

## A Guide to Creating a Life Story for Care-giving<sup>1</sup>

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### What are Life Story books?

Life Story books are tools that gather specific personal information about past life stories, important relationships and present and future needs of persons who experience memory loss from conditions such as dementia or a brain injury.



Life Stories are a small “snap-shot” of the person’s life put into mini-photo albums or picture frames and the information contained is used by health care providers to give more person-centred care. This guide is written from the perspective of using the Life Story as a tool to better support the care for persons with dementia.

Dementia is an umbrella term for a cluster of progressive brain syndromes that affect a person’s ability to think, reason and advocate for themselves. Alzheimer Disease is one of the more common types of dementia. As dementia progresses, long term memory of past life experiences remains active the longest, while short term memory deteriorates. By using the information in the Life Story books caregivers will be better able to meet the needs of the person with dementia when they are no longer able to speak on their own behalf. These books are intended to help enhance the care-giving relationship and satisfaction between caregivers, persons with dementia and family members and thus improve quality of care and life.

### What is person-centred care?

Person-centred care is an idea that originated from Professor Thomas Kitwood<sup>2</sup> in the U.K. in the 1990’s. While traditional models of dementia care have focused mainly on physical

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<sup>1</sup> This *Guide to Creating a Life Story for Care Giving* is one of a number of education and practice support tools developed by the Kootenay Boundary Dementia Core 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 materials. The KB Core Dementia Working Group wishes to gratefully acknowledge the efforts and energy of those Human Services Program students involved in drafting this guide and piloting the Life Story template during the Winter of 2010.

<sup>2</sup> Kitwood T, Bredin K (1992) Towards a theory of dementia care: person-hood and well-being. *Ageing and Society* 12: 269-287

care needs (e.g., bathing, dressing, feeding), person-centred care recognizes the needs of individuals as whole persons. Person-centred care is about improving quality of life for individuals with dementia by:

- using unique information about the individual to plan and deliver personalized care;
- focusing on the needs of the whole person, not isolated tasks of care;
- valuing the retained abilities of the person, rather than focusing on losses;
- attempting to continue the pattern of people's lives by honouring historical preferences;
- engaging the person in meaningful conversations and using memories and pictures to provide comfort and pleasure.

### **Who might use Life Story books?**

Life Story books can be used by family members of the person with dementia while the person is living at home. The information can also be used by health care staff in community, adult day centres, hospitals and nursing homes. Life Story books are also an excellent teaching tool for students in the fields of human care.

### **How can Life Story books be used?**

These books can:

- provide a quick reference for new caregivers to discover likes and needs of the person;
- help celebrate life achievements, special events, holidays, and other special occasions that have been historically important to the person;
- promote and support mental stimulation;
- provide emotional comfort and pleasure;
- help engage the individual in meaningful conversations about the past where memories are more vibrant and clear;
- encourage social interaction between the person, caregivers and families caring for the person;
- help distract and divert the individual when upset;
- provide meaningful interaction to calm the person if overwhelmed by other people, events and noises in the environment;
- be a refocusing tool to support the person when in new and unfamiliar surroundings (e.g., in hospital, moving to nursing home, changing rooms, etc.).

## Creating a Life Story book

There are four sections to the Life Story book. The categories of information were selected from research to best represent information that is helpful for caregiving. The following information explains the intent of each category and will guide you to ask the right types of questions.

### 1. My Life Reflections

Description: This section is best explored in one or more conversations with the person with dementia. As their long term memory is often the sharpest, they likely can tell you interesting stories about what is important to them! Ask a few open questions, then simply listen with all your attention. The person will tell you about the events in their life that were most important, most funny, what achievements made them feel proud, or what lifetime habits make them feel most comfortable.

Cues found in the Life Story template:

- *I am.../I was.../I did...* (List Major Life Achievements and Accomplishments)
- *I always...* (Identify Life-long Habits that would help provide care)
- *I remember...When I...* (Identify significant positive memories, life and/or historical landmarks (e.g., marriage, children, sports, war years, immigrating, familiar family stories, etc.).

Examples of conversation starters:

- “Can you tell me about the time you ...” (first came to Canada, got married, had your first job, your children were small, etc.)
- “What did you used to do for work?” “What work/job did you enjoy best?”
- “Do you enjoy sports?” “What sports did you enjoy?” (Ask specific sports, e.g., hockey, ball)
- “What was it like back then when you...” (worked for the railroad, raised your family up the lake, rode to school on horseback, etc.)

