

## What is a Phased Pathway for Dementia?



### Introduction

There is increasing interest in finding ways to describe health care delivery in words that will lead to better understanding of the many services and their connections. The terms “pathways” or “maps” are tools that help care providers and clients understand the increasingly complex web of health care. Commonly, “encounter-based” pathways are developed. These are descriptions of how clients should receive services as they move throughout the health care system. They describe the types of service ‘encounters’ which clients or families could expect, for example, on admission to hospital, or a residential facility, following surgery or upon discharge home.

While these are useful planning tools that focus on system design, the care needs of dementia clients are complex, continually changing, and depend on a recognition and a thorough knowledge of the stage or phase of cognitive loss the client is experiencing. To develop an encounter-based pathway for dementia would require each encounter point to include extensive information addressing the different dementias and multiple descriptions of cognitive staging. This would result in a very lengthy, complicated tool that would be difficult to apply clinically.

### Taking a different perspective

Instead of an encounter-based approach, the decision was made to follow the natural course of progressive dementias and identify common client, family or clinical concerns that occur as the disease progresses and the person with dementia experiences marked losses in cognition, function and independence. As a result, the unique physical, mental, emotional, social and spiritual needs of persons with dementia and their caregivers are described for different parts of the pathway. The pathway also guides the development of clinical practice recommendations<sup>1</sup>, which provide care providers with the direction and knowledge needed to address these clinical issues for any point in the disease course. The term ‘phased pathway’ therefore, describes *the client and caregiver’s journey of dementia from onset to end-of-life*.

### Dementia is a chronic disease

Dementia<sup>2</sup> is a chronic disease, and just like chronic lung, heart and kidney diseases, it takes many years to develop. Dementia is often thought of as “an old-person’s disease” because this is the time of life in which dementia is usually first clinically recognized. An understanding that dementia is a chronic disease, allows one to re-consider a life-course approach: that there are brain risks from the time in utero and birth, through childhood, young and middle age, and into older age. The accumulation of these brain risks across the life-course result in individual susceptibility to developing dementia. Now one can see that dementia is not just “an old person’s disease”, but a result of a life-time of wear and tear on the brain, similar to what happens to our hearts, knees, etc.

Dementia is also a progressive disease. The deterioration in cognitive function declines at varying rates, depending on the type of dementia involved, but usually over many years. For some dementias, like Alzheimers disease, there are recognizable “stages” of cognitive loss. For others, the patterns are less predictable or recognizable, but mental abilities are often categorized into early, middle and late stages of decline. The phased dementia pathway reflects the journey through the full spectrum of these cognitive changes: it begins “upstream” of any diagnosis of dementia with a goal of promoting brain health for everyone, then identifies the cognitive changes that can occur between normal healthy aging and a diagnosis of dementia, and once diagnosed, the pathway follows through the early, middle and late stages of dementia to the end-of-life<sup>3</sup>.

