Attainment’s

Person-Centered Care in Practice for Families

Finding Balance After a Diagnosis of Mild Cognitive Impairment or Dementia

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About this book

This book is for people with mild cognitive impairment or early dementia and their care partners. It is designed to provide basic information about mild cognitive impairment and early dementia, ideas for things you can do now to keep your brain and body as healthy as possible, practical strategies for managing the changes ahead, and suggestions for staying in control of your life.

So, someone you love has been diagnosed with mild cognitive impairment OR dementia. What does that mean? What can you do? What will this new future look like?
Dementia

The term dementia refers to a group of brain diseases and disorders. They are also known as neurocognitive disorders. These conditions may affect functions of the brain, such as thinking, remembering, talking, body movement, paying attention, planning, learning, or even personality. Alzheimer’s Disease is the most common type of dementia.

Mild Cognitive Impairment

Mild cognitive impairment (MCI) can affect memory, or it may affect other brain functions, such as attention, language, or planning and decision-making.

Not everyone diagnosed with MCI will progress to dementia. About two-thirds of people with MCI may eventually develop dementia.

There is currently no medication to prevent or cure MCI or any type of dementia.
Life Looks Different
Life will look different when mild cognitive impairment or dementia enters the picture. When someone in your family is living with mild cognitive impairment or dementia, the whole family will experience new responsibilities, situations, and emotions.

Some Changes to Expect
• The person with mild cognitive impairment or dementia may no longer remember or do things they used to do.
• The person with mild cognitive impairment or dementia may display unusual, repetitive, strange, or frightening behaviors.
• Now that life roles are changing, you may have the feeling of “losing” yourself and your identity (being the husband or wife, the parent and child).

Cohen & Eisdorfer (2001)

Life is More Complicated
An unexpected complication of living with mild cognitive impairment or dementia is the formation of new identities following the diagnosis. These identities are shaped by the medical mindset that dominates the conditions of mild cognitive impairment or dementia.

For the person with the condition, the new identity is “the MCI patient” or “the dementia patient.” For the spouse or other family member, the new identity is “the caregiver.”
A Person is More Than a Condition
With a condition like mild cognitive impairment or dementia, it’s easy to become fully occupied with all the health and medical needs: doctors, forms, appointments, medications. It may feel like the person with the condition becomes a “full-time patient.”

Under a mountain of diagnoses and deficiencies, it’s easy to lose sight of the person as a person, an extraordinary individual with a unique life story, preferences, interests, and a voice.

Different Life, Different Thinking
Making the most of life with mild cognitive impairment or dementia requires you to think differently about yourself, your family and friends, and the person at the center of it all.

This new life requires you to think about the whole person. About the person’s emotional, intellectual, spiritual, mental and physical health needs, not just their condition.

That Goes for Partners Too
This new role of care partner requires new thinking, too, about your own emotional, mental, physical, intellectual, and spiritual health needs.
Person-Centered Care is Different Thinking

Person-Centered Care is thinking about the person living with mild cognitive impairment or dementia in a way that focuses on the whole person, not just their condition.

Person-Centered Care is a mindset that sees the person first as a unique and extraordinary individual with many remaining abilities and future potential, then a person with a condition.

Kittwood (1997), Kittwood & Bredin (1992)
Respecting the Person

Being person-centered means respecting who the person is right now, who the person was, and who the person will be in the future, in spite of any health or medical issues. Respect includes a resolute commitment to being present and honest, even when the going gets tough.

Valuing the Person

Being person-centered means valuing the person. It means appreciating the person's perspective and opinions. It means acknowledging and actively seeking out the person's talents and skills. It means finding new ways to help the person find purpose.

Seeing the Whole Person

To be person-centered means considering the whole person, not just their medical or functional needs. Thinking about the whole person, we are reminded of the many dimensions—social, emotional, intellectual, spiritual, physical, occupational, and environmental—that contribute to quality of life and make life worth living.

Hettler (1980), Renger et al. (2000)
Empowering the Person

Being person-centered means empowering the person. A condition like mild cognitive impairment or dementia robs the person of independence and personal control. When we are being person-centered, we try to optimize the person’s independence and personal control in order to maximize the quality of their life.

Person-Centered is Person First

Being person-centered means remembering that regardless of mild cognitive impairment or dementia, the person comes first. Resist other people’s attempts to call or treat the person as a “patient” in situations other than the doctor’s office, hospital, rehabilitation facility or treatment center. Do not let the identities of “patient” or “care partner” take over.

Becoming a full-time patient or care partner is not good for the soul.
Person-centered care in practice: A Model Approach

Context refers to the ecological systems human beings live in. Human ecological systems include the social environment (people, relationships, and activities) and physical environment (surroundings). Behavior is a reflection of a person’s ability to adapt to the environmental context demands. Dementia and aging weaken a person’s ability to adapt to the environmental context because there are diminishing psychological, social, and physical resources to draw on.

Bronfenbrenner (1979), Lawton & Nahemow (1973)

A model is an abstract way of understanding complicated ideas and situations. Mild cognitive impairment or dementia complicate people’s lives, so a model can help you better understand and cope. In the Person-Centered Care in Practice model, context consists of the psychological, social, and physical environments.

Geboy & Meyer-Arnold (2011)
The Social Environment

The social environment refers to other people, relationships, activities, and events. This environment reminds us to always consider the potential effects of other people and activities on the person with mild cognitive impairment or dementia. Who is the person interacting with: family, friends, unhelpful strangers? What activities are happening? Are social elements supportive, or are they confusing, unfamiliar, and disturbing to the person? Think and manage the social environment as best you can.

The Psychological Environment

The Person-Centered Care in Practice model tells us to always start with the person’s psychological perspective, their point of view. What might the person be thinking? How is she seeing what’s going on? How is he interpreting what’s happening?
These Environments Shape Our Days

Sometimes, the psychological, social, and physical environments will affect the person with mild cognitive impairment or dementia all at once. The effects of all these environments on the person can be positive, negative, and unexpected. You can support the person by being more observant and thoughtful about the psychological, social, and physical environments.

The Physical Environment

Factors in the physical environment affect everyone, but especially the person with mild cognitive impairment or dementia. It can be frustrating and irritating if a place is too busy or noisy, bright or dark, hot or cold, or drafty. Is it easy to get lost? Think about how to use the physical environment to support and calm the person.