

Living with dementia and making decisions

September 29 2011

People with dementia can still make decisions in their everyday lives and with support from partners can continue to do so as their condition advances. This is one of the preliminary findings of a two-year research project funded by the Economic and Social Research Council (ESRC) into how married couples living with dementia make decisions on a daily basis.

The study is investigating how couples make decisions over issues such as what to eat or wear, as well as how they make more complex decisions on who manages the finances, and whether or not to attend a day centre. The aim of the study is to identify the practical support that can help couples make these decisions.

Dr Geraldine Boyle and Dr Katherine Ludwin from Bradford University along with Dr Lorna Warren from the University of Sheffield research relates to people with early stage [dementia](#) to those with more advanced dementia. They have been spending time at home with the [couples](#), interviewing each partner and observing them as they go about their daily routines.

Dr Boyle comments: "It's important for people with dementia to be supported to allow them to make decisions where they're still able to. Having dementia doesn't 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."

Key preliminary findings include:

Patterns of decision-making are influenced by the couple's relationship before dementia. The partner who always took the lead will often continue to do this however in most cases the partner without dementia will eventually take over this role.

Gender has a crucial impact on decision-making. Men with dementia are more likely to continue to take the lead if they have always done so.

People with dementia still like to be involved in decision-making, but may look to their spouses for help with this process.

The spouses of people with dementia try to support them to make decisions. For example, the partner with dementia may still pay at the till if the couple do the shopping together.

Spouses may make decisions at times when their partners can still make these decisions. This can be down to factors such as time pressures and a desire to reduce the burden on their partners.

However, complex decisions such as whether to attend a day care centre can cause anxiety and these have to be negotiated and sensitively handled.

People with more advanced dementia can still communicate their likes or dislikes, through facial expressions and behaviour for example.

The study has also found that people with dementia may need encouragement to make decisions as well as the opportunity to make these decisions for themselves.

Dr Boyle concludes: "Because dementia is still quite a stigmatised

illness, those living with the condition are sensitive to other people's reactions to them. Their confidence can be quite fragile. It is important that they feel good about themselves and know that their views still matter."

Provided by Economic & Social Research Council

Citation: Living with dementia and making decisions (2011, September 29) retrieved 15 May 2024 from <https://medicalxpress.com/news/2011-09-dementia-decisions.html>

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