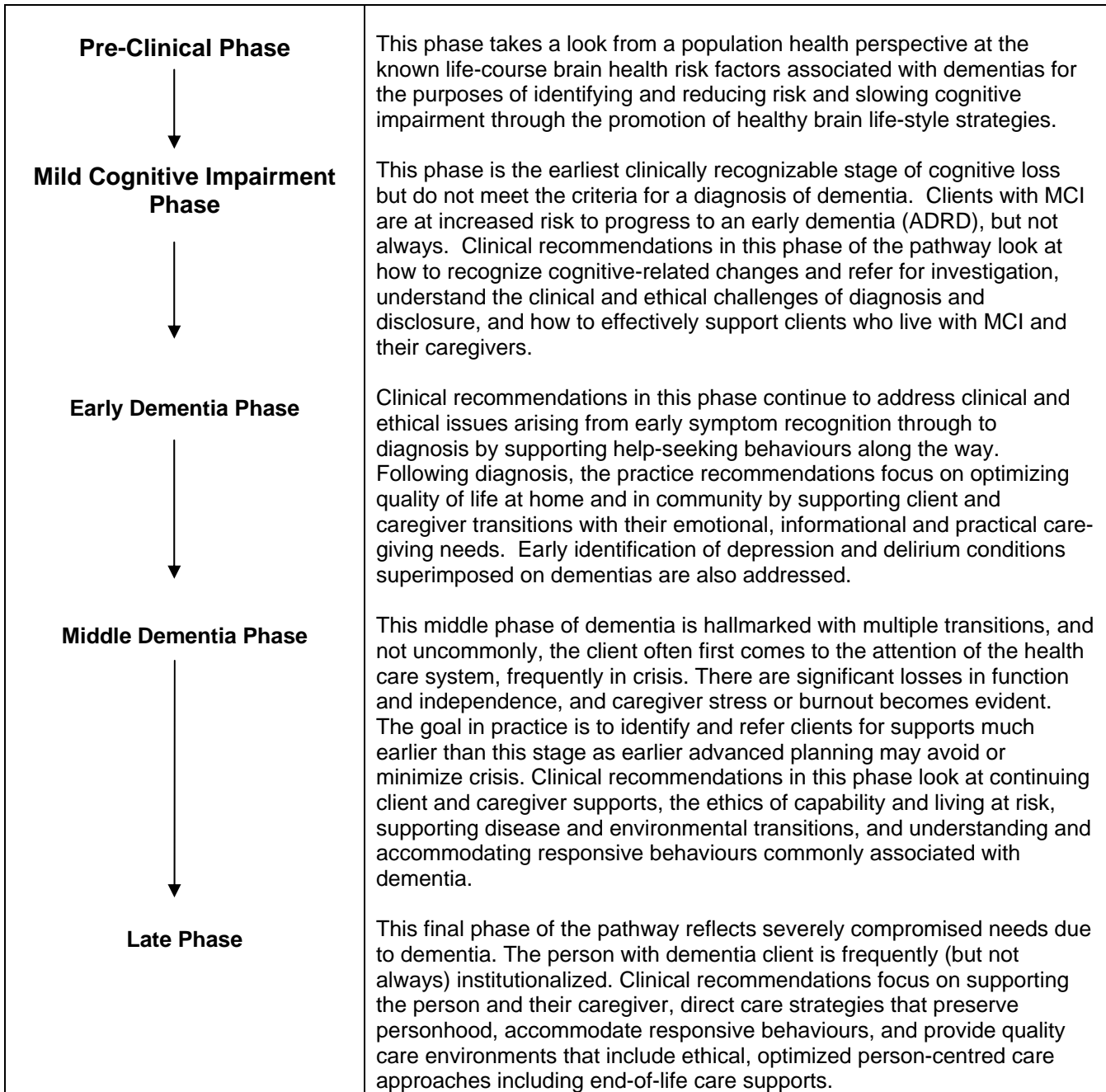
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<sup>1</sup> See section: “How are clinical practice recommendations developed?”

<sup>2</sup> The word “dementia” is used throughout the Pathway as an umbrella term for the constellation of various types of dementing disorders. While Alzheimer Disease is the most common and recognizable form, the word “dementia” also refers to related dementing disorders such as Vascular, Mixed, Lewy-Body, etc. The technical term for this is “Alzheimer Disease and Related Dementias (ADRD)”, however for ease of communication, the umbrella term “dementia” was chosen to indicate this.

<sup>3</sup> ***An Important Note about the Phased Dementia Pathway***

The Phased Dementia Pathway looks like this:



It is important to mention that phasing and staging of pre-dementia and dementia is a mental construct, not a precise science that results in clinical certainty. Progression of disease is a gradual process, and there are no tidy markers or easily distinguished “cut-off points” that develop between one day and the next to differentiate “normal” cognitive function from MCI or MCI from early dementia, etc. It is helpful to view the Phased Dementia Pathway as a continuum that reflects cognitive changes from normal healthy aging through to end-stage dementia. At any point along the Pathway, the understanding of cognitive function may be blurry, uncertain, and often described with terms such as “possible” or “probable” cognitive impairment or dementia. There is no intention of the Phased Pathway to provide clinicians with rigid linear descriptions of disease progression, but simply a framework for organizing information and knowledge about the various progressive diseases collectively known as dementias.