one-third family caregivers (36%) are high-intensity caregivers, providing more hours of care weekly and helping with more ADLs and IADLs
- Nearly 1 in 4 caregivers in Illinois (24.5%) is providing care to an individual with Alzheimer's or other form of dementia.

AARP & NAC: Caregiving in the U.S. 2025: Illinois

Alz. Assoc: illinois-cg-brfss-fact-sheet.pdf

Drivers of Caregiving: Aging population

Of people aged 65 and older, 70% will need long term services and supports

Most depend on family and friends

48% will need paid care services

Of this 24% will need more than 2 years of paid care services	15% will spend more than 2 years in a nursing home

What Is the Lifetime Risk of Needing and Receiving Long-Term Services and Supports? | ASPE (hhs.gov)

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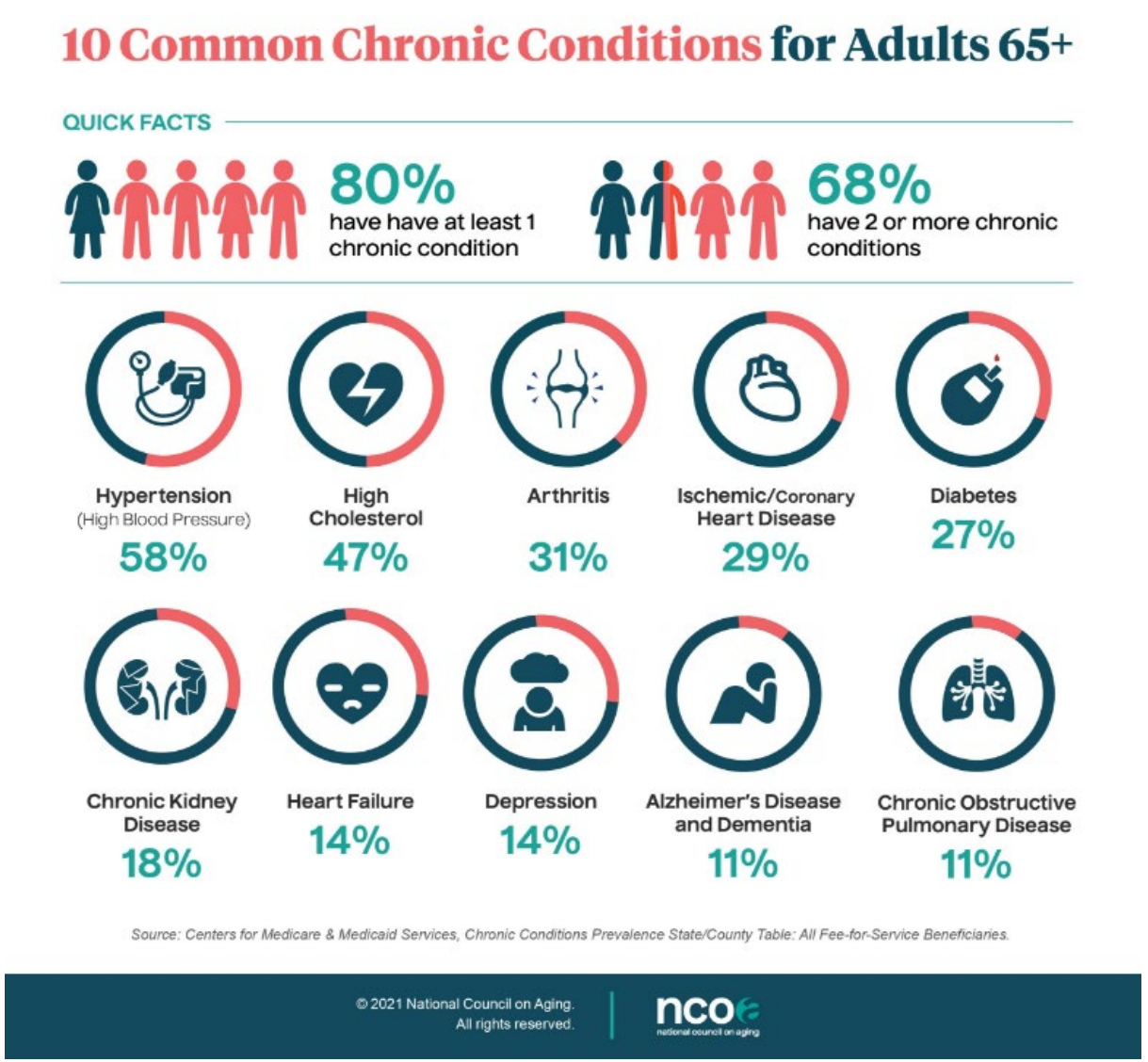
Drivers of Caregiving: Chronic Disease



