

Maine Chapter

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Legacy Storytellers Program

Welcome

Thank you for your interest in the Legacy Storytellers Program Volunteer Scribes Training. This initiative was developed in response to a strong interest among those with early-stage Alzheimer's disease to tell their life stories.

This training is to prepare you, as a Volunteer Scribe, for this exciting opportunity as you play a key role in safeguarding the life legacies of those living with Alzheimer's disease or related dementias.

Other Legacy Book Resources:

- <https://legacybooks.com>
- <https://www.legaciesofalifetime.com/legacy-books>
- <https://www.storyworth.com>
- <https://www.there remembering site.org>
- <https://yourstoryherehome.com>

Guidelines for Legacy Books:

- Photobook size: 8.5x11
- Hardcover
- Have a table of contents in the front of the book so that they can easily locate a specific memory
- The last page should be a gratitude page: Thank your legacy partners, include zoom photo or pic of you and the legacy partner, and possibly a quote that represents gratitude for legacy partner
- Ensure high contrast between background and text: Black text on white background is best. Avoid light text on dark background. Avoid decorative texts or artwork behind your writing Use matte, non-glossy paper. The glare can make it difficult for partners to read
- Make sure pages are not too busy- provide space for the eyes to rest and limit pictures to 1-3 large pictures per page
- Font type: Verdana or Arial (no feet on your letters)
- Font size: 14 points
- Avoid ALL CAPS, *italicized*, or *ornamental* font
- Present information in a logical order. Follow a lifeline progression as much as possible
- Book length 20-25 pages

Photobook Websites:

- Shutterfly.com
- Mixbook.com
- Snapfish.com
- Walgreens.com
- Blurb.com
- Videos: Just use your laptop or a phone with a camera!

What is early stage dementia?

For most of us, early-stage dementia dramatically defies all of the stereotypes associated with Alzheimer's disease and related dementias.

Typically, society has viewed those with dementia as individuals unable to care for themselves, struggling with loss of memory and identity, helpless and vulnerable.

Now, completely disregard this view. Those with early-stage Alzheimer's disease are generally independent, productive and, for the most part, able to communicate and interact just like those without an Alzheimer's diagnosis.

Many of them are still active, engaging in sports and activities such as cycling, kayaking, hiking and even ballroom dancing. It is not unusual for them to be still driving or holding down a job.

If you saw two individuals on the street, you would be hard pressed to tell the difference between the person with an Alzheimer's diagnosis and the one without a diagnosis.

And yet, there are key differences ...

Signs of early to moderate stage dementia

- Mild changes in the ability to think and remember
- Vocabulary strength decreases
- Difficulty finding the right word
- Taking longer to process information
- Challenges in maintaining a train of thought
- Struggle to remember some names, dates and new information

- Writing: For many, there is difficulty getting started, following through on the writing process

Social challenges for those with early to moderate stage Alzheimer's disease

- Rejection by peers, family
- Fear of saying the wrong word or thought
- Ashamed that they are now “stupid” in the eyes of friends, family
- Urge to withdraw, shut themselves off from the world
- Fear and misunderstanding from friends and the general public
- Subject to ridicule – sensitivity to Alzheimer's “jokes”
- Disbelief from friends and family – “you don't look like you have Alzheimer's”
- Frustration, embarrassment that things which once came easily to them are now more challenging
- Depression, fear, anxiety about a world full of loss and what lies ahead

Early Stage Dementia: Practical Observations

- There is little talk or discussion about diagnosis among program participants. This is even true in the Legacy Writers Groups where discussion focuses on long-term memories. Instead, there is joking, laughing, smiling during activities.
- For many group participants – both those living with Alzheimer's disease and their care partners – Early stage social engagement activities offer a welcome respite from diagnosis-related issues such as physician appointments, medications, safety issues and concerns.
- Group participants sincerely appreciate the ability to participate. For many, it is an opportunity to remain independent, active, and engaged for as long as possible.

- Participants welcome the opportunity to experience something new, even in the midst of loss.
- Some participants talk of “recalling” memories that had been lost to them due to their diagnosis. When this happens, it a deeply moving and meaningful experience for them. If this occurs with your talking participant, by all means, join with them in cherishing such special moments.

