

So Far Away: Long-Distance Caregiving



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I&R/A Specialists: Our Role in Aiding Long-Distance Caregivers

- Just imagine, it's the day after a holiday, and you receive this frantic call.

What is the first thing you do and/or say once the caller stops for a breath?

Great statements to say which equals great statements to hear!

“You’ve called the right place!”

“If I don’t have a referral or resource for you, I will do my best to find one.”

“Tell me more about your situation...”

“What is your primary goal? If the world was perfect and you could make your situation ideal, what would that look like?”

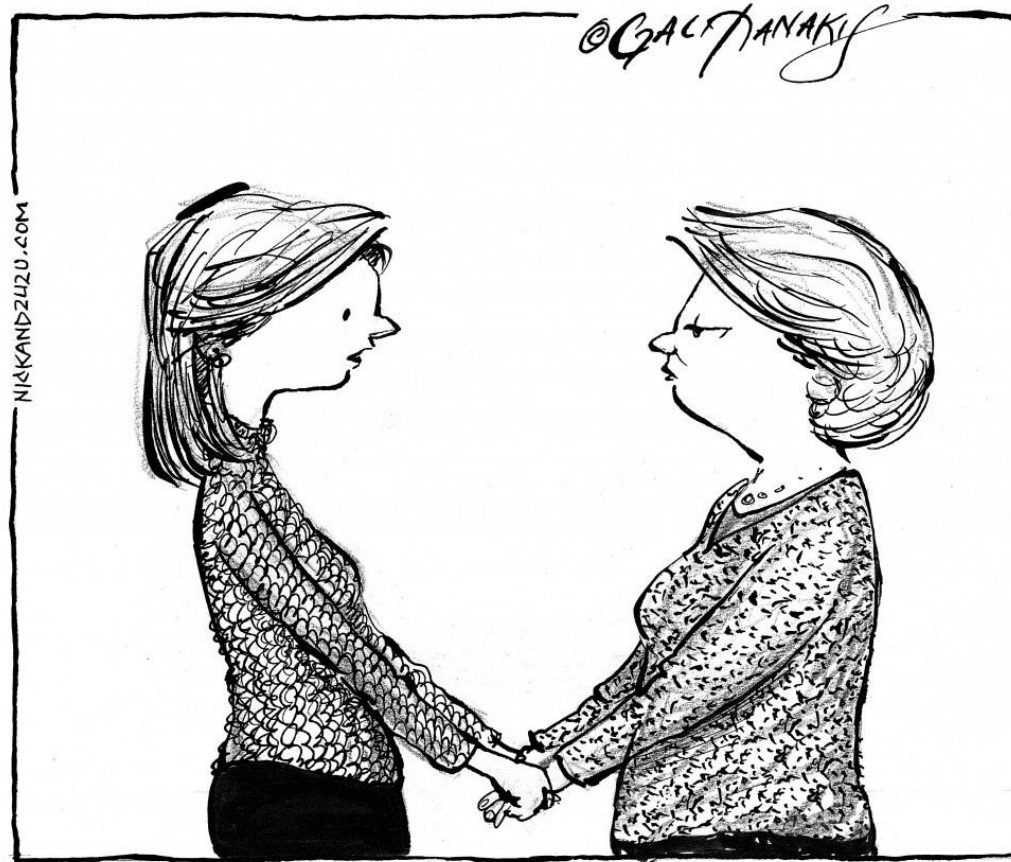




Three types of calls

- Call from the distant caregiver whose care recipient lives in our service area.
- Call from the caregiver who lives locally whose care recipient lives at a distance.
- Call from a professional (social worker, nurse, clergy, etc) regarding the caregiver or care recipient, identifying that assistance is needed.

Let's talk about caregivers



I WILL BE THERE FOR YOU WHEN YOU
NEED ME. IT'LL HELP, THOUGH, IF
THAT'S NOT FOR ANOTHER 20 YEARS.

Who is a caregiver?

Formal Caregivers are paid individuals providing care in one's home or long-term care facility.

Informal Caregivers are unpaid individuals (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting with activities of daily living and/or medical tasks.





