Sopping assistance with eating and drinking in severe dementia

More and more people will develop some form of progressive dementia because of increasing life span in most countries. Since there is no effective therapy for Alzheimer's disease and other progressive dementias, about 50% will die at a stage of severe dementia, characterized by complete dependence in all activities of daily living, inability to talk, ambulate and recognize family members. Severe dementia may last for many months or years and people are more afraid of developing dementia than developing cancer, because they may be afraid of losing their dignity, becoming a burden to others, suffering because of physical or mental problems, and spending their assets on their long-term care.

People who fear living with dementia may formulate advance directives, which avoid use of aggressive medical interventions. However, even with these directives in place, many people survive to severe dementia because they do not require life-sustaining treatments. Therefore, some people, who are diagnosed with early dementia, commit suicide when they still can do it. This deprives them of living with mild dementia for number of years, which they may still enjoy.

A strategy which would prevent living with a severe dementia. was suggested by Dr. Terman, who proposed that people who fear living with severe dementia could specify in their advance directives a situation at which they would not want to be assisted with eating and drinking, if they cannot do it by themselves (do not assist, DNA). They would die within several days of dehydration, which does not cause discomfort beyond dryness of the mouth that can be easily managed by ice chips or artificial saliva. This DNA option was acceptable to most relatives of people who died with severe dementia.

Existence of DNA poses a challenge to long-term care providers who may consider giving food and liquids as part of standard care, and not honor DNA. To find out if this attitude would be a problem for people with DNA, we conducted a survey that asked 134 long-term care professionals (mostly physicians) about their attitudes toward DNA.

Most respondents indicated that a person with DNA could be admitted to their programs and that they would honor DNA. However, they were less sure that DNA would be honored by their nursing staff: About half of the respondents would offer food and liquids even though the patient cannot eat and drink without assistance, and the majority felt that if a patient indicated non-verbally need for help with eating and drinking, this should be considered revocation of her DNA. Several respondents stated a need for hospice involvement, but only in a cooperative mode, instead of transferring the care to hospice

Surprisingly, almost half of the respondents had already patients with DNA or a surrogate who requested discontinuation of assistance with eating and drinking. Several respondents worried about legal implications caused by following DNA. The legality remains to be established, especially if a decision to stop assistance with nutrition and hydration would be made by a proxy. Availability of DNA may help to prevent suicide of persons afraid of prolonged living with severe dementia. This is especially important, as new advances in recognition of dementia risk factors, will inform some people that they have a high probability of developing dementia. The legislators might have to decide what is more important for the state: prevention of suicide by a person with mild dementia or prevention of death of a person in last stages of severe dementia.

Putting DNA into practice may force long-term care facilities to develop policies that would determine how would they deal with potential residents who have DNA, and to develop a training program for their staff. In conclusion, some people who fear living with severe dementia may consider establishing DNA which would be applied when they reach certain dementia stage.

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