

Enhancing Quality Care Relationships through Life Story

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Caregivers are people who provide assistance to someone of any age who is ill or disabled and in need of help. Such assistance often includes help with medicine, eating, hygiene, cooking, cleaning, paying bills, and emotional support. To better serve older adults and provide compassionate care, caregivers require a range of knowledge regarding a person's medical condition, physical needs, psychological status, future medical wishes, social history, and personal identity. Such knowledge can be gained through life stories and health histories and is linked to an enhanced caregiving relationship for both the caregiver and care receiver. Positive relationships, in turn, lead to higher levels of caregiving satisfaction and well-being.

Enhancing the Caregiving Relationship through Life Story

Sharing and documenting life story and health history promotes a quality caregiving relationship. A life story is an account of the series of experiences that make up our lives and define who we are. The story of our life is important because it helps explain where we've been, where we are, how we got here, and even where and what we may be doing in the future. Health history is an important part of life story. It includes information about existing diseases, previous health problems, injuries, medications, surgical procedures, and conditions that run in a family. Health history helps us, our families, and our health care providers better understand our medical concerns, conditions, and choices. The knowledge gained from composing and sharing life story and medical history nourishes the soul, defines identity, creates community, and strengthens care relationships.

Regardless of how life story and health history are captured and preserved—oral, written, in a scrapbook or journal—the sharing of life story allows both a caregiver and care recipient to learn about each other's meaningful life events and valued experiences. A more complete understanding can facilitate trust and add to a greater sense of support and well-being. Such understanding

can also reduce abuse and admissions to long-term care facilities as the sharing of information reduces stress and anxiety for both the caregiver and receiver. With first-hand knowledge of a care receiver's story, a caregiver adds to his/her caregiving abilities and confidence to provide quality care, including healthcare and end-of-life decisions. In turn, a care recipient will feel more secure and comfortable in knowing that the caregiver has accurate knowledge. When the care recipient has an understanding of the caregiver's life story, the recipient may also feel more confident in the caregiver's ability to provide care and carry out decisions.

More often than not life story discussions do not take place because people don't make the time, aren't interested, don't consider it important, or think that they already know everything there is to know about those they care about. Other people might think that they are going to talk about it later. Sometimes it takes a medical scare or crisis for people to find the time and make the effort to share and document life story. But in some situations, such a crisis may contribute to lost opportunities to share life story.

A person's life story can impact quality of care and life.

In order to provide quality care, caregivers need to know a person's medical condition, physical needs, psychological status, future medical wishes, social history, and personal identity. This information can be obtained from life stories and health histories.

A Story with a Lesson

Ted, recently diagnosed with early stage Alzheimer's disease, was a new resident in an assisted living facility. Unable to adjust to his surroundings, he wandered the halls at night grabbing at all the door knobs and windows. To protect him and other residents, Ted was prescribed medications to help him sleep and to prevent him from wandering at night. Despite the medicine, Ted remained unsettled. One day while participating in an activities program, Ted and the other residents were asked to talk about their old routines and habits. Ted shared that he used to be a night watchman—a job in which his charge was to lock all doors and windows. Using this information, the staff asked Ted to join them on their rounds so that he could check the locks and safety of the facility. With knowledge of Ted's story, the staff was able to create an activity that provided Ted with a sense of responsibility and purpose; consequently, his medications changed and he stopped wandering.

As a tool for caregiving, life story:

- Increases caregiver knowledge regarding a care recipient's social and psychological needs
- Helps caregivers better understand and meet specific care needs
- Provides care recipients with a voice and allows for active participation in the caregiving process
- Facilitates conversations and understanding about the future, including end-of-life care and wishes
- Reassures care recipients that caregivers have their best interest in mind
- Allows caregivers to learn about the care receiver's health history, medical conditions, and physical well-being as well as personal likes, dislikes, and other unique personality traits
- Allows caregivers to relate to the care recipient, affirm personal identity, and work toward improving the quality of care
- Provides long-term care staff access to a detailed and personal account of a care recipient's life, allowing staff to improve quality of care by better understanding resident behaviors

How to Enhance Caregiver Communication through Life Story and Health History

Talking about and sharing life story and health history not only enhances communication, but it can be fun to talk about the past, present, and future with someone for whom we care. It is also important to explore feelings and meaning when we talk about life story. When we share the meaning that we have attached to the events in our life, we gain a better understanding of ourselves and allow others to gain a better understanding of us. Some of the many ways to engage and enhance life story communication include:

- Make a list of significant life events and experiences regarding family/friends, places you have lived, education, work/volunteer experiences, hobbies, health, and historical events. Talk about and compare lists.
- Take time to talk about what your significant life experiences and events mean to you and how they influence your behavior, decisions, and future.
- Chose an event or experience that you share (such as a family reunion or holiday tradition). Listen to how your memories of this event are both similar and different.
- Discuss your "bucket list" (the things you want to accomplish while still living) and explore why these dreams and aspirations are on your list.
- Research, download, and/or purchase an online autobiography program that seems right for you. Or join an autobiography/life story group in your community.
- Talk about caregiving and the roles you anticipate people playing or not playing, and talk about finances.

