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Decision-making by couples when one spouse has dementia

People make many decisions each day, such as what and when to eat, what to wear, how to spend their time, how to spend their money. When one spouse of a married couple develops dementia, the other spouse not only continues as one of a couple, but also becomes a caregiver. The University of Bradford in Great Britain recently released preliminary findings of a research project that involved couples living with dementia, and how daily decision making was handled. Tim Takacs reports on this in the October 3, 2011 issue of Elder Law FAX (www.tn-elderlaw.com).

Dr. Geraldine Boyle and Katherine Ludwin, in collaboration with Dr. Lorna Warren from the University of Sheffield, have been following 24 couples since April, 2010. They wanted to better understand how couples, one of whom has dementia, make everyday decisions, and desired to identify the practical support that facilitates them making such decisions. They observed how these couples went about their daily routines, and how they chose to handle what each should wear or eat, how finances were managed, and if they decided to attend support groups, senior centers, and any other programs.

The researchers found that people with dementia can still make many day to day decisions, and participate in their care. With the support of their partners, the person with dementia can continue to do so even as their conditions progresses. Some key preliminary findings include:

- Decision making patterns do not change for spouses in early stage dementia, that is, whoever always took the lead, continued to do so. Gradually, the spouse without dementia eventually takes over the role of lead decision maker. The couple works with whatever dynamic existed prior to a dementia diagnosis. For instance, men with dementia are more likely to continue taking the lead if that is what they always did.
- People with dementia like to continue to be involved in daily decision making, but may start looking to their spouse to aid them. Spouses of someone with dementia try to support the decision making process wherever it is feasible (e.g. continue to encourage the spouse with dementia to pay at the register when grocery shopping). However, sometimes one spouse will make a decision at a time that their partner can still make decisions if time is a factor, or there is a desire to reduce the perceived burden on the spouse with dementia.
- Complex decisions need to be handled sensitively, and need to be negotiated, such as whether to attend an Adult Day Care. Even people with advanced dementia can continue to be involved, communicating their likes and dislikes non-verbally.

Dr. Boyle, commenting on the findings, stated "It's important for people with dementia to be supported to allow them to make decisions where they are still able to. Having dementia does not mean you automatically lose your decision-making ability – this needs to be considered on a decision-by-decision basis. Professionals need to facilitate the involvement of people with dementia in decision-making as much as possible."

It appears that spouses of persons with dementia have already learned how to include their partners in decisions, and do so as long as they can. Support needs to be provided to assist the spouse without dementia in doing so long term.