Drivers of Caregiving: Alzheimer's and Dementia

- An estimated **250,600 people aged 65 and older** are living with Alzheimer's in Illinois.
    - 12% of older adults aged 65 & older (2/3 are women)
    - 7.4% of the LGBTQ+ older adult population are living with dementia.
- **19.1%** of people aged 45 and older have **subjective cognitive decline**.
- **465,000 family caregivers in Illinois** bear the burden of the cognitive disease, **providing 668 million hours of unpaid care** for family and friends with Alzheimer's or related dementia.
- **Fear of discrimination** based on race or sexual orientation can delay care.
    - 36% of Black Americans, 18% of Hispanic. and 19% of Asian Americans see discrimination as a barrier to receiving Alzheimer's and dementia care.
    - 40% of LGBTQ+ older adults reported that their healthcare provider does not know their sexual orientation.

Illinois Department on Aging

Illinois Chapter | Alzheimer's Association LGBT Older Adults and Dementia Infographic

Caregiving Challenges



Dolly Parton, from people.com

- Sandwich (Panini) Caregivers (32%)
- Navigating new family roles
- Financial Costs
- Emotional toll
- Managing healthcare
- Caregiving from a distance
- Stress due to demands of caregiver role
- Finding supportive community resources

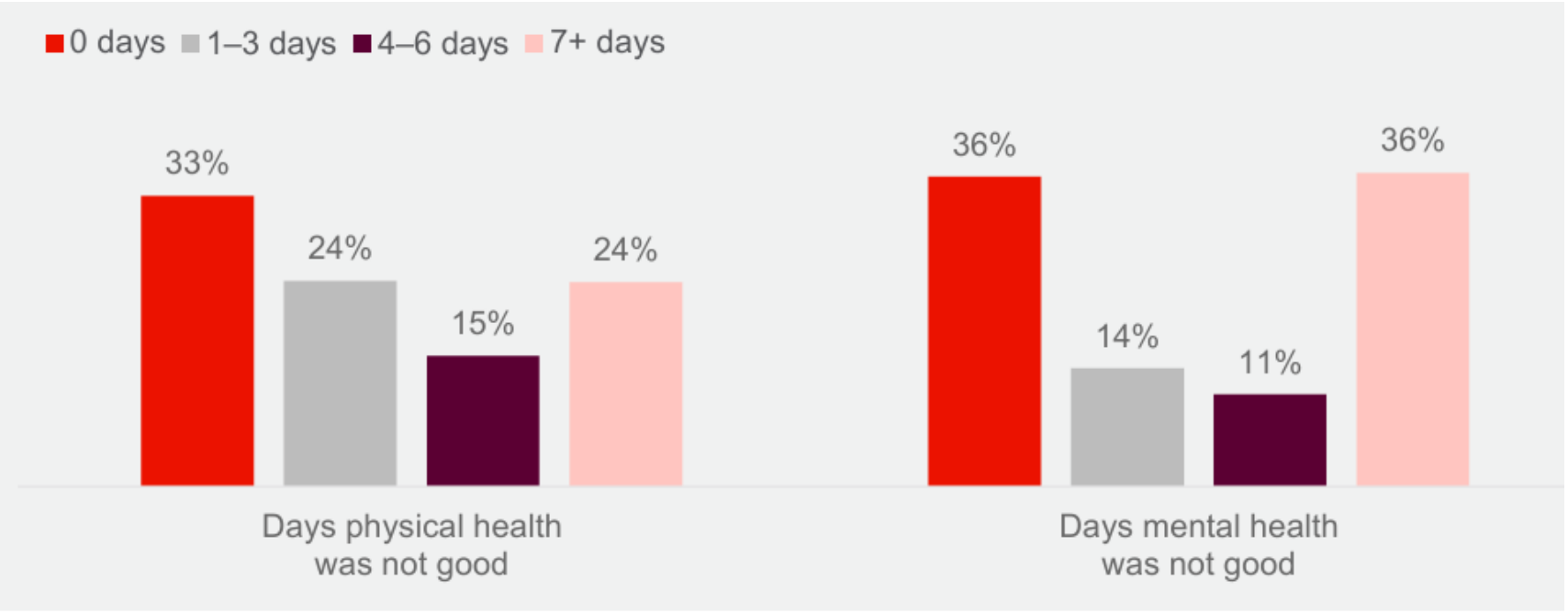
Epidemic of Loneliness

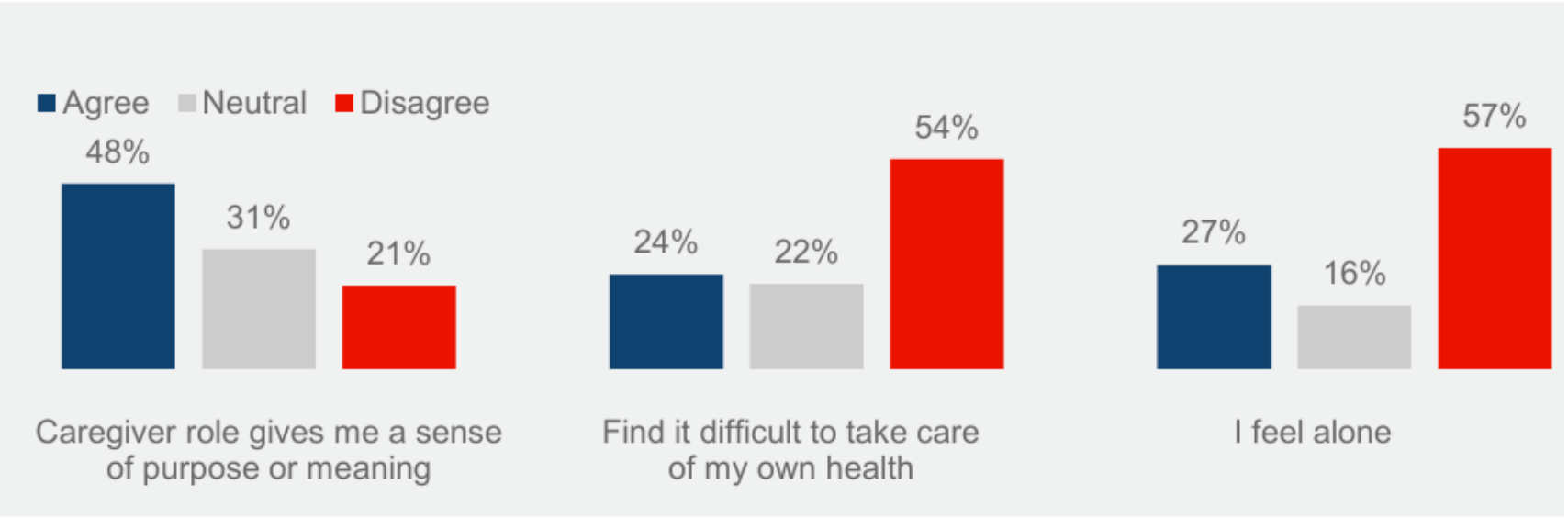
- About **1 in 3 adults** in the U.S. report **feeling lonely.**
- About **1 in 4** U.S. adults report **not having social and emotional support**.

- 2023: The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community: Our Epidemic of Loneliness and Isolation

- BYU KIND Study: One act of kindness per week improves social and community connection and reduces feelings of loneliness: Loneliness and Isolation Present Serious Mortality Risks—Antidote Found in Acts of Kindness - BYU College of Family, Home, and Social Sciences

- Social isolation and loneliness can increase a person's risk for:
  - Heart disease and stroke.
  - Type 2 diabetes.
  - Depression and anxiety.
  - Suicidality and self-harm.
  - Dementia.
  - Earlier death. (CDC)
- Increase in cortisol levels (stress hormone)
  - Can impair cognitive performance
  - Compromise the immune system
  - Increase risk for vascular problems, inflammation and heart disease (Cleveland Clinic: How Loneliness Impacts Your Health)





Caregivers Healthy Days Measure

- [AARP and National Alliance for Caregiving: Caregiving in the U.S. 2025: Illinois]

