

Legacy Storytellers Program

Training Manual



The Legacy Storytellers program is designed by the Alzheimer's Association, Maine Chapter. The program enables those living with Alzheimer's disease or other dementias to have their life stories written and preserved by trained volunteers. In turn, the volunteer scribes gain the valuable experience of hearing these stories and learning from the rich lives of those living with a dementia.

Legacy Storytellers Program Training Manual

This manual was designed to provide organizations interested in conducting a Legacy Storytellers program in their community with the resources, information, and tools to be able to do so.



About the Alzheimer's Association

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research.

Our Vision: A world without Alzheimer's disease®.

Our Mission: To eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our History: The Alzheimer's Association was founded in 1980 by a group of family caregivers and individuals who recognized the need for an organization to support those facing Alzheimer's and advance research into the disease.

Key Facts about Alzheimer's: More than 5 million Americans are living with Alzheimer's disease, the 6th leading cause of death in the U.S. and the only disease among the top 10 causes that cannot be cured, prevented or even slowed. By 2050, this number is expected to reach 14 million. Additionally, more than 16 million Americans provide care to people with Alzheimer's or other dementias in the U.S.

Impact of Alzheimer's in Maine: As the oldest state in the nation, over 28,000 people ages 65+ in Maine are living with Alzheimer's disease and this number will exceed 35,000 by 2025. Maine has nation's 6th highest death rate from Alzheimer's.

What We Do

Our work to end Alzheimer's and help families facing the disease today is shaped by the six key strategic areas of our mission:

 Providing and Enhancing Care and Support	 Accelerating Research	 Advancing Public Policy
We work on a national and local level to provide care and support for all those affected by Alzheimer's and other dementias.	As the largest nonprofit funder of Alzheimer's research in the world, the Association is committed to advancing vital research toward methods of treatment, prevention and, ultimately, a cure.	The Association is the leading voice for Alzheimer's disease advocacy, fighting for critical Alzheimer's research and care initiatives at the state and federal level.
 Increasing Concern and Awareness	 Strengthening Diversity and Inclusion	 Growing Revenue
Increasing concern and awareness of the disease will translate into action, so that more people will seek a diagnosis and the help they need. We share facts and information about the disease to educate the public and combat stigma.	We prioritize outreach to diverse audiences as part of our mission to reach and support all those affected. We offer culturally sensitive programs and information and partner with expert organizations that reach diverse communities.	We rely on donations from constituents, companies and organizations to fuel our mission. Volunteers play a key role in the success of these efforts by extending our reach. To raise critical funds, volunteers lead efforts to mobilize communities in support of fundraising efforts.

We are dedicated to ensuring that all affected families have access to high quality care and support.

- Our free 24/7 Helpline (800.272.3900) is available around the clock, 365 days a year. Callers can receive support and advice from master's level clinicians and get connected to community resources.
- Our website [alz.org](https://www.alz.org) has hundreds of pages of information on the disease, caregiving and current research. For many people, [alz.org](https://www.alz.org) is the first stop for more information, whether they are a professional seeking education, a newly diagnosed individual looking for support or a caregiver in need of resources.
- We offer education programs, both online and in-person, so people can learn about the signs of Alzheimer's, healthy lifestyle habits and the stages of living with and caring for someone with the disease. These in-person programs are conducted by trained volunteers in communities across the country.
- We provide in-person support groups, moderated by volunteers, that encourage communities to share the challenges of living with Alzheimer's and caregiving.
- We encourage access to timely and accurate diagnosis, so those with the disease can learn how to live well.



Welcome to the Legacy Storytellers Program

Program History

In the summer of 2012, the Maine Chapter launched the Early Stage Social Engagement Program with a grant from the Home Office of the Alzheimer's Association. The main objective of this pilot initiative was to develop a robust series of activities for people living with early-stage Alzheimer's. The "Volunteer Scribes" program was created to help capture the memories of those living with Alzheimer's and other dementias. Since then, the Legacy Storytellers program has expanded to include over 7 universities and colleges, connecting students and individuals living with dementia throughout the state of Maine.

