

innovative approaches to improve the experience of dying. This project makes a start in meeting the challenge.

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END OF LIFE CARE FOR PEOPLE WITH DEMENTIA: THE CHALLENGE FOR SPECIALIST PALLIATIVE CARE

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Introduction There are 613 661 people with dementia in England, rising to over a million by 2030, an increase of 72%. They should have the same access to palliative care as others but many are not receiving it. Specialist palliative care (SPC) should consider how it can help to achieve a 'good death' for them.

Aims To examine the end of life care needs of people with dementia; to identify gaps in the provision of care and to develop a hospice strategy.

Methods A literature search identified issues in the care of people dying with dementia. Consultation with providers of care confirmed these findings. A focus group of bereaved carers provided insight into the experience of caring for someone dying of dementia. Models of care from other hospices were explored to generate ideas. Hospice teams were encouraged to share experience of caring for these patients.

Results Emerging issues were the risks associated with hospital admission; symptom burden; the emotional impact of decision making on families and uncertainty about the role of SPC. Effective communication; advance care planning; symptom assessment; recognition of dying and support for families were identified as essential for improving care.

Discussion A hospice strategy was developed, based on different levels of SPC. Most people with dementia need generalist palliative care, with SPC providing education and consultancy for professional carers. A practice development role with partnership working between the hospice and care providers is being explored. The hospice should also create a dementia friendly environment for people requiring its services.

Conclusion The increasing incidence of dementia and the inadequacy of palliative care provision challenges SPC to find