Being Active and Having Purpose

- Having purpose, helping, and connecting others helps with feelings of loneliness, both for the caregiver and care receiver
- Purpose driven activities that allow for a person with dementia to contribute or be active

- Setting the table for meals
- Decorate placemats
- Fold clothes and pair socks
- Twist nuts and bolts together
- Safe woodworking projects
- Pull weeds and rake leaves
- Trace leaves and color
- Paint by number projects
- Simple puzzles
- Sort coins or other objects
- Listen to music the care receiver enjoys (and dance)
- Reminisce with family photo albums (consider getting a digital frame)
- Explore books of art
- Continue connecting with other people

Erik Erickson Stages of Development

Need for Social Connection across the lifespan

Erikson's Psychosocial Stages

Stage	Basic Conflict	Virtue	Description
Infancy 0–1 year	Trust vs. mistrust	Hope	Trust (or mistrust) that basic needs, such as nourishment and affection, will be met
Early childhood 1–3 years	Autonomy vs. shame/doubt	Will	Develop a sense of independence in many tasks
Play age 3–6 years	Initiative vs. guilt	Purpose	Take initiative on some activities—may develop guilt when unsuccessful or boundaries overstepped
School age 7–11 years	Industry vs. inferiority	Competence	Develop self-confidence in abilities when competent or sense of inferiority when not
Adolescence 12–18 years	Identity vs. confusion	Fidelity	Experiment with and develop identity and roles
Early adulthood 19–29 years	Intimacy vs. isolation	Love	Establish intimacy and relationships with others
Middle age 30–64 years	Generativity vs. stagnation	Care	Contribute to society and be part of a family
Old age 65 onward	Integrity vs. despair	Wisdom	Assess and make sense of life and meaning of contributions

Erikson's theory outlines eight stages of psychosocial development, from infancy to adulthood. At each stage, individuals face a conflict, such as trust vs. mistrust, which shapes their personality. Successfully resolving these conflicts leads to virtues like hope and integrity, while failure can result in guilt or despair.

