

87 **A STUDY TO EXPLORE THE EXPERIENCE OF ADVANCED CARE PLANNING AMONG FAMILY CAREGIVERS AND RELATIVES OF PEOPLE WITH ADVANCED DEMENTIA**

10.1136/bmjspcare-2011-000053.87

S Ashton<sup>1</sup>, B Roe<sup>2</sup>, B Jack<sup>2</sup>, B McClelland<sup>3</sup> <sup>1</sup>Liverpool John Moores University; <sup>2</sup>Edge Hill University; <sup>3</sup>Liverpool John Moores University

**Background** The North West NHS End of Life Care Initiative aims to improve the quality of care received by older people with dementia in care settings at the end of their lives. The implementation of advance care planning (ACP) by use of Gold Standards Framework was studied in one care home specialising in the care of people with advanced dementia.

**Aim** The purpose of this study was to gain an understanding of the experiences of family caregivers as proxy decision makers for a relative with advanced dementia at the end of life.

**Methods** Data were recorded using semi structured interviews from a self selecting convenience sample of 12 family relatives of residents with advanced dementia in a long term care setting. All respondents had been involved in proxy decision making relating to the care and treatment of their relative with advanced dementia.

**Results** Study participants describe ACP as a distressing but necessary activity. Knowledge of the person and the family dynamics was identified as an important factor before staff approach relatives about ACP. Study participants were able to give a good explanation of what was discussed during the completion of the ACP. This included management of pain, medical interventions and treatments and also nutrition and hydration needs.

**Conclusion** ACP is a relevant and useful activity to undertake with family carers. However the ethical burden 'to do the right thing' can contribute to the already distressed family carer and should therefore be supported by experienced and educated health professionals.