What is the Legacy Storytellers Program?

Legacy Storytellers is a program that involves a partnership with a local college/university and a community organization such as a day program, residential care center, or another community agency supporting those living with dementia. The program encourages those living with Alzheimer's disease or other dementias to participate, share, and have their life stories listened to, written and preserved. In turn, college/university students are trained in Alzheimer's disease and communication strategies to interview and assist in writing participants' life stories. The participation is private and confidential and care partners are welcome to be involved as well. Though tested with colleges and universities, the program is designed with the ability to be utilized by high school volunteer programs, family, friends or activities staff.

Who Benefits from the Legacy Storytellers Program?

There are many benefits from participating in this program. Volunteer scribes gain valuable experience listening to and writing about individuals living with dementia. The experience obtained by scribes positively impacts their future thoughts and beliefs about dementia when encountering it professionally. In addition to experiencing the healing that comes from being truly listened to by volunteers asking them to share their memories, participants act as teachers helping scribes to better understand the challenges of living with Alzheimer's or other dementias. Participants receive a written legacy which they can share with family, friends and loved ones which can be cherished and passed on to successive generations. Lastly, society recognizes and appreciates the strengths and abilities of those living with dementia.

"It was very interesting about [my scribe]. She let me learn a little bit about her life, too. She was just so sweet. I remember that first day, she was so comfortable, I thought, with herself, which makes the difference....**she was able to be the perfect scribe for me.** I think at times her questioning was to slow me down a bit, but **I don't know how she was able to just get even the flavor, my flavor of telling a story.** [My scribe] was able to keep an ear on me and ask me questions. **She got every joke, she got every sad feeling that I had, she knew what motivated me to go on. She was just perfect.**" – Program Participant¹

¹ Dimond, J. E. (2016). *Writing life stories: A phenomenological study of memory and meaning for people with early stage Alzheimer's disease* (Unpublished master's thesis). School of Social Work at University of Southern Maine.

Legacy Storytellers Program Guide

What the Sessions Look Like

Each session focuses on a specific period of participants' lives such as childhood, adolescence, and young adulthood. Volunteers interview and ask questions relating to the session theme; with childhood, for example, participants may be asked about their first pet. They then take notes on the interview and write a short story based on the session theme. Stories are reviewed by the scribe and participant at the next session for accuracy. Interview questions are a "launching point" – volunteers can elaborate, interject their own questions or skip questions – e.g. if they talk about a pet they lost in a severe storm, ask them to talk more about the storm! Participants may also have stories or topics that they would like to share during sessions and we encourage scribes to take the participant's lead. During the interview and writing session (45 – 60 min.) scribes will work in partnership with participants and take notes that will allow them to write the stories in between sessions. It is important to emphasize that scribes are not transcribing. Active listening during sessions is far more important. Scribes may choose to bring a laptop, handwrite notes or even bring a recording device. Whichever method works best for the pair and allows scribes to maintain good eye contact with participant and focus on listening well while capturing a few notes or details needed to write the story after the session. If time allows, the pair may outline together the next session and the scribe can encourage the participant to bring a photo or memento, etc. *Reminder: Participants should never feel forced or required to discuss any aspect of their life they do not want to discuss.*

Editing and Review

Following the first session, volunteer scribes will review the story they have written based on the previous session's interview with their participant to ensure accuracy, determine if it meets their expectations, etc. This review should take place before the session interview. The total time for each session is about 1-1.5 hours.

Recruitment

Universities wanting to reach out to a long-term care (LTC) facility or adult day center (ADC)

Universities/colleges are encouraged to research the local area for long term care facilities, particularly those with memory care units. The Alzheimer's Association's Community Resource Finder (alz.org/crf) can be utilized to find an organization in your community. After finding an organization of interest, reach out to them to see who is the appropriate contact. The executive director or activity director are likely key contacts within facilities, or can direct you to the appropriate contact. This guide can be shared with any interested parties to help illustrate the program. After determining interest in the program, coordinate a schedule that works best with the volunteers and the organization.

