

FINAL EXIT NETWORK

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SUPPORTING THE HUMAN RIGHT TO A DEATH WITH DIGNITY

WHAT YOU CAN DO IF YOU SUSPECT SYMPTOMS OF DEMENTIA IN YOURSELF OR A LOVED ONE

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1. EARLY DIAGNOSIS

Because forgetting, personality changes, disorientation, etc can be symptoms of dementia OR a treatable problem like medication interactions, other diseases, a brain tumor, depression, etc. it is essential to get as definitive a diagnosis as possible early on. Though treatments for Alzheimer's are currently not too effective, many other conditions can be ameliorated and the symptoms may disappear. Brain autopsy provides the definitive diagnosis but neuropsychological instruments and other diagnostic methods can have a high probability of accuracy.

2. CONTACT THE ALZHEIMER'S ASSOCIATION

They can provide support groups for the patient and the caregiver to lessen the burden of what will be a difficult course, especially for the caregiver. They can inform you about medications, day care, respite care, etc. They will NOT discuss dying – nor will any support group even if it's for terminal cancer.

3. ADVANCE DIRECTIVES

If you have not already done so, fill out your state's current advance health care directive forms which can be obtained online or at any hospital.

Designate when and if you want which treatments stopped or never started. Since most people with dementia are older they have other diseases which are likely to lead to death. If you do not want your dying prolonged make sure it is clear on paper and to your loved ones and doctors that you do not want artificial food and hydration, dialysis, antibiotics, breathing machines, etc. if they cannot restore you to normal functioning. You may want to add a Do Not Hospitalize order as well. Indicate that you want COMFORT CARE ONLY.

These forms allow you to appoint an agent or surrogate to speak for you if you are not able to express your wishes. Appoint a strong advocate who knows -- and agrees -- with your wishes. Discuss your wishes for him or her and with other people who may interfere or not understand what you want. Make an appointment with your doctor (pay out of your own pocket if necessary) to sit down and discuss these documents.

You can get a DO NOT RESUSCITATE (DNR) order and wear an official bracelet or necklace that indicates you do not want cardio pulmonary resuscitation. Just having it in a document or on the refrigerator will not help if your heart stops in the grocery store.

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In some states there is an additional form, usually called the POLST (Physician's Orders for Life Sustaining Treatment.) Fill this out with your doctor. This document follows you and is an order from your doctor. Find out how they work in your state.

Advance Directive for Alzheimer's Disease is a special list of wishes and is available on the ERGO/store website (www.finalexit.org).

4. CHOOSING A HASTENED DEATH

If you are considering hastening your dying and have a confirmed diagnosis of early dementia you can contact the Final Exit Network (www.finalexitnetwork.org or 866-654-9156). We can provide information and support to mentally competent members for peacefully ending your life quickly, painlessly and with certainty.

5. REFUSING FOOD AND FLUIDS

You can refuse food and fluids; death will occur within two weeks after all fluids are stopped. It is essential if you are doing this to have hospice or excellent medical or nursing care to minimize the difficulties of using this method.

6. FEEDING

Make sure to tell your caregiver or institution NOT to insist that you eat. If necessary sign a waiver of liability stating that you may not be interested in ingesting food or fluids and, if that is the case and it causes your death, you do not hold that institution liable because your wish is not to extend your life if you are demented.

7. INSTITUTIONAL CARE

It is unfair to your loved ones or caregiver to make them promise never to put you in a nursing home or residential care. Caregiving for dementia is extremely

difficult. There are many good facilities providing specialized care for memory disorders in which both the patient and the caregiver will find an improved quality of life.

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