



Developing and supporting practice at the end of life

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Outline of Presentation

- Identifying the palliative care needs
- Aim of development role
- Approaches used
- Impact on practice

Dorothy House Hospice Care

- Specialist palliative care
- 500,000 population
- Community and hospice based services
- Age range 18+
- No charge for services
- Charity with 32% funding from NHS contracts/grants
- 90% cancer patients
- 10% organ failure and neurological conditions





People with a learning disability

Generally have:

- Poorer health than general population
- ↑co-morbidities with ↓life expectancy
- Unmet health & social care needs
- ↑need of palliative care
- Reliance on residential carers, support staff and family when faced with terminal illness



Implications for end of life care

- People with learning disabilities live in the community and rely on mainstream health services
- Staff in learning disability services are often not experienced in caring for dying people
- Palliative care services not necessarily experienced in caring for individuals with learning disabilities



Evidence and personal experience (Residential Homes & Supported Living)

- Services have policies for managing the 'dead body' but not for end of life or palliative care
- Policies or guidelines for bereavement support for service users and/or staff limited
- Staff pulled between the needs of the dying person and those of others in the home
- 'Supported living – not supported dying'
- Staff wanting to do their best – lacking confidence and skill in end of life conversations
- Asking the question – 'Can this person die at home?'
 - Support, resources, environment, alternatives?
- Findings mirror Todd (2005)



Aim of practice development role

- Supporting practitioners in developing end of life care
- Working with managers to support practice development initiatives
- Supporting implementation of theory to practice in end of life care priorities



How does it work?

- Contact made with provider organisations by phone and meeting arranged with most appropriate person usually the manager
- Information shared – development role and service provider
- Reflection on end of life care experiences within the service, learning opportunities identified and prioritised
- Manager decides which approach best fits what they would like to improve/achieve



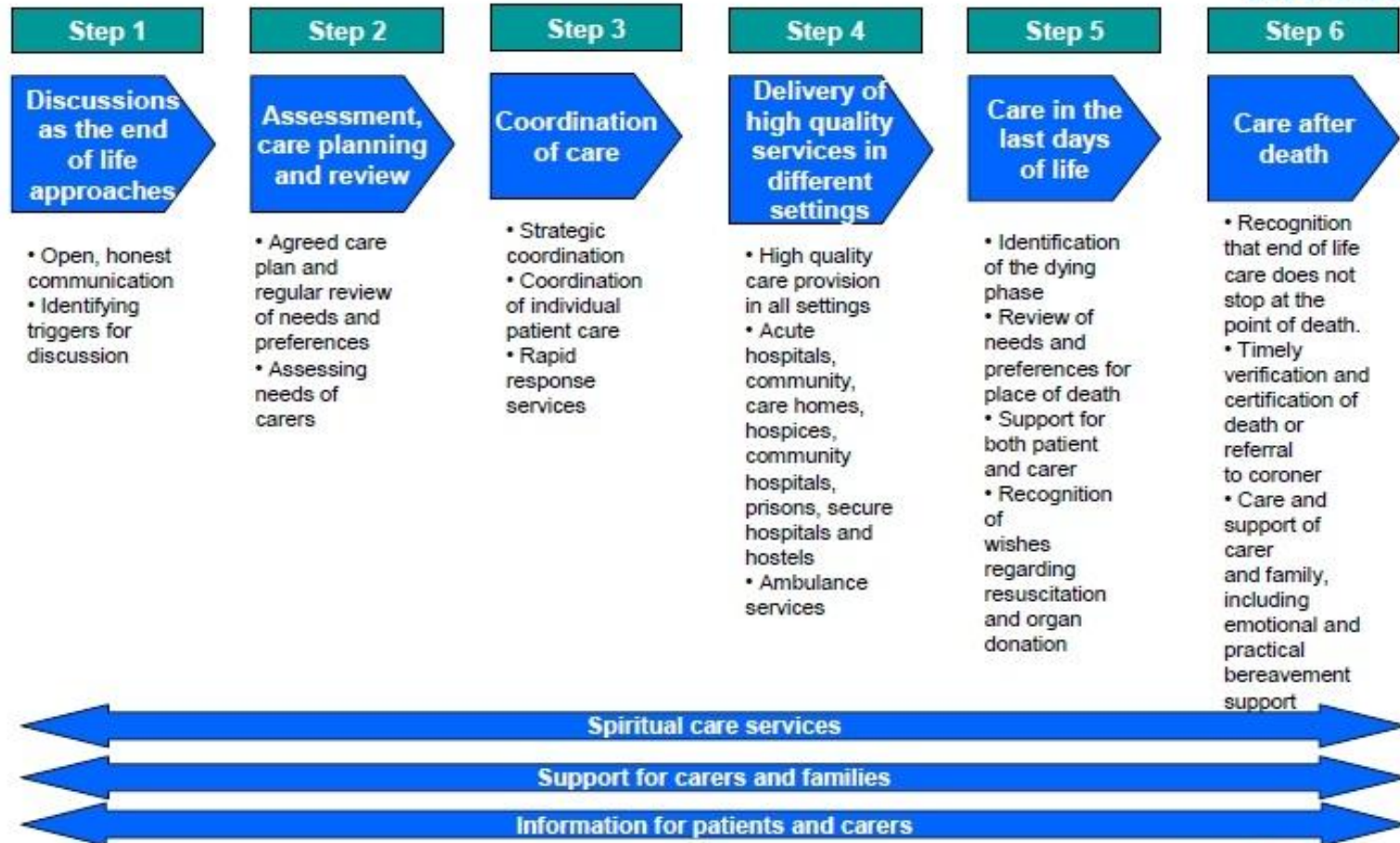
Which approach to use?

