

Student-to-Student: Learning Tips to Create Life Stories for Caregiving in Dementia

Background:

This Student-to-Student Learning Tip Sheet is one of a number of education and practice support tools developed by the Kootenay Boundary Core Dementia Working Group during the implementation of their chosen [IH Phased Dementia Pathway](#) priority to promote personhood in dementia care. At the time of its development, this group partnered with Selkirk College in the winter of 2010 to pilot the Life Story materials. Two Human Services students from Selkirk College were involved in drafting *A Guide to Creating a Life Story for Care-giving* and piloting the *Life Story* template. Their practical feedback and suggestions were very useful in modifying the original materials selected from research. This learning tip sheet contains some of the specific suggestions these students made for future student colleagues who choose to create Life Stories as a practicum experience.

In the Beginning

Tips on getting ready for your Life Story practicum

- Inform yourself about dementia, have some understanding of the condition and how it affects people's memories, and learn effective ways to communicate and understand behaviour. A suggested resource sheet is attached to the appendix of this document.
- People with dementia can be visited in their own homes, in Assisted Living facilities, and in Adult Day Centres.
- Think about the generation and era in which the person was born and lived their active years. What do you know about this time period in terms of world history? Researching about the time period and culture of the person you are working with can help trigger stories of interest for the person. Go to your home visits prepared with possible conversation starters.
- Be sure to read the accompanying document, *A Guide to Creating a Life Story for Care-giving*, to learn more useful tips for creating Life Stories.

Tips to successfully engage the person with dementia

- *Establish rapport and seek permission*
 - At the beginning stages you will need to meet with the person on a regular basis to gather information.
 - Approaching the person for permission to start the Life Story is important. They will need to sign a consent form accepting you as a guest in their home for the purposes of your practicum, but bringing this up immediately might be scary, especially if they are not comfortable or familiar with you.
 - If you don't know the person it might be good to use your first visit just as a "meet and greet" for the purposes of building rapport.
- *Engage support from family or caregivers if needed*
 - You may also need to ask permission of their family or caregiver if the person with dementia lacks understanding of what you are asking of him or her.
 - You may need to get collateral information from friends, families or those who are working with the individual as the person with dementia may not be able to provide enough information, but do this only when necessary.

- *Work respectfully with the person*
 - Be sure that the person you are working with understands the purpose of the Life Story book and what to expect from the interviews, e.g., how many visits, when, and for how long.
 - Explain to the person with dementia that the information will be used to create their Life Story book which is designed to help their present and future caregivers. You may need to re-explain this several times, or at each visit, as they may forget.
 - The person may be tired, not feeling well or just not in the mood to engage in conversation, so be sensitive to changes in health and energy levels at each visit. Usually an hour is an appropriate amount of time to spend with someone when gathering information. Watch for signs of fatigue or increasing confusion.

Working Together

Tips on Getting to the Heart of Life Story Information

- **Prepare.** It can be helpful to review the Life Story template before each meeting. Write down new questions or areas that need clarifying to bring up at your next visit. This can help guide conversation in a useful direction.
- **Inform.** Gently remind the person with dementia of the purpose for the interview each time you visit. They may have forgotten who you are or why you are there. Show them any work that you have completed so far, so they can be reminded of earlier visits. Start the new visit in a positive way, by telling them what you wish to achieve today, e.g., “*Today, I am hoping to hear more information about...*”
- **Listen.** Listening skills are very important. Using phrases like “Can you tell me more about..”, or “I would like to hear more about...” will show interest and attention and guide the conversation. Be aware of your body language, especially if you don’t understand part of a story or it is confusing to you. Rephrase important points the individual makes in order to ensure you have understood him or her correctly.
- **Observe.** Be aware of personal items in the person’s surroundings that can be used for discussion. Often their home may have clues about interests and what is most important to them. Photos and mementos can make great conversation-starters. Always use information that is meaningful to him or her.
- **Engage.** Try to keep the flow of conversation in the interview natural and not “drill” the person with constant short questions. Assist the person by guiding the direction of discussion to areas in the template. Here are some sample questions that may be useful for gathering personal information.
 - Tell me about your childhood.
 - Where did you grow up?
 - What fun things did you do as a child? Did you have any exciting adventures?
 - Do you like animals? What are your favourite pets?
 - Which holidays or celebrations are most important to you?
 - What are you most proud of? e.g., volunteer, published a book, built own house or raised a family.
 - What are your favourite memories?
 - What would you like to do more often? Who might you like to visit or where might you like to go and what would you like to see?
 - What is your idea of a perfect day? What would you do every day, if you could?