Program Description and Need

As a Volunteer Scribe, you will play a key role in a vital expansion of the Legacy Storytellers Program.

Your efforts will make it possible for individuals living with early to moderate stage Alzheimer’s disease or related dementias to tell their life stories and have them written and preserved by Volunteer Scribes, like you.

Throughout Volunteer Scribes sessions, a participant (an individual diagnosed with Alzheimer’s disease or related dementias) is matched with the same one to two Volunteer Scribes. The participant tells their stories to the Volunteer Scribes who take notes during their interview sessions (this can be done through writing, laptop computer, or use of an audio recording device).

Later, the Volunteer Scribe transforms their notes into stories depicting the life of the participant.

In some instances, two Volunteer Scribes are matched with one participant. In such cases, one Scribe does the interviewing while the other takes notes. Then, both Scribes collaborate on writing their stories.

Getting Started

For Volunteer Scribes, it is important to keep two primary considerations in mind:

You don’t have to be a “writer” to effectively document a participant’s life story....

- Telling your life story is challenging for most people and especially so for those living with Alzheimer’s disease or related dementias.
- When we refer to Volunteer Scribes and what they do, we are referring to writing in the broadest, most general sense possible.

- In short, Volunteer Scribes should not feel pressured to compose the “Great American Novel.” On the contrary, your goal should be to record and write the participant’s life story as accurately and efficiently as possible.
- Time is of the essence when it comes to dementia. Consequently, it is more important to write as much as you can about your participant’s life as quickly as possible rather than developing a stylish memoir.
- However, it is also helpful to keep in mind that others may read what you write (even if the audience is restricted to family members and friends).
- So you may want to give some attention to interesting episodes or experiences in your participant’s life that may be of special interest to your readers. For instance, a wedding ceremony or military service – milestones that may be especially compelling to family members.

Telling a life story can be challenging ...

- Many of us don’t like to talk about ourselves. For members of the “Greatest Generation,” this is especially true. They may view the detailing their exploits during World War II, the Korean War, or the Vietnam War, for example, as “boasting.”
- And, of course, dementia adds another factor to this process. Embarrassed by his or her struggle to recall life experiences, your participant may be hesitant to speak with you, at first.
- However, with sincere caring and respect, it will be possible for you to make progress in writing your participant’s story.
- Under no circumstances, though, should you force your participant to work with you. Even if they have agreed to tell their story to you, there will be days when it is especially difficult for them to remember.
- At these times, step back and allow them to continue the interview process with you at their leisure. If necessary, thank them for working with you and indicate that you look forward to working with him or her at the next session.
- Motivation for both Volunteer Scribe and participant can be found in working toward a common goal: the telling and preserving of life stories.

- For this reason, Volunteer Scribes should emphasize they are working in partnership with their participant. This helps establish a “level playing field of respect” between Volunteer Scribe and participant and, just as importantly, works to enhance the participant’s sense of self-worth.

Communication challenges for your participant

More than likely, your participant will experience one or more of the following communication challenges:

- Challenges in participating in group discussions
- Repeating themselves and unaware they are doing so
- Needing a little longer to formulate thoughts and responses
- Difficulty with trains of thought
- Struggle with abstract concepts
- Attempting to compensate or “cover” for things they don’t understand

Communicating with your participant

- *Be patient* – allow your participant to have the necessary time to talk and respond in conversation
- *Be concise* – avoid long or extended explanations or discussions. This will allow your participant to engage more effectively with you during conversations
- *Be as specific as possible – avoid generalities.* If discussing a participant’s childhood, address a specific life experience such as their first pet, the first place he or she lived, etc.
- *Be positive* – as much as possible, emphasize any progress being made in your efforts and congratulate your participant on their work.

- *Emphasize that you are glad to see and work with them* – smile, make eye contact, provide your full attention
- *Be normal* – don't treat the talking participant as someone who is "less than" – don't infantilize them. They are more than familiar with people treating them differently, so strive to be different – treat them as if you are talking to, and working with, a friend.
- *Be relaxed* – don't be nervous, focus on putting yourself and your participant at ease. You will make greater progress in this way.
- *Empower whenever possible* – allow your participant to be an equal partner in this process. Give them time to talk, respond, convey their thoughts and opinions. Furthermore, allow them to dictate the course of your interview. If your participant is speaking about her grade school experiences and then decides to dwell upon summer camp episodes, go with the flow.
- *Offer help only when requested to do so* – If your participant is having difficulty finishing a sentence, do not finish it for them. Doing so may needlessly interrupt their train of thought. However, if your participant asks you to finish the sentence, do so to the best of your ability. Such understanding promotes independence and empowerment.
- *Always be sincere* – By displaying honest intentions, you will build a positive, productive and meaningful bond with your participant that will make this experience even more meaningful for both of you.