https://www.simplypsychology.org/erik-erikson.html

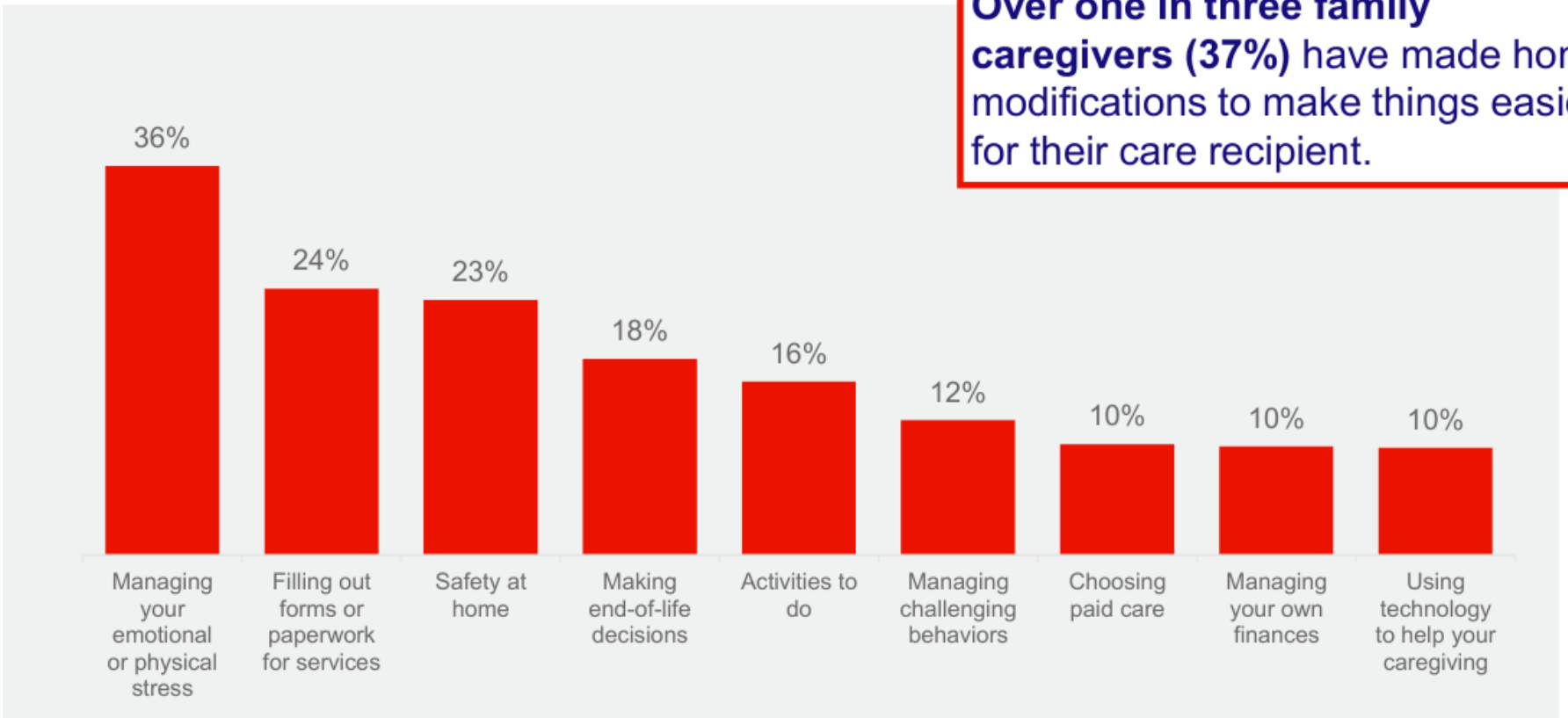
Integrity vs Despair

Helping care receivers leave their legacy, look back at their life with integrity

- Recording video, audio, written, music, or other art forms
- Life Stories
- Family History (& Lore)
- Family Recipes
- Family Cultural Rituals

Caregiver Resources

Information Needs of Family Caregivers



Over one in three family caregivers (37%) have made home modifications to make things easier for their care recipient.