What do caregivers “give up”?

“Family support is a key driver in remaining in one’s home and in the community, but it comes as substantial costs to the caregiver’s themselves, to their families, and to society. If family caregivers were no longer available, the economic cost to the U.S healthcare and long-term services and supports (LTSS) systems would increase astronomically.”

THIS IS THE “HIDDEN COST” OF CAREGIVING!

Caregiver Statistics: Financial

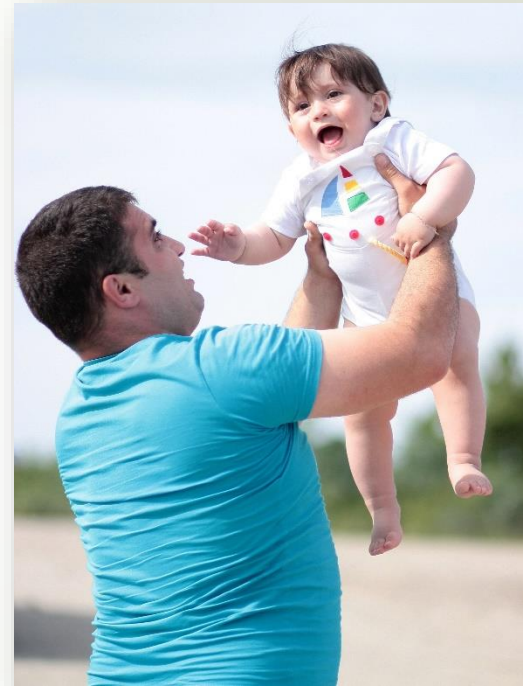
About 34 million Americans have provided **unpaid care** to an adult age 50 or older in the past 12 months.

The value of services provided by informal caregivers had an estimated value of **\$470 billion** in 2013.



Caregiver Statistics: Post-traditional families

- Divorce, remarriage and relationships with children
- Singlehood and childlessness
- Same-sex couples and families
- Immigrant families



Caregiver Statistics: Gender

75 percent of all caregivers are female

40 percent of male caregivers use paid assistance for a loved one's personal care



The “average caregiver” is a 49 year old, college-educated female who works outside the home and cares for a 72 year old parent.

Why are most caregivers female?

This is a picture of the average caregiver in the U.S.
This was me, one year ago!

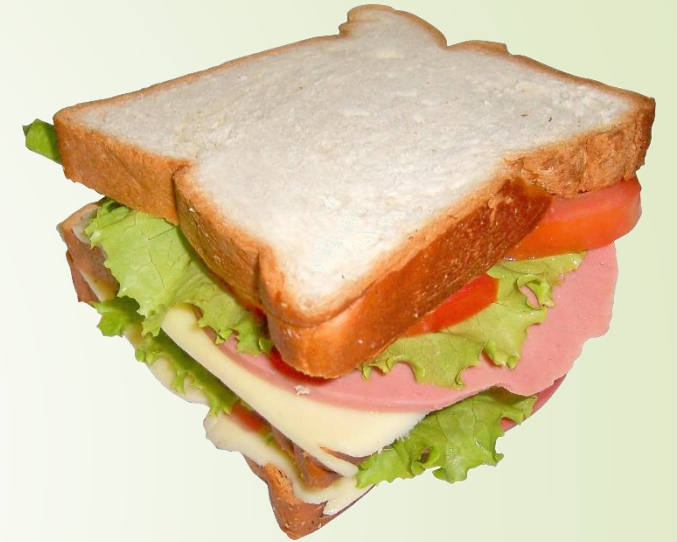


- Female.
- College-educated.
- Employed full-time outside the home.
- I was 48 years old.
- My dad was 71 years old.
- Two children (one in college, one in high school).

The “Sandwich Generation”

The “sandwich” metaphor is outdated:

- It does not convey that more than one generation may provide elder care
- It does not convey that members of any generation can be both caregivers and care recipients



Researchers are finding that adults may spend more years caring for their parents than caring for their children.

Caregiver Statistics: Distance



Question:

How many hours away defines a “long-distance caregiver”?