Considerations for Interviews completed via zoom....

- Avoid background noise during interview
- Speak clearly during the interview
- Place computer at height to provide direct eye contact to the storyteller

- Use good lighting to enable them to see you clearly
- Have a neutral background to avoid distraction.
- Do not have any movement in the background.
- Smile!

Legacy Storytellers – Session Structure

Session Structure: Sessions will feature a specific agenda to promote productivity among talking and writing participants. Sessions will feature the following highlights:

Ice Breaker Activity: This can involve a simple “get to now you” game or the sharing of valued items or pictures.

Introduction: The group moderator will spend 5 minutes introducing the suggested story theme for the session. The goal of this introduction is to give participants direction and guidance in developing their stories. It should be emphasized, however, that such themes are strictly suggestions. If participants wish to address another segment (or episode) of their lives for their next story, they are more than welcome to do so.

- Session themes feature the following chronological life order: Childhood, Adolescence, Young Adulthood, Adulthood/Parenthood and, finally, “Life Lessons Learned” for a total of five sessions.
- Each scribe will receive a list of interview questions he will ask his or her participant. The questions center around the session theme as indicated in the example below:

Example: Childhood – ages 4 to 12

- Where was your first home – what do you remember about it?
- What was your favorite toy as a child?
- Tell me about your first pet?

It should be noted that these questions are meant to be a “launching point” for discussion. Scribes should feel free to elaborate on questions, interject their own questions, or not ask certain questions.

Such decisions will depend a great deal on the course of the interview. So, for instance, you ask about your participant's first pet. Your participant tells you they lost their pet in a severe snowstorm. You may want to ask about the storm, how he or she felt when they couldn't find their pet, etc.

Interview and Writing Session: This is the heart of the program. Volunteer Scribes will interview participants, taking notes as the participant speaks.

- These interviews will serve as the basis for the participants' completed story to be written by the Volunteer Scribe and read at the next session.
- If time allows, teams can actually begin outlining or writing their stories (for the following session) during these interview segments.
- Depending upon their abilities, participants can simply be interviewed or they can actually work more actively in partnership with Volunteer Scribes to develop their stories.
- Please note: Under no circumstances should a participant be forced or required to discuss an aspect of their life they do not want to discuss.

Story editing and review. Following the first session, participant and scribe should allow a few minutes (10 to 15 minutes) to review the story written by the scribe. This is to ensure the accuracy of the story and to make sure it meets with the participant's expectations.

Time: 45 minutes to 1 hour. Total time allowed for each session will be 1 to 1.5 hours.

Legacy Writers Group: Volunteer Scribes Project First Session Agenda and Questions

- **Introductions & Welcome**
- **Today's Assignment: Childhood (Ages 3 to 12)**
 - **Early family memories**

- **Your view 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 Agenda and Questions

- **Introductions & Welcome**
- **Childhood Assignment Review between Scribes and Participants**
- **Today’s Assignment: Adolescence (Ages 13 to 18)**
 - **Describe your junior high and high school**
 - **Describe your family life**
 - **How did you interact with your mom, dad, guardian as a teen?**
 - **How did you make money as a teen-ager?**
 - **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 is 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?

Legacy Writers Group: Volunteer Scribes Project Session Three

- **Introductions & Welcome**
- **Adolescence Assignment Review between Scribes and Participants**
- **Young Adulthood (Ages 18 to 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 7 years after high school?
 - Did you move around – 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 – what were they?
 - As you became an adult, did your relationship 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 and what was it like searching for the home? What challenges did you face as a first-time homeowner?