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Caregiver Information Services (Title III-E of Older American Act Services)

"One in five family caregivers (21%) have difficulty getting local affordable services such as delivered meals, transportation, or in-home health services."
Caregiving in the U.S. 2025: Illinois

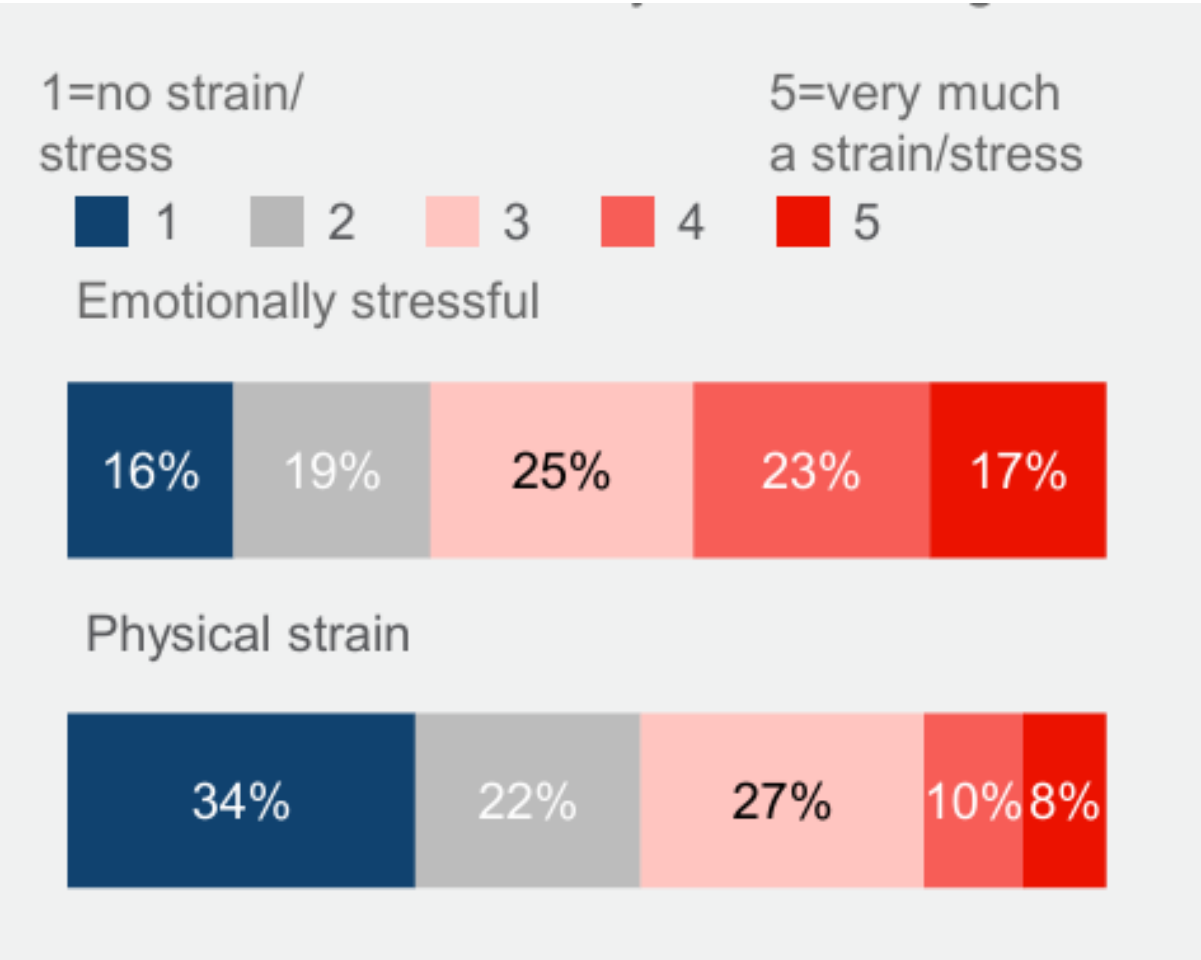
A service for caregivers that provides the public and individuals with information on resources and services available to Family Caregivers and Grandparents Raising Grandchildren or Older Relatives Raising Children within their communities.

