

***“Why the devil they don’t ask us what we’re thinking?”* The
Need for Residents’ Council Meetings in Special Care Units for
Persons with Dementia in Assisted Living Residences**

Eilon Caspi Ph.D.

A Residents’ Council Meeting was held in 2008 in a special care unit (SCU) of an Assisted Living Residence (ALR) dedicated to seniors with dementia. This was the first time that such a meeting was held in the ALR since it opened 10 years earlier. The meeting was led by the Chaplain and the Director of Recreation Therapies in the main activity room of the Higher Cognitive Functioning Unit of the ALR. The meeting lasted for about 45 minutes.

Shortly after the meeting opened, the Director of Recreation Therapies explained to the residents the purpose of the meeting: “As a group...how can we work proactively to make things better.” The Chaplain added: “Opportunity to think how we can make a better community.” At a later point in the meeting, the Chaplain asked the residents: “If we could create a mission statement, what would it be?”

A series of constructive suggestions and comments were made by several residents who attended the meeting. A selection of these suggestions is presented here: In response to the opening invitation, Mrs. Connors said: “To create understanding of the relationship between management, staff, and residents.” Mrs. Solomon asked: “What is the goal?” Another resident answered: “To establish goals and priorities.” Mrs. Connors: “Programming, care, management.” Mr. Randolph said: “Patience, understanding, and

trust.” Mrs. Solomon suggested that one of the topics that should be discussed in these meetings should be: “How do we help each other?” [and added] “What is the mechanism to help each other whenever necessary?” [then she went on to give an example] “A resident is distressed...wants to talk to someone” [and added] “Often it is hard to talk to someone...often it is hard to find someone to talk with you.” Another resident said in response: “Goals that are realizable” [and then went on to say that care staff have responsibilities and they can’t sit and talk with anyone who wishes to at anytime]. Towards the end of the meeting, Mrs. Connors said: “I think a meeting of this type should be held on a regular basis.” [and added] “The meeting is important...it gives us a chance to voice our opinions...as long as we know that someone is listening.”

Then the Director of Recreation Therapies asked the residents at what frequency they would like to have the meetings and went on to suggest meeting on the third Thursday of every month. The residents seemed to agree.

As demonstrated during the Residents’ Council meeting, residents in the early-stages of dementia are capable of contributing meaningfully to a discussion about their needs and the care issues they think need to be improved. Previous research has indicated that, when the right conditions are created, persons with mild to moderate dementia can be considered good informants of their quality of life (Brod et al. 1999).

The following excerpt further illustrates the need to regularly hold Residents’ Council Meetings. A few months prior to the Residents’ Council meeting, Mr. Randolph said: “Nobody asks us what we’re doing. We are cut off. Nobody inquires about how things could be improved. If they only would ask us, things could be improved.” Still, a couple of weeks later, the same resident said angrily about management: “Nobody ever

asks us what we think. Why the devil they don't ask us what we're thinking? *They* could benefit from that. I really don't understand why they do not ask us."

Attempts to seek residents' opinions about ways to improve the care did take place occasionally by care staff and managers at the assisted living residence. In addition, Family Council meetings were held regularly during which family members expressed their opinions regarding areas of care they believed need to be improved. At the same time, Mr. Randolph's request demonstrates the need for a more structured forum in which residents' needs, opinions, concerns, and complaints could be voiced and requests and suggestions for improvement can be made. Residents' Council meetings can also serve as a forum in which residents can express their appreciation regarding areas of care they are satisfied with and/or see an improvement/progress in.

Because residents with dementia experience difficulty with short-term memory, documentation in writing of such meetings is necessary. Summary of the main points raised and decisions made during each meeting should be made available to the residents sufficient time prior to (though not too long before) the following meeting. To make sure that these points are remembered by the residents, the main points should be briefly brought up and refreshed at the beginning of each meeting. Review of the extent to which progress has been achieved since the last meeting in the suggested areas for improvement should be conducted. Then, the discussion should be opened for new ideas for improvement in care and the ways in which such improvements can be accomplished.

One of the main goals of the Resident s' Council meetings is for residents in the earlier stages of dementia to represent the voices of those residents in the later stages of dementia who cannot participate in these meetings due to their cognitive-impairment.

Recommendation for change in regulations: It is suggested that the regulations pertaining to SCUs of ALRs in the state of Massachusetts should require that Residents' Council meetings be held on a regular basis (at least once a month). Currently, no such language exists in the regulations and therefore care providers in the state of Massachusetts are not required to hold Residents' Council meetings. Other states and countries should consider adding this requirement to the regulations governing SCUs of ALRs, if such requirement is not specified in their regulations.

As stated in the current regulations of ALRs in the state of Massachusetts:

“Every Resident of an Assisted Living Residence shall have the right to present grievances and recommended changes in policies, procedures, and services to the Sponsor, Manager or staff of the Assisted Living Residence, government officials, or any other person without restraint, interference, coercion, discrimination, or reprisal.”

* This manuscript is dedicated to the Assisted Living residents who participated in the reported Residents' Council meeting.

Note: All the names used in this manuscript are pseudonyms.

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Reference

Brod M, Stewart AL, Sands L, Walton P. (1999). Conceptualization and measurement of quality of life in dementia: the Dementia Quality of Life Instrument. *The Gerontologist*, 39(1), 25-35.