

Prevention of Suicide in Persons with Progressive Neurological Diseases

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People suffering with neurological diseases are at risk of committing suicide. A case-control study found increased risk of attempted suicide in patients with nine chronic neurological diseases [1]. Similarly, people diagnosed with neurological disorders were twice as likely to die of suicide than people not diagnosed with such disorders [2]. This increased risk could be caused by psychiatric comorbidities that are quite common in people with neurological diseases [3] but could be also caused by fear of prolonged suffering. This fear is especially common in people diagnosed with a progressive degenerative dementia [4].

Fear of dementia, also called “dementia worry,” is the most feared health condition in Britain [5]. US survey found that 31% of respondents were concerned about developing dementia [6] and a German study found that 41% of adults older than 40 years with no cognitive impairment exhibited dementia worry [6]. Dementia worry is precipitated by knowing someone with dementia, by knowing about a famous persons living with dementia (e.g., Ronald Reagan, Margaret Thatcher, and Glen Campbell), and by media reports about the lack of progress in finding a cure for Alzheimer’s disease and other dementias. The number of people with dementia worry is likely to increase, because of growing efforts to identify with biological markers cognitively intact individuals who are at high risk for developing dementia [7,8].

Most people develop dementia worry because they fear the eventual loss of autonomy, dependence on family and friends, and loss of dignity in the advanced stage of dementia. They do not understand that they can enjoy

and appreciate life for years after dementia diagnosis, especially during the mild and moderate stages. It is possible to maintain quality of life even in advanced dementia stages if appropriate activity programs are provided, for instance Namaste Care [9]. Unfortunately, some persons commit suicide soon after diagnosis of Alzheimer’s disease [2] and in one study the mean age of individual who attempted suicide was 58.7 years [1]. However, suicide may occur even many years after a dementia diagnosis [10] and some people with dementia attempt suicide several times [11].

Suicide has significant consequences for spouses of persons with dementia who are at higher risk for developing mental disorders, suicidal behavior, and mortality [12]. In addition, relatives and friends bereaved through suicide, experience distress caused by media reporting, stigmatization, shame, and a sense of rejection [13]. Even more tragic are murders and suicides by a spouse caring for a person with dementia [14]. Suicides also occur in long-term care facilities. A recent Kaiser Health News investigation found that several hundred older Americans are killing themselves in nursing homes and assisted living communities every year. It is not known how many of them had dementia, but some people consider such suicide to be a rational choice [15].

Advance care planning may decrease the risk of suicides, but most advance directives may be inadequate. They usually specify what kind of life-sustaining medical care the person does not want to receive when he/she can no longer make informed decisions, including cardiopulmonary resuscitation, transfer to an acute care setting, tube feeding, and antibiotics for the treatment

of generalized infections. But such refusals do not prevent living with advanced dementia, because these interventions may not be required. Consequently, even people with advance directives may live with advanced dementia for many years. The rate of progression for Alzheimer's disease varies widely. On average, people with Alzheimer's disease live between three and 11 years after diagnosis, but some survive 20 years or more [16].

To overcome this problem, it is suggested that advance directives could also ask caregivers to discontinue help with eating and drinking at a certain stage of dementia when the person can no longer eat and drink independently (AD for SED) [4,17]. Discontinuing assistance results in death by dehydration, which is generally thought to be peaceful and comfortable, if dry mouth is treated [17,18]. Dying in a dehydrated state has also some beneficial effects, including less distress and pain, less respiratory secretions, and less nausea and vomiting [19].

Stopping assistance with eating and drinking when the person progressed to an advanced stage of dementia was acceptable for family members of persons who died with advanced dementia on hospice [20]. A survey of physicians and nurse practitioners working in US long-term care facilities showed that 87% of them would honor an AD for SED, although only half of them were sure that their staff would honor it. Almost half of the respondents reported that they had already cared for patients with an AD for SED, and 1 respondent said that she had this AD for herself [4]. However, there may be difficulties in honoring AD for SED in US long-term care facilities.

The Ethics Committee of AMDA (The Society for Post-Acute and Long-Term Care Medicine) prepared a White Paper recommending universal rejection of AD for SED in nursing and assisted living facilities and recommending instead continuation of "comfort feeding" [21]. The Committee based rejection of AD for SED on ethical and practical grounds. They proposed that AD for SED presents an ethical dilemma because wishes expressed by a person with little or no cognitive impairment may not apply when this person develops advanced dementia. They assumed that person with advanced dementia has no decision-making capacity and, therefore, person's best interest, judged by others, take precedence over AD for SED and "comfort feeding" must continue. This paternalistic assumption is not consistent with recommended comfort feeding, because comfort feeding requires stopping it if the person with dementia refuses food or liquids and, therefore, assumes that the person with dementia still has decision-making capacity to make this decision.

Practical issues that may prevent implementing SED by AD that the Committee invoked include perceived

need to separate the resident from others during mealtimes, having to instruct staff and visitors to not help the resident with eating and drinking, and having to medicate the resident if a lack of assistance with eating and drinking results in the resident's agitation or other apparent discomfort. Since it is recommended that food and drinks should be always offered, it may be stressful for staff to ignore requests of patients with SED by AD for assistance with eating and drinking.

Both of these problems could be resolved if it is accepted that a person with advanced dementia has still some decision-making capacity. Clare et al. [22] found that even patients with a Mini Mental State Examination score of zero were able to describe aspects of their situation and their emotional response to it. Sabat [23] found that healthy people often underestimate the ability of people with dementia to communicate, resulting in negative stereotyping. Therefore, if the person with dementia who has SED by AD asks verbally or nonverbally for assistance with eating and drinking, such a request should be considered a temporal revocation of the AD and the assistance should be provided. When the person with dementia stops asking for assistance, the help should stop and the person's wishes, reflected by AD, will allow comfortable death by dehydration.

This strategy, called Request for Assistance with Eating and Drinking (RAED) can be implemented in any long-term facility and does not cause stress for staff, who does not have to ignore person's requests. At the same time, it also assures that person with dementia will not live with advanced dementia for an extended time period, because the person will eventually ignore food and liquids or lose the ability to request them. This assurance should be sufficient to prevent suicide of person who does not want to live with advanced dementia for a prolonged time. On average, people with Alzheimer's disease live between three and 11 years after diagnosis, but some survive 20 years or more [16].

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