Caregiver Assistance Services

(Title III-E of Older American Act Services)

A service that assists caregivers in obtaining access to the services and resources that are available within their communities and establishing follow-up procedures to ensure they receive the service.

- Case Management
- Information & Assistance
- Outreach services



Only “14% of family caregivers receive training to help with ADLs, IADLs, or behavioral management.” (AARP & NAC, 2025)

Caregiver Counseling, Support, & Training Services

(Title III-E of Older American Act Services)

The service is provided to caregivers to assist them in the areas of health, nutrition, and financial literacy, and in making decisions and solving problems relating to their caregiver roles, includes individual and group and caregiver training.

- Counseling, Support Groups
  - Memory Café’s
- Training & Education
  - Trualta
- Alzheimer's Disease and Related Dementias Evidence Based Education
  - Stress Busting for Caregivers

Caregiving in the U.S. 2025: Illinois

Caregiver Respite Services

(Title III-E of Older American Act Services)

"While four in ten (44%) family caregivers would find respite care helpful, Nearly nine in ten (87%) have never used such Services."
Caregiving in the U.S. 2025: Illinois

Services that offer temporary, substitute supports or living arrangements for care recipients in order to provide a brief period of relief or rest for caregivers.

- Respite
- Respite Alzheimer's Disease and Related Dementias

Caregiver Supplemental Services

(Title III-E of Older American Act Services)

- The service is provided on a limited basis to complement the care provided by caregivers.
  - Gap-Filling
  - Legal Services

Homecare and Long Term Care Ombudsman Programs

"59% of family caregivers say they advocate for their care receivers with health care providers, community services, or government agencies."
Caregiving in the U.S. 2025: Illinois

The Long Term Care Ombudsman Program works to resolve problems faced by residents and participants and advocate for broad policy, regulatory and/or legislative changes to improve care of residents and participants.

Housed within the Long-Term Care Ombudsman Program at the Department on Aging, the Homecare Ombudsman Program works to resolve complaints made by or on behalf of waiver participants when the rights of individuals are violated.

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Elder Abuse Prevention Activities

IDoA's Elder Abuse and Neglect Program (now Adult Protective Services Program) was established to prevent abuse, neglect, and financial exploitation of persons age 60+ and people with disabilities between the ages of 18-59 living in the community.

Nutrition Services

Congregate Meals

- A meal served at Senior Center and Community Centers or other nutrition site.
- In some areas of the state there are restaurant programs.

Home Delivered Meals

- Meals delivered to homebound older adults (and their unpaid caregiver).
- Requires assessment and referral from the local Care Coordination Unit (CCU) or the Managed Care Organization (MCO).