Session Four Agenda and Questions

- **Introductions & Welcome**
- **Young Adulthood Assignment Review between Scribes and Participants**
- **Today's Assignment: Adulthood/Parenthood (Ages 25 to 55)**
 - Have you or 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 successes important to you?
 - Are you married or in a long-term relationship? If so, what was your courtship like with your spouse (or life partner)?
 - What have you learned in your marriage, long-term relationship? What are some of the best moments that 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 about your children?
 - What kind of challenges have you faced as a parent? How did you deal with these challenges?

- How did your relationship with your own parents change when you became a parent?
- What new hobbies, interests have you developed as an adult?
- How have you changed personally from when you were younger (as an adolescent or as a child)?

Legacy Writers Group: Volunteer Scribes Project Session Five Agenda and Questions

- **Introductions & Welcome**
- **Adulthood/Parenthood Assignment Review between Scribes and Participants**
- **Today's Assignment: Life Wisdom: What You Have 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, friends, that has proven valuable to you in your life?
 - What about your children, have they taught you anything about how to live your life?
 - If you could offer 5 pieces of wisdom in your life to a younger person (for instance, your own Volunteer Scribe), what would they be?
- **Next session: Life Story Celebration!**

Week One:

- Where were you born?
- Were you named after someone?
- How many brothers and sisters did you have?
- What was your relationship like with your brothers and sisters?
- Describe your relationship with your parents.
- What are some of your early family memories?
- What is your earliest family memory?
- What were your views of the world as a child?
- What are some of the major historical events that happened when you were a child?
- Describe any major life events in your childhood that shaped your life?
- As a child, what did you want to be when you grew up?
- What are some of the games you used to play as a child?
- Describe your first home.
- Describe your first school.
- What was your favorite subject in school?
- Tell me about your first pet.
- Describe your childhood friends?
- Tell me about your first “crush”.
- How has the world changed since you were a child?
- Describe a favorite birthday memory.
- What were family traditions you had as a child growing up?

Week Two: Adolescence

Questions from the Legacy Storytellers packet:

- Describe your junior high and high school
- Describe your family life
- How did you interact with your mom, dad, 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
- Girlfriends or boyfriends?
- If there is one (or two) things you could change about yourself as a teenager, what would it be?
- If you could go back in time and talk to yourself as a teen, what would you tell yourself?

Other questions we want to ask:

- Were there any strict rules in your household about curfews, etc? If so, did you listen to them or were you rebellious?
- Did you and your siblings get along well or did you argue?
- How many years of education have you completed?

Reworded to be open ended:

Week Two: Adolescence

- Explain your hobbies and interests as a teenager?
- How would you explain your family life?
- What was your relationship like with your mom as a teenager?
- What was your relationship like with your dad as a teenager?
- Describe your relationship with your siblings as a teenager?
- What was your relationship like with your guardian as a teenage?
- Explain the rules you were expected to follow as a teenager?
- What were the different ways you made money as a teenager?
- Describe what it was like getting your license?
- What was your first car? Is there a story behind how you got your first car?
- Explain your personality as a teenager?
- Tell me about your junior high experience?
- Describe your typical weekends during junior high?
- Tell me about your high school experience?
- How would you describe your relationship with your best friends in high school?
- Tell me about your high school sweetheart?
- Describe your typical weekends during high school?
- How many years of education did you complete? And why?
- Tell me one or two things that you wish you could have change about yourself as a teenager, and explain what they would be and why?
- If you could go back in time and talk to yourself as a teenager, what would you tell yourself?

Legacy Story Questions

Week Three: Young Adulthood

Other questions we want to ask:

- Did you attend college? If so, where did you go and what did you study?
- What are some jobs that you had during your teen and young adult years? Were they jobs you enjoyed or jobs you had just to make money?
- ^adding on to the above question, how long did you have to work each day at your job?
- What do you think of the challenges that young adults face now versus what you faced as a young adult? (Such as: finishing college, possibly going to graduate school for a Masters or a Doctorate, getting a job quickly, making enough money to afford basic essentials, etc.)
- Have you traveled? Where? When?

Week Four: Adulthood/Parenthood

Questions from the Legacy Storytellers packet:

- Have you or 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 successes important to you?
- Are you married or in a long-term relationship? If so, what was your courtship like with your spouse or life partner?
- What have you learned in your marriage or long-term relationship? What are some of the best moments that 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 about your children?
- What kind of challenges have you faced as a parent? How did you deal with these challenges?
- How did your relationship with your own parents change when you became a parent?
- What new hobbies or interests have developed as an adult?
- How have you changed personally from when you were younger (as an adolescent or as a child)?