Helpful Tips:

- Use old photo albums or pictures, or ask the person to tell you the story of “back then” to trigger rich conversations.
- Capture the story as the person recalls it. Accuracy of who did what and when is not important.
- Keep the memories positive; there is no therapeutic benefit in bringing up unhappy times or painful memories in the context of creating a Life Story. It is helpful to listen to the underlying emotion as the story is told to know if you should include it or not. If it brings laughter and bright eyes, it’s a keeper. If

the person is sad, comfort them, distract them and move on. Do not include this information in the Life Story.

- Write down the information in the first person, using the words “I” or “my” as if the person was speaking directly to care providers. e.g., “I am a good cook.”, “My mom was always proud of us kids for helping around home.”
- Capture the information in whatever tense the person speaks, e.g. “I was an engineer” versus “I am an engineer”. If the person mixes tenses, that is fine, it captures where their memories are strongest and what period of time they believe themselves to be living in currently. This type of information is useful for providing care.

## 2. My Family and Home

Description: This section is intended to capture the personal information of the people and the home as recognized by the person with dementia.

Cues found in the Life Story template:

- *Family, friends and pets who are **important** to me are: (List names and relationships, both current and past);*
- *My favourite memory(ies) of time with... (family, friends, pets) is/are...*
- *My special memories of home are (specify)...*

Examples of conversation starters:

- “Can you tell me who this is?” (using an older “long ago” picture)
- “Tell me about your home – what do like best about it?”
- “Are you an animal lover? Do you have pets?”

Helpful tips:

- It is common for persons with dementia to not recognize their spouse or children, because in their memory, that person is living at an earlier time and should look much younger. Using photos of an earlier time will often enhance their recognition of important people.
- “Home” can have many meanings. It can be the last place they lived, the person’s home from the years of marriage and raising a family, or it may be the home of their childhood. Listen to the context of the home. To better understand which home they are talking about, ask the person who lives with them, then ensure that you accurately describe the details of the home they enjoy talking about most.

### 3. Helping Me in Everyday Life

Description: This section is intended to capture the unique personal preferences and life long daily habits of each individual. This information can be used by care providers to re-create and continue those patterns of living in a respectful way that provide the person with familiar structure, expectations and comfort. The information can be gathered from the person with dementia in the earlier stages or from a caregiver who knows them well.

Cues found in the Life Story template:

- *My personal preferences when helping me with my care include: (examples: sleeping position; food/beverage favourites)*
- *I like talking about...*
- *I like it when others ask me... (for..., about....)*
- *I am most comfortable when...*
- *What give me pleasure is... (sensory information: sight, hearing, smell, touch, taste)*

Examples of conversation starters:

- It helps the people who care for you to know what your habits are and what choices you prefer in everyday life. Can I ask you some questions about food, sleep and other everyday things?
- Can you tell me what a “typical day” looks like for you?
- Note: If not able to answer the above question, try using simple, direct questions such as:
  - Tell me about sleeping – are you a night owl or a morning lark?
  - What time do you like to get up in the morning? go to sleep?
  - What is your favourite food? Do you have any you really dislike?
  - What do you like to drink in the morning? afternoon? before bed?
  - Some people like showers, some like tubs to soak in. What do you prefer?
  - When you go to sleep, what is your favourite position to fall asleep in – on your side or back?
- If you need help with something, do you feel comfortable asking for help or do you like it better if someone offers to help you?
- What gives you great pleasure or comfort? e.g., music? socks to warm your feet at bedtime? flowers? hugs?

Helpful Tips

- Many older people are not comfortable talking about their personal needs and preferences or asking for help. Past generations may have more of a staunch, uncomplaining and self-reliant attitude to life. It may take a few conversations to gather this information in a sensitive and respectful manner.

#### 4. I look forward to... (Hopes and Dreams)

Description: Too often caregivers forget that people with dementia are still living their lives and may have hopes, dreams and things they look forward to even if they are no longer able to say this or organize it for themselves. This “looking to the future” category of information is another very important way of continuing life patterns and creating hope and comfort in the moment.