Organizations looking to start a program with a local college/university

Research local universities/colleges to determine appropriate contact. This might be a club on campus or key staff in areas such as psychology, nursing, social work, communications, occupation therapy, etc. that may have students interested in the program. Ask the university to assemble a team of volunteers, explain what the program is via the manual and coordinate a time that works best for volunteer students and your residents. Encourage volunteers to utilize online training to build their confidence and competence in working with people living with dementia and let them know about how rewarding and appreciated a program like this is.

“Working with the Legacy Storytellers Program was an awesome experience. There are no words that can match the feeling of knowing you are helping someone capture their life story before it is gone and knowing that **their legacy will live on with their family and friends who receive the story**. Creating this story allowed me to work with my participant to reach a greater understanding of their life, but also of what it is like to work with someone who lives with Alzheimer's. Going into a medical profession, this experience is surely helpful in promoting a humanizing approach to any task we undertake when working with someone who has a chronic disease: **everyone has a story, and it is greater than their diagnosis.**” – Volunteer Scribe

Setting Up Your Group

Facilitators

The best practice is to select a facilitator for both partner sites who will take point on organization of the program. The facilitators' roles are to coordinate dates, timing, and communication with scribes.

Identifying Legacy Storytellers Participants

Identifying Legacy Storytellers Participants is one of the most important factors in implementing a successful program. Some key early-stage characteristics that you should consider when looking at participants include:

- Ability to express his or her needs, wants and feelings.
- A clear understanding of the questions being asked of him or her.
- Ability to articulate their past experiences verbally and share stories utilize long-term memory.

Materials needed

Name tags, something to write with (pen, paper, or laptop), and a comfortable environment.

Scheduling

If possible, this program should run on a weekly basis. The schedule is typically coordinated between a LTC facilitator and a volunteer facilitator. The facilitators should determine if it works best for participant and volunteers' schedules to visit as a group or establish case-by-case schedules. For some groups, volunteering in dyads may be best practice to ensure consistency in participation. It is important to get email addresses for all the participants and/or organizations' facilitator and send a reminder email a few days ahead of each upcoming session.

Training for Potential Scribes

We understand potential scribes are interested in volunteering for a variety of reasons: some have personal experiences with this disease while others want to learn or provide community service. Whatever the reason, we strongly encourage volunteers to participate in trainings to learn more about dementia. While all training courses are offered online, and this is likely the most convenient option, we do periodically offer classes in person. You can find more on [alz.org/crf](https://www.alz.org/crf) and searching your local community. By participating in these trainings, volunteers are able to learn more about dementia, dispel possible misconceptions and learn techniques to enhance their interaction with Legacy Storytellers' participants.

Confidence to Connect: [alz.org/confidence](https://www.alz.org/confidence)

Basic training is quick and easy and is recommended for all volunteers. Confidence to Connect is a training designed to help people learn methods to interact comfortably with people living with Alzheimer's or other dementias. This training has three main objectives:

- Offer firsthand insight from people living with Alzheimer's or other dementias on social and communication challenges they often face.
- Provide basic information about the early-stage experience and core concerns.
- Teach new strategies to build scribes' confidence to work with people with early-stage Alzheimer's or other dementias.

In addition to the Confidence to Connect program, the Alzheimer's Association has many other educational opportunities. Through the association's e-learning programs we offer a variety of additional education programs. We encourage volunteers to also attend our *Understanding Alzheimer's and Dementia* and *Effective Communication Strategies* to build additional skills to help facilitate dialogue during the Legacy Storytellers program.