- a) 7 hours
- b) 5 hours
- c) 2 hours
- d) 1 hour

1 Hour



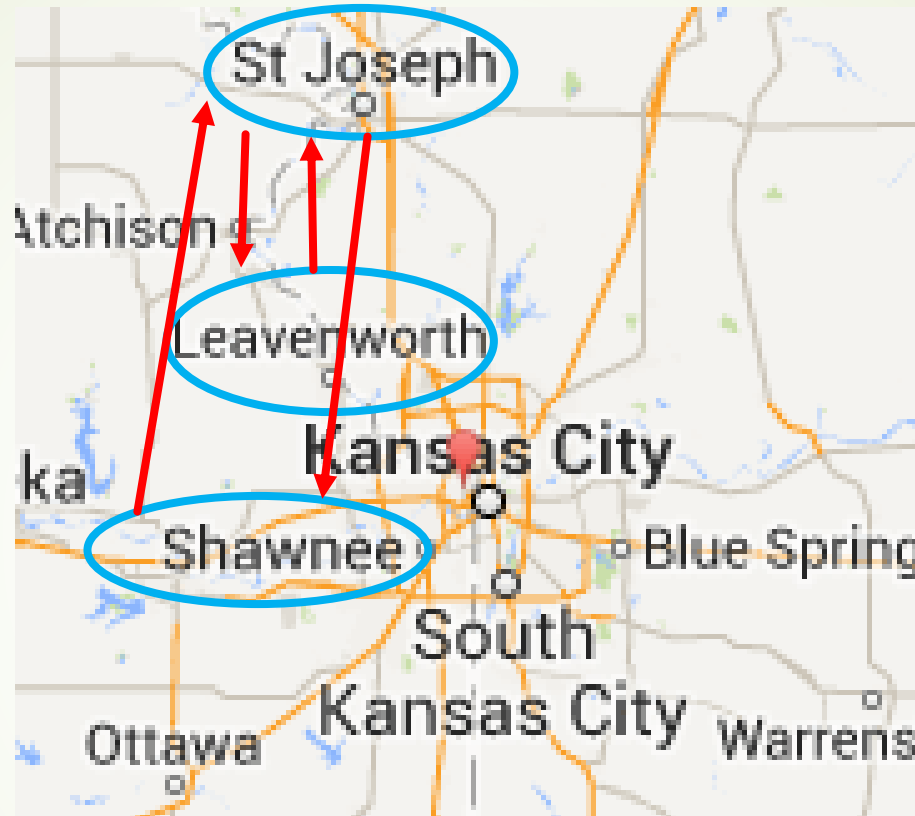
Question:

What is the average distance between a “long-distance caregiver” and a care recipient?

- a) 6 hours
- b) 5 hours
- c) 4 hours
- d) 3 hours

4 hours

Here's the big deal about one hour away...



2 hours and 48 minutes of drive time only!

Shawnee to St. Joseph – 1 hour.
St. Joseph to Leavenworth – 48 min.
Leavenworth to St. Joseph – 48 min.
St. Joseph to Shawnee – 1 hour

Definition of “Long-Distance Caregiver”

“An individual providing care to another individual living at least one hour away.”







7th Inning Stretch!

More Hidden Costs of Long-Distance Caregiving

Long-distance family caregivers are prone to the following:

- Physical strain
- Mental health struggles
- Interpersonal problems





Physical Health Problems

The extra burden placed on family caregivers can lead to

- Chronic stress
- Lower immune function

Self-care is often compromised:

- Forgetting to take medications
- Not taking time to exercise
- Skipping doctor's visits
- Avoiding rest when ill

Also, caregivers are more likely develop chronic diseases and die earlier!

Mental Health Problems

Studies indicate that long-distance caregivers have higher levels of clinical depression and anxiety than the general population.



Long-distance caregivers struggle with

- Guilt
- Anxiety
- Ambiguous loss
- Disenfranchised grief

Interpersonal Problems

Disagreements with friends and family members

- Roles and relationships
- Gender and personality
- Making decisions in a family context





Innovative Solution: Change in Healthcare Model

Change in healthcare model to person- and family-centered, rather than doctor-centered care.