Life stories provide meaning to the human experience and enhance personal understanding.

A person's life story is a key component of personal identity and well-being.

- Talk about medical and end-of-life decisions. While these conversations can be difficult, they are important at any age because it allows your wishes to be known and respected in the event that you can no longer make medical decisions yourself. Advanced care planning has been shown to improve end of life care as well as patient and family satisfaction and reduce levels of stress, anxiety, and depression in both care recipients and their family.
- Talk about death and funeral wishes. It can be helpful to make an appointment with a local funeral director, tour a facility, and talk about end-of-life and funeral decisions.

Documenting and recording life and health history allows others to know what is important to you rather than what others believe to be important.

How to Enhance Caregiver Communication with Someone Who Has Memory Loss

Talking about life story with someone who has memory loss can be difficult. People with Alzheimer's disease or other dementias, for example, have trouble remembering periods or details of their life and may have trouble expressing thoughts and emotions. They may also have difficulty understanding others. Communicating with someone with memory loss often requires patience, understanding, sensitivity, and engaged, empathic listening. The knowledge gained from taking the time to encourage a person with memory loss to share their story and to listen to their story has a direct impact on quality of life and care. Don't be afraid to ask open-ended questions about a person's life. Visual cues, such as a photo or memento, may even help trigger a memory. We may have to listen carefully and put the puzzle pieces together to find meaning in a story. The Alzheimer's Association recommends the following tips to help facilitate communication with people with memory loss:

Tips to Help People with Memory Loss Communicate
Be patient and supportive.
Show your interest.
Offer comfort and reassurance.
Give the person time.
Avoid criticizing or correcting.
Avoid arguing.
Offer a guess if the person uses the wrong word or cannot come up with the right word.
Encourage unspoken communication.
Limit distractions.
Focus on the feelings, not the facts.
Tips to Help Caregivers Communicate with People with Memory Loss
Identify yourself.
Call person by name.
Use short, simple words and sentences.
Talk slowly and clearly.
Give one-step directions.
Ask one question at a time.
Patiently wait for a response.
Turn questions into answers.
Repeat information or questions.
Avoid confusing expressions.
Avoid vague words.
Emphasize key words..
Turn negatives into positives.
Give visual cues (photos, mementos) .
Avoid quizzing and encourage reminiscence.
Give simple explanations.
Write things down for a person to see/understand.
Be aware of your tone of voice—speak slowly, calmly, gently, and distinctly.
Pay attention to your body language—avoid sudden movements, keep good eye contact, approach person from the front, use friendly expressions.

Alzheimer's Association (2010)

Conclusion

Poor communication and inadequate knowledge can cause a caregiver and care receiver to not fully understand each other's needs and wishes. This can lead to a decline in the psychological as well as physical well-being of both the caregiver and care receiver. Documenting and sharing life story can be used as an effective tool to enhance and strengthen communication, relationships, and the overall caregiving process in both formal and informal caregiving settings. It is fairly easy and even fun and meaningful to document life story. Journaling, scrapbooking, voice and video recordings, and formal programs that promote reminiscence and life story are all valid methods to record life story and health history. Documenting our story is important, but sharing our story can lead to enhanced relationships and compassionate care.

Resources

Alzheimer's Association

24/7 Hotline: 1-800-272-3900

www.alz.org

Kentucky Area Agency on Aging

Cabinet for Health and Family Services

Office of the Secretary

275 E. Main St.

Frankfort, KY 40621

1-800-372-2973

<http://chfs.ky.gov/dail/areaagenciesonaging.htm>

Memory Banking. Contact your local Extension Agent for more information about this life story program. Memory Banking is a 4-week program designed to increase participant's knowledge and skills to collect, document, and maintain life stories and health histories. The program is valuable for promoting an active brain, quality relationships, mental healthiness, and legacy building.

National Family Caregivers Association

10400 Connecticut Avenue, Suite 500

Kensington, MD 20895-3944

Toll Free: 1-800-896-3650

Phone: 301-942-6430

http://www.nfcares.org/contact_us/index.cfm

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