These Additional Free Online Trainings are available at: [training.alz.org](https://www.training.alz.org)

Communication Tips

When communicating with an individual living with the disease it is important to remember they may not immediately understand what you are saying. Some tips on how to communicate are to begin by identifying yourself and address him/her by name. It is important to show that you are listening and trying to understand what is being said. Encourage the participant to continue to express thoughts even if he/she is having difficulty or you don't understand. It is best to avoid criticizing, correcting, and arguing and approach conversations by being calm and supportive. You may want to ask your participant if they'd like you to help them find the right word or if they prefer to work it out on their own.

Confidentiality

All information shared during Legacy Storytellers is confidential. It is important to respect participants' privacy and not share their personal information and stories.

The types of information that is considered confidential can include:

- name, date of birth, age, sex and address
- current contact details of family, guardian, etc.
- personal care issues
- individual personal plans

Participants do not have to share information if they do not want to. It is important to respect if they want certain information taken out of their stories, such as locations or names.

Please note for stories and/or pictures of participants to be shared, the Alzheimer's Association strongly recommends that written releases be completed by all involved and/or by the person's legal representative. Please coordinate between the university/college and the LTC facility to discuss the proper documents for this.

Legacy Storytellers Session Process

- Each session focuses on a specific period in the participant's life. Session agendas found later in the guide include ideas of what participant/volunteer teams can review for the session.
- It is not mandatory that volunteers address each session agenda question. If the participant wishes to discuss aspects of their life that are not part of the session agenda, they are welcome and encouraged to do so.
- Following each session, the volunteers review their story from the prior session with their participant.
- Writing prompts are used to reinforce the partnership between participants and volunteers. Prompts are introduced after the facilitators welcome participants and volunteers to the session. Participant/volunteer teams review the prompt and the participants provide responses (if participants feel comfortable).
- At the start and conclusion of each session, facilitators should thank the participants and volunteers for being involved in the Legacy Storytellers Program.
- In some instances, it is only possible to do 4 working sessions, instead of 5. Under such circumstances, the childhood session is combined with the teen session.
- It is strongly recommended that participants and volunteers be supplied with name tags, already written out at the start of each session. It is also suggested that participants and volunteers be seated at the same tables for each session. Both of these recommendations are for the convenience of participants.
- Often sites have a sixth session where finished products of printed and provided to the participants. This sixth session is a great time for celebration and appreciation and may include family, food, music, etc.

Legacy Storytellers Program Session Prompts

Often, we find that our storytellers already have ideas on things that they might wish to talk about. However, below are some ideas/suggestions that might be helpful to get you started in the event that people do not.

First Session:

Today's topic: childhood, ages 3-12

- Early family memories
- Your views of the world as a child
- Games you used to play as a child
- Your first home
- Your first school
- Your first pet
- Childhood friends
- Your first “crush”
- How has the world changed since you were a child?

Second Session:

Today's topic: adolescence, ages 13-18

- Describe your high school
- Describe your family life
- How did you interact with your mom, dad, or guardian as a teen?
- How did you make money as a teenager?
- Your first driver's license
- Your first car
- Your best friends in high school
- A typical Friday or Saturday night in junior high, high school
- Your hobbies, interests as a teen
- Important moments, events as a teen
- Girlfriends or boyfriends?
- If there are one or two things you could change about yourself as a teen, what would it be?
- If you could go back in time and talk to your teen self what would you tell yourself?

Third Session:

Today's topic: young adulthood, ages 18-25

- What did you do after high school (for example, did you go to college, enlist in the military or go to work)?
- What did you like best about your life in the first years after high school?
- Did you move around or relocate to another state, city, etc. during this time? If so, tell me about your moves--what were they like for you?
- As children, we have this idea of what life would be like when we “grow up”. Did your early adulthood live up to these expectations? Were there any surprises?
- As you became an adult, did your relationships with your parents or the rest of your family change? How so?
- Did you get married during this time? How did you meet your spouse? Tell me about your courtship and wedding?
- What were your first professional jobs like during this time? What steps did you take to become better at your job?
- Did you have children during this time? What was first-time parenthood like for you? How did parenthood change you as a person?
- How did you save for your first home? What was it like searching for the home? What challenges did you face as a first-time homeowner?

