

20 Reasons Why We Want to Know the Early Life History of Older People With Dementia?

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*“After everything I am doing,
marching like escort,
the child I was years ago,
the boy in his first love that I was,
the soldier that I was in those days,
and the gray hair that I was one hour ago”
- Yehuda Amichai*

1. The **right** of older adults with dementia is to be with people who know their life story including cultural habits and religious faith (Bell & Troxel, 2003).
2. Developing **friendships, relationships, and trust** with people with dementia is the foundation of person-directed care (Bell & Troxel, 2003; Zgola, 1999). Knowing, understanding, and using the life history of the person with dementia is the key to creating and maintaining this foundation.
3. The only way to truly understand an individual in later life in a **holistic** manner is to see her or him in a life-course perspective.
4. Although more and more cueing is required as the disease progresses, the **long-term memory** remains relatively intact until the later stages of Alzheimer's Disease. Therefore, there is a need to "capitalize on what can be remembered from the distant past to help counter the threat to personhood" (Chaudhury, 2002).
5. "**Neurodevelopmental Sequencing Approach**" in Dementia: Behavior, movement, and functional losses in people with dementia occur in approximately the reverse order of their original development (Buettner, & Kolanowski, 2003). Functional abilities, skills, and activities a person acquired, learned, and enjoyed in infancy, childhood, and early adult life may be relatively preserved into the later stages of dementia. This key principle can be described as "What Goes In First, Goes Out Last."
6. To be able to have a **meaningful interaction and communication** with the older person with dementia (e.g., conversation prompter) and to be able to attribute meaning to seemingly incoherent speech (Chaudhury, 2002).
7. To be able to identify, focus, and capitalize on the person's **remaining abilities** (yes, we need to understand and proactively compensate for the lost abilities but we also need to avoid focusing excessively on these lost abilities). Due to the progressive nature of Alzheimer's disease, this is a "moving target" that requires regular assessment and adjustment.
8. To be able to plan, encourage, and engage the person in enriching, appropriate, and **meaningful activities** based on her or his life-long interests, current abilities, disabilities, and preferences. This, while remaining open to the possibility that life-long interests may change in certain individuals.
9. To understand the meaning of behavioral expressions for the person (Rasin & Kautz, 2007). For example, to be able to **identify and address remote triggers from the distant past of distressing behaviors** (Landerville et al. 2005). Research and practice have demonstrated a relationship between various early-life stressful events (e.g., life-threatening experiences and traumas) and current distressing behaviors (Cohen-Mansfield & Marx, 1989; Feil, 2002).
10. To be able to **design a physical environment** in a way that is personalized, familiar to the individual, understandable, and consistent with her or his lifelong positive experiences such as in their homes. This, from general design of physical spaces to cultural, ethnic, and familiar symbols, favorite and personally meaningful objects, and furniture. This, while continuously adapting the physical environment to the person's cognitive disabilities.

11. To know what in the person's life gives her or him **hope** (Kivnick, 1993) and to use this knowledge to nurture this sense in the present.
12. To know **what** it is in the person's life (from *her/his* perspective) that is most **worth living for** or that makes her/him **feel most alive** (Kivnick, 1993).
13. To know whom or what the person **especially cares about** (Kivnick, 1993) and use this knowledge to plan conversations, activities, and care.
14. To know the **things** that have always **given** the person **confidence** and **made** her or him **proud** (Kivnick & Murray, 2001) and use this knowledge on a regular basis to promote those feelings and experiences in the person.
15. To know the person's **fears** and to make every effort to avoid situations, conversations, activities, and care tasks that trigger those fears.
16. To be able to **anticipate and proactively address** the person's physical, emotional, psychological, social, occupational, cultural, and spiritual **needs**. Various unmet needs related to the person's psychosocial history often contribute to distressing behaviors (Whall & Kolanowski, 2004).
17. Many family members want to remain involved in the care of their relative when the person lives in a long-term care residence (such as a nursing home or an assisted living residence). Learning about the unique life-history of the person is a great way to **involve family members** in her or his care (Chaudhury, 2002). This, in turn, could inform and lead to more individualized and effective care.
18. To be able to develop an **individualized care plan** that respects the person's values, beliefs, faith, personality, lifestyle, daily routine, habits, coping style, areas of sensitivity, fears, traumas, accomplishments, expectations, interests, special skills, likes, dislikes, hobbies, and preferences.
19. To relate to the person with **empathetic identification** and make her/him feel that she/he is **understood as a real person** (Chaudhury, 2002).
20. To be able to **see the person behind the dementia and/or her/his behavioral expressions** and to **preserve her or his personhood**, identity, sense of self, and dignity as long as possible (Kitwood, 1997).



Wood carved piece made out of Butternut. Wood Carver: Eilon Caspi

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