

Concurrent Session 4

ACP and Chronic Illness

79 **LETTER ON FUTURE CARE; AN INDIVIDUALISED DISEASE-SPECIFIC FUTURE CARE PLAN FOR PEOPLE WITH ALS**

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An individualised disease-specific letter expressing patient's wishes for their future care was offered to people with Amyotrophic Lateral Sclerosis (ALS) from 2001 to 2008. All patients attended a multidisciplinary ALS service where they were seen by a palliative physician. Each letter was developed in a process of drafting and revision over several consultations. The letter conformed with government and Catholic health guidelines on advance care planning. It rapidly developed into a tool to facilitate discussion and became known as the Letter on Future Care (LFC). Although individualised care planning is now the standard, an LFC is not known to be in use elsewhere. A series of studies was undertaken to evaluate the LFC, focussing initially on the carer's experience. Past carers were identified: 10 past carers where an LFC was written and 9 past carers where there was no LFC. Semi-structured interviews were held with each carer. Each was shown a sample LFC for consideration or as a memory prompt. Interviews were audio-taped, transcribed and analysed. Themes were extracted and characteristic quotes identified. A questionnaire was developed to elicit a critique of the LFC from a purposive sample of ALS health professionals including neurologists, palliative physicians and nurse specialists. Data were analysed. An expert panel was convened to develop Guidelines. In this presentation, we will examine the views of the carers, and the critique given by health professionals. We will examine the structure of sample LFCs. We will propose the Guidelines for comment and discuss prospective testing of this approach.