Community Care Program (CCP)

- Medicaid Waiver for the Elderly
- Assists older people in maintaining independence and providing cost effective **alternatives to nursing home placement.**
- Services include:
  - **Comprehensive care coordination**
  - **Homemaker Services**
  - **Automated Medication Dispenser**
  - **Emergency Home Alert System** (with fall detection and/or GPS technology)
  - **Adult Day Service (and Transportation)**

Who is eligible? People who...

- Are 60 years old or older;
- Are either U.S. citizens or eligible non-citizens within the specific categories;
- Are residents of Illinois;
- Have non-exempt assets of $17,500 or less (Your home, car, or personal furnishings are classified as exempt assets.); and
- Have an assessed need for long term care (to be at risk for nursing facility placement as measured by the Determination of Need (DON) assessment).
- **Must apply for Medicaid**

Where to find Caregiver Resources



Family and Caregiver Resource Centers

Funded by the Area Agencies on Aging (AAA), each center *can help someone locate* such services as...

- Adult day service for the older adult and respite services for the caregiver
- Individual counseling and support groups for the caregiver and/or older adult
- Services that help older adults remain in their homes:
  - Home-delivered meals
  - Assistance in housekeeping
  - Home modification
  - Assistance finding assistive devices
  - Training, counseling and emotional support
  - Transportation services
- Financial information and services
- Legal services
- Caregiver training
- Case management assistance
- Employment programs

TCARE- Tailored Caregiver Assessment & Referral

- On-line, self-paced, Caregiver Assessment that can help get caregivers connected to a local Caregiver Specialist

Find the Caregiver Services and/or the TCARE Assessment on the local AAA website

- (PSA 1) Northwestern IL AAA: Caregivers
- (PSA 2) AgeGuide (Chicagoland – 8 Collar Counties): Caregiver Services – AgeGuide
- (PSA 3) Western IL AAA: Western Illinois Area Agency on Aging
- (PSA 4) AgeCentral: Caregiver Support Program - Age Central
- (PSA 5) East Central IL AAA: Family Caregiver Resources
- (PSA 6) West Central IL AAA: Caregiver Support – West Central Illinois Area Agency on Aging
- (PSA 7) AgeLinc: Caregiver Support - AgeLinc
- (PSA 8) AgeSmart: Caregivers- AgeSmart Community Resources, Providing Options for Independence
- (PSA 9) Midland AAA: Midland Area Agency on Aging – Offering Services to Older Adults, Persons with Disabilities, and Caregivers in the Counties of Clay, Effingham, Fayette, Jefferson, and Marion
- (PSA 10) Southeastern IL AAA: Community Cafe Resource Centers - Southeastern Illinois Agency on Aging
- (PSA 11) Egyptian AAA: Home - Egyptian Area Agency On Aging
- (PSA 12) City of Chicago: City of Chicago :: Support for Family Caregivers & Care Partners
- (PSA 13) AgeOptions (Suburban Chicago): TCARE (Tailored Caregiver Assessment and Referral) - AgeOptions



Care Coordination Unit (CCU)

- Individuals are referred to their local CCU for a comprehensive assessment by health systems, community providers, family, friends, neighbors, or self
- Care Coordinators from local Care Coordination Unit (CCU) conduct a comprehensive assessment
- Person-Centered Plan of Care is developed to coordinate CCP Services and/or other services based on their person-centered plan of care

Where can you get started?

- Start with your local Area Agency on Aging (AAA) or your local Care Coordination Unit (CCU)
  - Find your local AAA or CCU on IDoA's website, Provider Profile page:
  - https://webapps.illinois.gov/AGE/ProviderProfileSearch
- Contact the IDoA Senior Helpline for more information: 1-800-252-8966
- Check out the resources on IDoA's Family Caregiver Page: Support for Caregivers
- Join the Illinois Family Caregiver Coalition: Illinois Family Caregiver Coalition

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“Ode to the Caregiver”

by Sandy Pastore



Ode to the caregiver
Young and old
Helping loved ones with futures untold

Ode to the caregiver
For keeping us fed
Prepping the pills and helping to bed

Ode to the caregiver
For shuffling about
Tending to things inside and out

Ode to the caregiver
For getting us well
Returning to a new normal from a sick shell

Ode to the caregiver
You know who you are
Many thanks to all caregivers, near and far