



## Timing a Chosen Death in Early-Stage Dementia

Some people faced with dementia wish to hasten their death before they descend into the later stages of the disease. This involves both personal and practical considerations. At a personal level, the choice of if and when to conclude your life is deeply individual and based on your values and what makes life meaningful to you. This is a reckoning only you can make.

At the practical level, you need to consider your ability to make a life ending choice in the face of progressing cognitive decline. If you are in early-stage dementia and you are planning a chosen death through FEN's Exit Guide Program, via assisted dying in Switzerland, or by voluntarily stopping eating and drinking (VSED), you must have decision-making capacity at the time of your chosen death or when you begin VSED.

You have decision-making capacity for a chosen death if:

1. you understand your diagnosis and the options available to you,
2. you can communicate your reasoning for ending your life, and
3. you can demonstrate that you understand the consequences of your choice, i.e., that death is permanent.

Most people retain decision-making capacity in early-stage dementia, but that capacity deteriorates continuously as the disease progresses.

We are frequently asked by people facing dementia who wish to hasten their deaths how to know when the time is right—and by “right,” they mean the time at which they can choose to conclude their life just before they lose decision-making capacity and their cognitive window of opportunity closes.

### Bad News – It is Challenging and There is no Formula

The harsh reality is that there is no single “right” time. When timing a chosen death in the face of dementia, there is only too early or too late. There is no fail-safe method to predict when you will pass the cognitive point of no return. In part, this is because people's dementia symptoms progress differently. While there are general patterns of cognitive decline, different people lose different capacities at different times. Also, there is no bright line between competent and incompetent. Instead, there is a murky period of months in which you have days of sharper mental acuity and days of foggier functioning, with the latter slowly becoming more common than the former. The changes are gradual, we adapt, our loved ones adapt, and the proverbial frog's water gets warmer and then hotter.

Finally, and importantly, self-awareness, mental focus, and memory to track observations over time are the tools you need to evaluate the progression of your dementia—and those are the

very tools that dementia is degrading. If you cannot self-assess, decide, and take the necessary steps, you are unlikely to act in time to successfully carry out your plan. Dementia is cruel. If you wait for some unmistakable sign that it is time to go, you will likely end up waiting too long. Our experience is that people who successfully exit, by whatever path, usually leave at least some good life on the table.

## Good News – There are Strategies to Track the Progression of Symptoms

Incident Notebook: Keep a notebook to record incidents such as forgetfulness, getting lost in a familiar place, losing your train of thought mid-conversation, putting something in the wrong place, emotional swings, and other senior moments (don't dismiss them as insignificant). Review it each week or twice a month—set a regular schedule—and notice if the frequency increases or new symptoms appear. Have someone help with this, because as your forgetfulness increases, you will increasingly forget to record incidents.

Enlist Trusted People: Find one or two people who are prepared to be honest and are committed to helping you evaluate your condition. Someone who sees you regularly will be able to observe the frequency of incidents. Schedule a regular check-in so that you don't need to remember to ask and they don't wait to be asked, e.g., every Friday, or the 1st and 15th of every month. Also consider enlisting someone you see only occasionally, as that person may be better able to notice the magnitude of change over time because their expectations have not been slowly adjusting day-to-day.

Notice Diverging Impressions: Keeping in mind that self-awareness can fade as dementia progresses, notice if your impression or evaluation of your cognitive functioning is diverging from the impressions or evaluations of loved ones whom you trust to be honest with you.

## Additional Considerations

People with other physical conditions (e.g., metabolic disorders like diabetes, high blood pressure, or heart problems) are likely to have a shorter window of capacity for a chosen death than people who are otherwise healthy.

Those planning to travel to Switzerland for a chosen death should keep in mind that travel can be particularly disorienting for someone with cognitive impairment or dementia. Someone who demonstrated capacity prior to travel may not be able to do so upon arrival.

Those who live alone and don't have anyone to be a sounding board will have to lean heavily on strategies such as an incident notebook. Pay attention if the frequency of incidents decreases; that may mean your focus and memory have slipped and you are failing to note everything.

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