“The movement toward person- and family-centered care calls for identifying and addressing family needs, and integrating family caregivers as partners in care.”

The core concepts of patient- and family-centered care are

- Dignity and Respect
- Information Sharing
- Participation
- Collaboration



Patient / Family Board

Today is: May 21, 2017

Your doctor: Dr. B. Well

Your nurse: Cara Lotte

Your aide: Kleen Sheets

PT: Dr. Range O. Motion

Room number: 201 - East

Telephone: 816-555-1234

Goals for today:

1) Walk outside with walker

2) Lower dosage of diuretic

3) Add more solid foods to diet

Medical Orders:

Low-sodium diet

Oxygen at 4L/hour

DNR in patient's chart

Instructions from family:

Call daughter Ima with any changes

Call pastor to arrange friendly visitors

Family / Caregivers:

Ima B. Deere, daughter, PCG

Lives in Portland, OR

Cell: 440-555-4321

Teacher, works 8-4 pm

Messages:

Please have social worker call with info about rehab facilities

Ida will be in town on May 25th

Questions:

Last INR reading? Range of motion exercises working?

Innovate Solution: Use of Technology



Health Care

Telemedicine

- Video or messaging technologies.
- Patients don't have to leave home.

Chronic care

- Digital tools and wearable technology can monitor symptoms.
- Apps can monitor blood glucose, blood pressure and other health indicators.

Health records

- Emergency contacts
- Insurance providers
- Prescription history
- Allergies
- Health history

Medication management

- Can help reduce medication errors
- Alarms can remind users when to take medications
- Pill boxes can be locked until the appropriate time
 - Can send messages telling users which medication to take and when
 - Track missed doses
 - Provide voice description of a medication and how it should be taken



Safety Monitoring

Fall prevention and response

- Fall detectors/ sensors
- Sensor pads
- Personal Emergency Response Systems (PERS)
 - Lifeline, Life Alert, Vital Link, etc.



Motion detectors

- Light turning on when someone enters a room
- Monitor for activity in a particular area or room of the house
 - Notified if there has been no activity for a given period of time

Webcams

- See what someone is doing (sleeping, watching TV, eating)
- Privacy issues may need to be addressed

Social

Telephone/video check-ins

- Volunteers make daily calls to older adults who live alone
- Video chatting

Communication aids

- Phones with large buttons and enhanced audio
- Computers with enlarged type



What do you do when a caller is desperate?

And you wish you had a magic wand to instantly solve the problem?

And you wish you were a wise sage with all the answers?

JUST REMEMBER...





I&R/A Specialists are NOT magicians, therapists, or friends.

We offer:

- Options.
- Resources.
- Guidance to help the client solve his/her problem.

A good tool for a client in need of a starting place and a place to offer resources is by asking a form of the MAGIC QUESTION:

“If the situation and circumstances were perfect, what would you like to happen?”

Answer to the “magic question” is the goal →

Based on the goal, ask follow up questions to find the need(s).





The Importance of Active Listening Skills

- Uncovering deeper concerns
- Getting to the main concern
- Client feels comfortable and heard
- Client feels like you care

Let them know you are listening.

Using Active Listening Skills





Positive reinforcement

“Yes, mmm, I see...”
Be intentional or it seems insincere.

Remembering

Take brief notes so you remember important details. Like...what is the caller's name?

Questioning

“Does your mother feel unsafe when your father drives?”

Reflection

“You feel like your parents need help due to physical ailments and memory issues.”

Clarification

“Is there a reason that your mother refuses to see a doctor?”

Summarization

“You're looking for some solutions to keep your parents healthy and safe in their own home.....”



Summary

- Three types of calls I&R/A professionals receive regarding long-distance caregiving
- Descriptions and statistics about caregivers in general and long-distance caregivers
- Hidden costs of long-distance caregiving
- Physical health, mental health and interpersonal difficulties of long-distance caregivers
- Innovated solutions
- The “magic question” technique
- Active listening skills

Any questions or comments?



