

STAYING ORGANIZED — A Checklist for Patients and Families

Perhaps your loved one has been exhibiting changes; perhaps they have just been given a diagnosis of dementia. You may be wondering about what steps to take.

There are many issues that all of us should discuss with our families, whether we are ill or in good health. With some exceptions, dementia typically follows a gradual, yet progressive course. The better prepared you are, the more in charge you will most likely feel. With advancing dementia, it is expected that the person's ability to make decisions will falter. It is generally best to have these discussions with your loved one while they are able to carefully consider their values and future wishes. In this way, you can feel comfortable carrying out their desires when the time comes that they are no longer competent to make decisions like healthcare planning, financial planning, and surrogate decision-making. This is also true for end-of-life decisions such as treatment and autopsy. While it may be years before you encounter these situations, it is best to be prepared.

The following is meant to serve as a general guide of tasks to complete in order to ensure important decisions have been made.

EVALUATION

The diagnosis of dementia involves a comprehensive evaluation of the person with cognitive and/or behavioral changes. The evaluation may encompass the following: medical examination and history taking, tests of cognition, and blood work. A scan or image of the brain is often useful. Your healthcare provider (physician or nurse practitioner) may assist you in arranging such an evaluation. Specialty organizations such as The Alzheimer's Association offer information on where to turn for an evaluation.

EDUCATION

If you are given a diagnosis of dementia you should expect a description of the clinical course and prognosis. Features and prognosis varies with the different types of dementia. Alzheimer's disease is the most common cause of dementia; other causes include Frontotemporal dementia, Dementia with Lewy Bodies, and vascular dementia. There are also rapidly progressive dementias such as Creutzfeldt-Jakob disease. Refer to Internet sites and reading materials. Place yourself on mailing lists for relevant newsletters so that you will be informed of advances, announcements, classes and lectures.

