

Thirteen Lessons – the Gathering Place group lessons for others



A Springboard for Further Discussion

The men and women of the Gathering Place with John Zeisel

“What would you like to tell others about yourself and what you need that you think will help you?” This question started vibrant conversation among Gathering Place participants. The I’m Still Here Foundation’s John Zeisel employed the Tuesday Group Process to facilitate the conversation. The discussion resulted in the group’s insightful, honest, and meaningful lessons below.

These Thirteen Lessons are offered at the express wish of participants, who would like them to be used as a ‘springboard’ for more conversation. To use these Lessons to talk with and learn from your loved one, we recommend reading it all to yourself first. Then, pick one lesson from the list – not necessarily the first one – and read it aloud with them. Ask them to tell you a little bit about what it means to them, then listen patiently.

The Lessons

When you ‘break the news’ to others about your memory issues use a script:

- A “script” – a planned short statement you use each time the same way.
- Make sure you personally feel comfortable with the particular script you use.
- It has to fit your personality:
 - One person’s script might be general: *“I’m 78 years old and I don’t recall as much as I used to ...”*
 - Another person might be more comfortable being specific: *“A doctor diagnosed me with a medical condition ...”*
- If possible, have two scripts in your toolbox for different situations.

If you are anxious that you may be repeating yourself and that your memory lapses might be evident to another you are with, raise the issue first:

- Pre-empt the ill-at-ease situation by raising the issue before the other does.
 - Try saying: *“I may have already told you this”* or *“Let me know if I’ve already told you this.”*
 - Don’t apologize or make an excuse; make a statement about the way it is.
- Bringing up memory issues yourself reduces your anxiety and can make the other person feel more at ease.

If the other person seems to take over too much and try to take things off your shoulders, ask for the right support:

- Make it clear how important it is to you that you keep doing as much as possible that you used to do, even if you have some anxiety about making mistakes.

- Ask the person close to you to support you in doing the things you are capable of.
 - Tell that person an important support is being ready to fix mistakes that you might make, so that you feel less anxious about doing something wrong.
 - For example, if you are writing checks to pay the bills, ask her to check the figures before she seals the envelopes.

There can be humor in Memory Loss situations that most people are afraid to acknowledge.

- Tell others not to be overly serious about memory issues.
- Humor is not a problem. In fact, it can lighten the situation – as long as:
 - You are included in the joke rather than a subject of it, and
 - When there is love behind the humor.

Admit your social worry

- If you feel anxious about staying relevant, admit it to yourself and be ready with a short script to explain it to others close to you:
 - *“I want to stay relevant, no matter what is going on with my memory issues; I don’t want to fade away; I want to retain my relevance and be helpful to others. In conversations it is important to me not to be marginalized.”*
- Especially share this with those close to you with whom you have shared your memory challenges – share with her or him that it is important to you to remain relevant.
 - If you can do this, it can put you and them more at ease.
- Sharing these personal thoughts is not easy to fit into a conversation. Consider handing a person this document as a beginning.

When others say: “I forget things too,” tell them about your Memory Issues

- Realize they are saying this to be empathetic and kind, not to be dismissive.
 - They mean to say: “I’m in the ballpark with you.”
- Develop a “Response Script” to when someone says, “I forget things too.”
 - Keep it in your pocket if you want a reminder.
 - Make sure the script distinguishes your situation from normal aging which the other person may be referring to.
 - For example, you might say: *“Thank you for understanding; but a Neurologist has diagnosed me with a memory loss condition – MCI: Mild Cognitive Impairment.”*

Relieve the Stress with further explanations

- Don’t just stop with a short explanation of your situation, use the opportunity to explain more about what’s going on with you.
 - *“When I lose the train of thought, I’m not being rude. You might think I’m just not listening; but I am losing the train of thought. Please be patient.”*

- Or you can say: *“I’m perking along at 80%-90%”* or *“I need more time to figure out what I’m thinking and how to say it.”*

Decide What is Important to you

- Explaining to others – even those close to you -- how you are feeling and what is happening in your life, is extremely difficult.
 - You have to get over feeling embarrassed.
 - You have to face that the other person might feel uncomfortable – at first. Being so direct flies in the face of a natural feeling to make the other person feel comfortable.
- Because of all this, you need to take the time to decide for yourself if it is worth overcoming these feelings in order to be present and recognized.
 - Whatever you decide is OK.