Thank you for attending!



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References

- AARP Public Policy Institute. (2015). *Valuing the invaluable: 2015 Update*. Retrieved from <http://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html>
- Abramson, A. & Dunkin, M.A. (2011). *The caregiver's survival handbook (Revised): Caring for your aging parents without losing yourself*. Berkeley Publishing Group: New York, NY
- Angel, J.L. & Settersten Jr., R. A (2015). "What changing American families mean for aging policies." *Public Policy & Aging Report*, 25(3): 78-82.
- Boerner, K., Carr, D., & Moorman, D. (2013). "Family relationships and advanced care planning: Do supportive and critical relations encourage or hinder planning?" *Psychological Sciences & Social Sciences*, 68(2): 246-256.
- Bookman, A. & Kimbrel, D. "Families and elder care in the twenty-first century." (2011): *Future Child*, 21(2): 117-24
- Boss, P. (2000). *Ambiguous loss: Learning to live with unresolved grief*. Harvard University Press: Cambridge, MA.
- Coleman, E.A. (2016). "Family caregivers as partners in care transitions: The caregiver advise record and enable act." *Journal of Hospital Medicine*, 0(00).
- DeJong, P. & Berg, I.K. (2008). *Interviewing for solutions*. Brooks/Cole: Belmont, CA.

Doka, K. (2002). *Disenfranchised grief: New directions, challenges and strategies for practice*. Research Press: Champaign, IL.

Family Caregiver Alliance. (2016). *Caregiver statistics: Demographics*. Retrieved from <https://www.caregiver.org/caregiver-statistics-demographics>

Gilbert, K. (2007). *Grief in a family context*. Retrieved from <http://www.indiana.edu/~familygrf/index.html>

Glekman, Howard. (2009). *Caring for our parents: Inspiring stories of families seeking new solutions to America's most urgent health crises*. St. Martin's Press: New York, NY.


Grohol, J. (2016). "Become a better listener: Active listening." *Psych Central*. Retrieved from: <https://psychcentral.com/lib/become-a-better-listener-active-listening>

Hudson, R. (2015). "Aging families and lagging policies." *Public Policy & Aging Reports*, 25(3): 75-77.

Johnson, B., Abraham, M., Conway, J., Simmons, L., Edgman-Levitan, S., Sodomka, P. ... & Ford, D. "Partnering with patients and families to design a patient- and family-centered health care system: Recommendations and promising practices." *Institute for Family-Centered Care and Institute for Healthcare Improvement*, April 2008.

Miller, W.B. & Rollnick, S. (2013). *Motivational interviewing: Helping people change*. The Guilford Press: New York, NY.

Molyneaux, V., Butchard, S., Simpson, J., and Murray, C. (2011). "Reconsidering the term 'carer': A critique of the universal adoption of the term 'carer'," *Aging and Society* 31: 422-37.



National Alliance for Caregiving and AARP (2015). *Caregiving in the U.S.* Retrieved from <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>

Pillemer, K. & Suitor, J.J. (2013). "Who provides care? A prospective study of caregiving among adult siblings." *The Gerontologist*. 54(4): 589–598.

Rohr, M. & Lang, F. (2016). "The role of anticipated gains and losses on preferences about future caregiving." *Journals of Gerontology: Psychological Sciences*, 71(3): 405-414.

Rosenblatt, B. & Van Steenberg, C. (2014). "Handbook for long-distance caregivers: An essential guide for families and friends caring for ill or elderly loved ones." Family Caregiver Alliance. Retrieved from: https://www.caregiver.org/sites/caregiver.org/files/pdfs/LongDistanceCG_Handbook_2014.pdf

Schumacher, K., Beck, C.A., & Marrien, J.M. (2006). "Family caregivers: Caring for older adults, working with their families." *American Journal of Nursing*, 106(8): 40-49.

Lawrence, B. (2015, Jan 8). How emerging technologies can help with care for ill or frail family members. *PBS Newshour*. Retrieved from: <http://www.pbs.org/newshour/updates/emerging-technologies-can-help-care-ill-frail-family-members/>