Cues found in the Life Story template:

- *My favourite traditions, holidays, seasons are...*
- *I always celebrate...(describe)*
- *I want to see... I hope to....* (List known aspirations and hopes)
- *I always wished...*
- *I would like to...*

Examples of conversation starters:

- Tell me about how you celebrated... (your birthday, your anniversary, Christmas, Hanukkah, Easter).
- What is the celebration that you have always enjoyed?
- Which season do you like best?
- What did you do in the... (winter time, spring time, summer, fall...?)
- What do you look forward to...?

Helpful Tips:

- As dementia advances the person loses a sense of time and memory. It is up to the people around them to organize and provide a larger sense of time through the use of seasonal events such as holiday decorations, drawing attention to changing weather, and continuing special celebrations that the person always enjoyed (birthday, religious holidays, and anniversaries).

## Practical Considerations

### 1. Life Story Template:

The four categories of personal information can be used in many different ways. A free electronic (Power Point) template has been created and is downloadable at: <http://www.interiorhealth.ca/YourCare/ChronicConditionDisease/Dementia/Pages/Resources.aspx>. Information can be filled in and saved directly into the template, then printed and put into a small photo album. The template can also be printed and handwritten if that works better. The use of pictures is encouraged (see section on photos below). However, other formats can also be adopted. When creating a Life Story, one can incorporate the four categories of personal information into picture frameworks (see example on right), story boards, or other types of creative presentations.

Using Life Story Information during Caregiving can Promote Personhood



Names and some facts changed. Used with permission of family. B2 Care Dementia Working Group, May 2016

Example of using the four categories of Life Story information in a picture frame presentation to hang on a wall.

### 2. Telling the Person's Life Story

When writing the person's Life Story, it is important to capture the voice of the individual as if they were speaking and telling their story. When a caregiver reads the Life Story, the information should sound as if the person is speaking directly to caregivers. Where you can, use quotes. For example, "I remember when I..."; "I like to..." Remember the focus for personal information should be of a positive nature (e.g., Life Achievements) and avoid capturing life tragedies or upsetting events.

### 3. Permissions and Respect

Before engaging in creating a Life Story book, it is important to seek the permission of the person with dementia if at all possible, and/or of a key family member(s) if the individual is unable to give informed consent. While many family members may be the creator of the Life Story book, the creator may not be related to the person (e.g., may work in a nursing home, an adult day centre, or be a student or volunteer, etc.). Seeking permission is especially necessary if you are using photographs that may have other family members in them. Contacting a key family member to seek family permission is recommended.

Respect for the person with dementia requires being sensitive to their stories, listening attentively and capturing or summarizing their main ideas. Creating a Life Story is a process and could take several visits. Be aware to work with the individual in a respectful manner that does not exhaust them physically, mentally or emotionally.

#### **4. Pictures and Photos**

Pictures and photos enrich the telling of a person's Life Story. This is a method that is especially helpful for caregivers to explore and work with the retained memories of the person. Pictures and photos can be used as tools in multiple ways: to help caregivers envision the person in their younger days as active and vibrant; to provide a focus for engaging the person with dementia in meaningful conversations or story-telling about themselves; and to distract a person, or to provide them with comfort and pleasure.

##### A few tips in using pictures and photos:

- Do not use original photos – they are rare and precious and may become lost. Instead, use colour photocopies or scanned electronic images of photos inserted into the template and then printed on a colour printer. Another advantage of using alternative versions is that more than one copy of the Life Story can be created.
- Try to match the picture to some of the information in the Life Story category, e.g., Life Reflections: “I remember when we used to go sledding down the big hill at my grandparents farm” matched with a photo of winter or sledding.
- When possible, include action photos as well as portraits or still family pictures. The action in the photo can become a focal point for conversation.
- Pictures of pets are also valuable.
- Digital photos of any piece(s) of art (weaving, sewing, paintings, sculpture, etc.), construction (wood workings, building, etc.), or other items (e.g., cars) that the person may have completed or worked on are lovely to include in a person's Life Story.
- Maps are an alternate sort of picture. When a person has immigrated, a map of their country of origin with their town identified may be meaningful. Including a small picture of a flag from the country of origin may also bring back memories.

#### **A Final Note**

Families will find the process of creating Life Stories a satisfying and enriching experience. The Life Story can become a legacy of family relationships and personal history that will support the individual with dementia by purposefully sharing information that is needed to give individualized, person-centred care.