

Friday 12 March 2010

09:00-10:00

Advance Care Planning: for good or ill?

Dr Fiona Randall

Consultant in Palliative Medicine, Christchurch Hospital, Dorset

Mr David Ardron

Chair National Cancer Research Institute Consumer Liaison Group

Advance Care Planning (ACP) is a voluntary process of discussion about future care between a patient and a health care professional in advance of anticipated future loss of capacity, so that the patient's preferences may be known when capacity is later lost. The outcome of the discussion is recorded, if the patient so wishes, in an advance statement/advance care plan which informs best interests judgements about treatment and care (including location of care) when capacity is later lost. ACP is thus different from ordinary care planning.

But in ACP the patient has to contemplate much information (often unpleasant) about future illness scenarios - yet many of those scenarios will not actually occur. Regarding future treatment preferences, patients will need similar information as they would need to give or withhold consent. Emotional distress or trauma may result from contemplation of future illness scenarios, treatment possibilities, and ways of dying.

Patient and family may disagree about future preferences leading to conflict, but it is the patient's wishes which are sought and which will count in best interests judgements.

There is currently much political emphasis on the importance of patients dying in the place of their advance choice. But the questions on ACP documents refer to place of care (not death), and preferences change, so these documents may not accurately reflect a patient's last stated preference for place of death. The ACP process may lead to unrealistic expectations in terms of achieving place of death.

Patients' preferences change – if such changes are not recorded, the statement/plan will give misleading information.

Patients and professionals may not adequately understand the purpose and process of ACP and the important role that the advance statement/advance care plan will play in decision making once they lose capacity.

Dr Fiona Randall has been a Consultant in Palliative Medicine in an NHS Specialist Palliative Care Service since 1982. She has a special interest in health care ethics and in 2000 completed a philosophy PhD on the philosophy of palliative care.

Publications include "Palliative Care Ethics" 2nd Edition 1996, "The Philosophy of Palliative Care: critique and reconstruction" published in February 2006, both by Oxford University Press. A book on ethics in end of life care is in press.

She has been a member of the BMA and APM Ethics Committees. She was the APM's representative in discussions on the Mental Capacity Act and its Code of Practice. She has served on a research ethics committee.

She has been involved in compiling both The End of Life Care Programme and the RCP evidence-based guidance on Advance Care Planning, as well as the guidance on Advance Decisions to Refuse Treatment. She has clinical experience in these areas. Within her own acute hospital setting she is a member of the clinical ethics committee.

Mr David Ardron has worked widely in consumer affairs in lung cancer research now for five years. Both of his parents were cancer patients, his father with lung cancer and his mother with breast cancer. He is chair of the North Trent Cancer Research Network Consumer Research Panel and acting vice chair of the North Trent CN Patient Partnership Group. He is also a member of NCRI Lung Cancer Clinical Studies Group, and Chair of the NCRI Consumer Liaison Group. He was a member of the NCRI PET Scanning Research Strategic Planning Group. He sits on the trial management group for the MRC QUARTZ trial in Lung Cancer. He is interested in the practical role that local consumer research panels have to play in health research, and has been invited to describe the work of the North Trent Panel at many meetings and conferences. He engages in peer review, both for network cancer services, and national research applications. His background is in science teaching and computer literacy. He sits as a member of other National Cancer Initiatives including, NICE, NCIN, and the National Lung Data Audit.