- **Balance.** People with dementia often enjoy sharing memories. While biographical information is an important part of capturing their Life Story, be clear that the purpose of the book is to identify the information that will help caregivers provide more personalized care for them. Follow the other categories of information to guide your questions. Focus the conversation on things that make this person's life meaningful. What makes him or her feel useful? What abilities or skills is this person most proud of? What makes this person unique? Explore the person's strengths.
- **Gather information respectfully.** Be aware that some information may be "made up" to fill in the gaps when memory fails the person. It is important to go along with this information and not challenge or correct the person, as it may only cause distress. You can clarify the information with a family member if it is important for the Life Story, otherwise simply leave it out. The Life Story should never be used as a way to "test" the memory of the person with dementia, e.g., asking them to recite names or relationships. If memory loss occurs, reassure the person and move on to something else to minimize distress. If there are certain areas that seem consistently unimportant to this person, it may be best not to focus on them in the Life Story.
- **Be flexible.** Be aware of the type of memory loss the person experiences, as he or she may have very clear memories in some areas but not in others. For example, the person may have very clear memories of childhood, but feel uncomfortable discussing later years due to insufficient memory recall or bad memories. If the person with dementia seems to struggle with one area of conversation move on to another topic; you can always come back to it another time. Focus on their strengths and positive achievements. Finally, be prepared that the person may forget appointments. If possible, call ahead the same day to remind and confirm that a visit is good for that day. It may help to have the person mark your next visit on the calendar. If the person has more advanced dementia, you may wish to speak with family members or current caregivers for assistance, but first try to coordinate and communicate with the person before resorting to asking others for help.

Finishing the Story

Tips to close the relationship with dignity

- Many older people live in isolation and are lonely, and may want you to continue with your visits. If you are visiting in the capacity of a student to gather the information for the Life Story and won't see the person after your practicum, it is important to close the relationship in a professional way.
- Try not to offer more of yourself than you are willing and able to give, or make vague promises to see them again.
- Formally close the relationship by letting the person know that this is your last visit and you have completed your assignment.
- Thank the individual for their contributions to your learning.

Closing Suggestions: Practical Tips

Tips about using photos and pictures:

Some tips to consider when collecting photos for Life Stories.

- Be sensitive. Photos are important and often irreplaceable. The person may feel some anxiety about letting you borrow their photos. Reassure the person that you that you will promptly return them.
- If you have access to a portable scanner, laptop or a digital camera, you may be able to scan or take pictures of photos without needing to take them from the person's home.
- Bring a digital camera to take pictures of any important pieces of art (e.g., weaving, sewing, painting, sculpture), construction (e.g., carvings, buildings), or other items (e.g., car) that the person may have completed or worked on. These are lovely to include in a person's Life Story.
- Some individuals may not have pictures with them or pictures may be in storage with other family members. It may be necessary to contact family members to find pictures for the Life Story.
- If there are no available pictures, you could (with their permission) take a few photos of activities the person is currently doing for fun. For example, if they reside in a facility you can take pictures of outings, playing cards or bingo with friends, recent birthdays, or a pet.
- If the person you are interviewing has limited vision, pictures may take on a different value. In this case, adding pictures may be of greater use to the caregiver and still important to include in the Life Story.

Tips about gathering information about family and friends

- Remember to focus on family and friends who are currently important to the person with dementia.
- You can list past relationships that are important to the person with dementia, such as deceased children, parents or spouse if they talk about them a lot. The purpose of the Life Story is to help caregivers to understand the person's current perspective and who they may be speaking about.
- Some individuals may not have family or caregivers readily available to assist you with gathering personal information. While this may feel like a barrier, it can also be an opportunity to focus only on what really matters to the person whose book you are creating.

Tips about compiling, printing out and assembling the Life Story

- The Life Story template is made in Power Point. Take time to become familiar and play around in Power Point; framing pictures that are inserted, choosing different colours and font size all contribute to a successful looking Life Story.
- When you think you are ready to print out the information for the Life Story it's a good idea to read through it with the person to make sure your information is correct and they are agreeable to sharing it with others for care-giving.
- Small, inexpensive 4X6 photo albums work well. Try department or dollar stores. Try to organize the Life Story so that when it is open the information on one page corresponds with the photo on the opposite page.
- Request a duplicate copy be made – one for the person to keep and one to give to caregivers or accompany the person into new care settings, e.g., hospital, facility, etc.

Enjoy and Good Luck!