Fourth Session:

Today's topic: adulthood/parenthood, ages 25-55

- Were you in the same profession your entire working life? If not, what other types of jobs have you had?
- What do you regard as your best career/professional successes? Why were these important to you?
- Are or were you married or in a long-term relationship? If so, what was your courtship with your life partner like?

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- What have you learned in this long-term relationship? What are some of the best moments you have shared?
 - Do you have children? If so, what have you liked best about being a parent? What are some of your best memories that you have shared?
 - What kind of challenges have you faced as a parent? How did you deal with these challenges?
 - What new hobbies or interests have you developed as an adult?
 - How have you changed personally from when you were younger?

Fifth Session:

Today's topic: life wisdom, what have you learned

- What are some lessons you have learned from successes in your life?
- What are some lessons you have learned from challenges or failures in your life?
- Is there anything that your parents taught you that has proven true throughout your life?
- What have you learned from other family members or friends that has proven valuable to you?
- What about your children, have they taught you any lessons?
- If you could offer any pieces of wisdom in your life to a younger person, what would they be?

The Finished Product:

At the end of the program, participants receive a written compilation of the stories recorded by the volunteer scribe. Volunteers create this tangible object to preserve memories for the individual, family members and other loved ones. Some volunteers have provided a printed word document, while other volunteers have created final “books” that include pictures or other memorabilia that the participant has shared. Volunteer scribes may want to make copies of pictures, awards, etc. that can be integrated into the final story. Scribes may also want to add a picture of themselves with the participant. Book

creation is a creative process, unique to each pair. After the final session, the volunteers and long-term care facility should organize a final party to celebrate the time spent together. In the past, these parties have been open to family members and friends and included light refreshments. This final party allows for the stories to be shared with family and friends and reflect on the time that the volunteers and individual spent together.

Continue to Make a Difference

Everyone can help in the fight to end Alzheimer's. Join the cause by staying informed, volunteering with your local chapter, making a donation, or becoming an advocate for those with Alzheimer's disease and their families.

Volunteer with the Association

Given your experience participating in the Legacy Storytellers program we would love for you to consider joining the Alzheimer's Association as a Volunteer. Our ability to reach and support those affected depends on people like you who are dedicated to the fight against this disease. As an Association volunteer, you can use your unique talents to make a meaningful impact in your community while connecting with others who share your passion. To learn about the wide variety of ways you can get involved and find the role that's the best fit for you, visit [alz.org/volunteer](https://www.alz.org/volunteer). Opportunities include:

- Community Educators
- Support Group Facilitators
- Community Representatives
- Community Volunteer Leaders
- Early Stage Social Engagement Leaders
- Faith Outreach Representatives
- Promotores

Participate in an Event

The Alzheimer's Association *Walk to End Alzheimer's*® is the world's largest event to raise awareness and funds for Alzheimer's care, support and research. This inspiring event calls on participants of all ages and abilities to join the fight against the disease. Make a team, walk with a team, or donate to a team! Or join us for *The Longest Day* in June when thousands of participants from across the world come together to fight the darkness of Alzheimer's through an activity of their choice. Together, they use their creativity and passion to raise funds and awareness for the care, support and research efforts of the Alzheimer's Association.

Donate

From face-to-face support to online education programs and promising worldwide research initiatives, your donations make a difference in the lives of those impacted by Alzheimer's disease. You can donate online, via phone, or mail.

Advocate

Support the fight against Alzheimer's. Alzheimer's disease is one of the most critical public health issues in America. This is why we are unrelentingly advocating for public policies that increase critical research funding and support all those affected. Now is the time to join us. Help persuade policymakers to make Alzheimer's a national priority.