Other questions we want to ask:

- What were the favorite years of your adulthood? Why?
- When looking back on your adulthood, was your life what you expected it to be? Why or why not?
- How did you know that your spouse was “the one”?
- What is the most difficult thing about raising children?
- Describe your wedding ceremony.
- Did you have a honeymoon?
- What is the most amazing thing that has ever happened to you?
- Did you continue any traditions from your childhood with your children? Did you create any traditions with your own family?

Reworded Questions Week 3 & 4:

- What was your highest level of education?
- What was your favorite subject to study?
- Describe the jobs you had as a young adult?
- Describe if you had the same job your whole life or changed jobs and why?
- Describe your favorite job and why?
- Describe what your typical work week would look like? (how many hours, type of job, physical demands etc.)
- What was the best thing about your job (could be considered a stay at home mom)?
- How would you describe your best professional success and why?
- How would you describe your best personal success as an adult and why?

- Describe when you knew your spouse was the one for you?
- Describe the best moment of your wedding ceremony?
- Describe the honeymoon and what you loved most about it?
- How would you describe your relationship with your spouse/life partner?
- What are some of the best life lessons you learned throughout your marriage?
- Describe some of the best moments you shared together?
- Describe the best lesson you learned about raising children and how?
- Explain what you feel was the best thing about being a parent?
- Describe how becoming a parent influenced your relationship with your parents?
- Explain your favorite family tradition that you had with your children?
- How did that family tradition begins?
- Explain the hobbies or interests you developed as an adult, and why you think they changed as you got older?
- Explain if you traveled at this time, and why or why not?
- Describe your favorite trip/vacation and why?
- How do you feel you have changed personally as you enter adulthood, and why?
- Describe what your favorite time in your adult life was and why?
- When looking back on your adulthood, do you feel your life went as you imagined it? Why?
- Describe the most amazing thing that has ever happened to you?
- How would you compare the experiences that a young adult faces now versus what you faced as a young adult? (finishing college, raising a family, supporting a family, etc.)

Week Five: Life Lessons Learned

Questions from the Legacy Storytellers packet:

- 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 in your life?
- What about your children - have they taught you anything about how to live your life?
- If you could offer 5 pieces of wisdom in your life to a younger person, what would they be?

Other questions we want to ask:

- What is your best advice when it comes to relationships, dating, and marriage?
- From experience, what is your best advice for someone to do when they are worrying about something, such as applying for a new job or studying for a big exam?

- If you could choose one word to describe your life, what would it be?
- What is the best advice you have ever received? Why? From who?

Reworded:

Explain something your parents taught you, that has proven true throughout your life?

Describe what you have learned from other family members or friends throughout your life? How has that proven valuable to you?

Explain what your children have taught you about life?

Describe the life lessons you have learned from successes in your life?

Describe lessons you have learned from challenges in your life?

Describe the best piece of advice you have ever received? Why do you believe this is the best piece of advice and who was it from?

Describe pieces of wisdom from your life that you would like to offer to younger people?

Describe your best advice when it comes to relationships? Marriage? Etc.

From experience, tell me about the best advice you have for someone when they are worrying about something, such as applying for a new job or studying for a big exam?

If you could choose one word to describe your life, what would it be?

Other Ideas to use as prompts...

**You have discovered an amazing time portal
inside the linen closet of your bathroom.**

But this time portal only takes you to one destination: you, as a student, at your middle or junior high school.

What advice do you offer your younger self – what do you hope to teach your younger self about life as you know it?





HINT: It can't be a family member – living or deceased

Why did you choose this person to talk to?

What would you talk about?

Good Luck!



It was so good that, to this day, I can almost taste it!

Increasing research points to a direct connection between memory and taste. Often, a favorite food, meal, or sensation (bitter, sweet, salty) can help evoke remembrances.

In this writing prompt, we ask you to recall a favorite (or not so favorite) food, meal, or taste that evokes a specific memory or memories. Recount this memory (or memories) in as much detail as possible, as well as the taste sensation itself. Also, try to determine why this particular food brings up this specific memory. Enjoy!