Listen carefully so that you can fit into every situation and don’t appear out of place.

- Listen to perceive others and what they are saying, to assess the present situation at that moment and to be relevant.
 - Listen for key words, past experiences, and associated thoughts, all of which can help you assess the situation and remain relevant.
- Do not listen in order to remember; you won’t do either well.
 - Listening and at the same time trying to remember are in conflict. Do not listen in order to remember later, because then you will not really be listening, you will be out of place, and you won’t remember anyway.
 - Someone said: *“I worked so hard to recall what was being said that it was exhausting.”*

Take notes when you feel recalling a situation is going to be important later.

- Taking notes to help listen carefully & deeply enables you to feel less “left out in the cold” and makes it so “others can rely on you.”
 - In taking notes, jot down only the important points.
- Taking notes can help some people to listen; taking notes can refresh your brain.
 - It doesn’t mean walking around with a notebook and pen everywhere.

Another way to write notes – a Daily Evening Diary

- Another type of note taking you might consider (for recall and to reduce stress) is an evening recap of the significant events of the day.
 - Even if this is “I had a good hour sitting with my warm and cuddly cat.”
 - Knowing you are going to write an experience down at the end of the day, for some makes the experience itself more memorable.

- Sometimes picking up the journal and reading the notes brings a person positively back to the feeling of that event – not the details, but the gist of it.

If you want to explain to another why to be patient when they ask you something, explain what your thought process is and what they can do to help.

- Start by saying: “Give me the time to respond” or “I’m 78 and I can’t pull it up so quickly.”
- Someone explained it this way: “When asked a question I have to go into the attic of my brain full of boxes and find the right box and find the thought in it. That takes time.”
 - You might use that analogy and add: “and the box is very jumbled.”
- Other reasons for taking your time to answer might be:
 - I have to distinguish between what I might want to do and what I actually have to do.
 - I have to think a little if I actually want to do what is being asked of me.
 - I might want to read a book rather than go someplace another is suggesting.
 - I need to check my calendar.

Unless you tell them, there is no clear way for others to know how best to offer you support or to invite you to do something.

- So, tell them:
 - “I would rather you ask me to do something specific like take a walk so that I don’t have to figure out what to do” *if that’s how you feel* about a general question like: “Let’s do something together.”
 - If you feel more comfortable with an open request rather than a specific one tell them that and explain that specifics hang over you and that you feel guilty about not doing it correctly or forgetting it entirely.

NOTE: Some of the authors of this document plan to share it with their children and grandchildren in order to start a discussion and have them acknowledge that they are still here.



I'm Still Here Foundation is dedicated to changing the dementia narrative from despair to hope, bringing this message to those living with dementia, their care partners, and society at large. We promote acceptance, integration, and social justice to overcome stigma for everyone living with Alzheimer's and other memory challenges.

The Tuesday Group, five residents of Westminster-Canterbury of the Blue Ridge (WCBR) in Charlottesville, Virginia, developed the first set of "Lessons". The WCBR Lessons are available at www.imstillhere.org/TuesdayGroup



The Gathering Place is an early-stage memory loss enrichment program that offers a weekly community with the pillars of cognitive stimulation, exercise, social engagement, and activism. The Gathering Place is part of a larger Memory Loss Program offered by the Phinney Neighborhood's Greenwood Senior Center in Seattle, WA. The Memory Loss Program Director is Carin Mack, MSW, and the Gathering Place is facilitated by Kristen Oshyn, MSW.