- Working with manager & key staff team with a 'one-off' session using person-centred thinking tools
- Working directly with group of managers from provider services over 12 months
- Regular sessions 4/6 weekly within practice environment over 6-12 months with manager & core group of staff

The end of life care pathway



End of Life Care

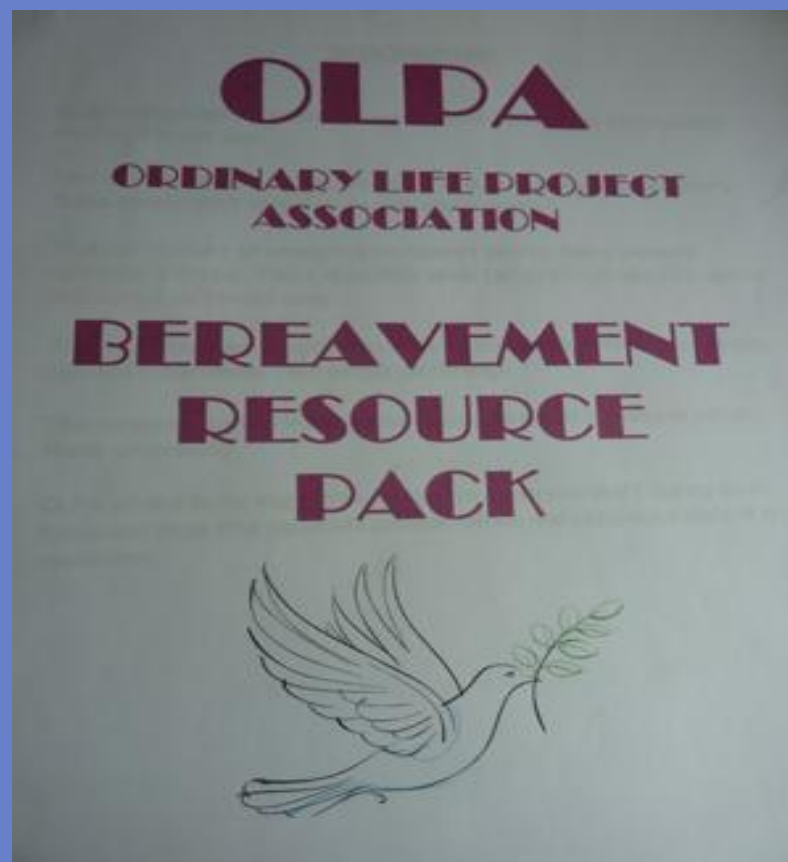
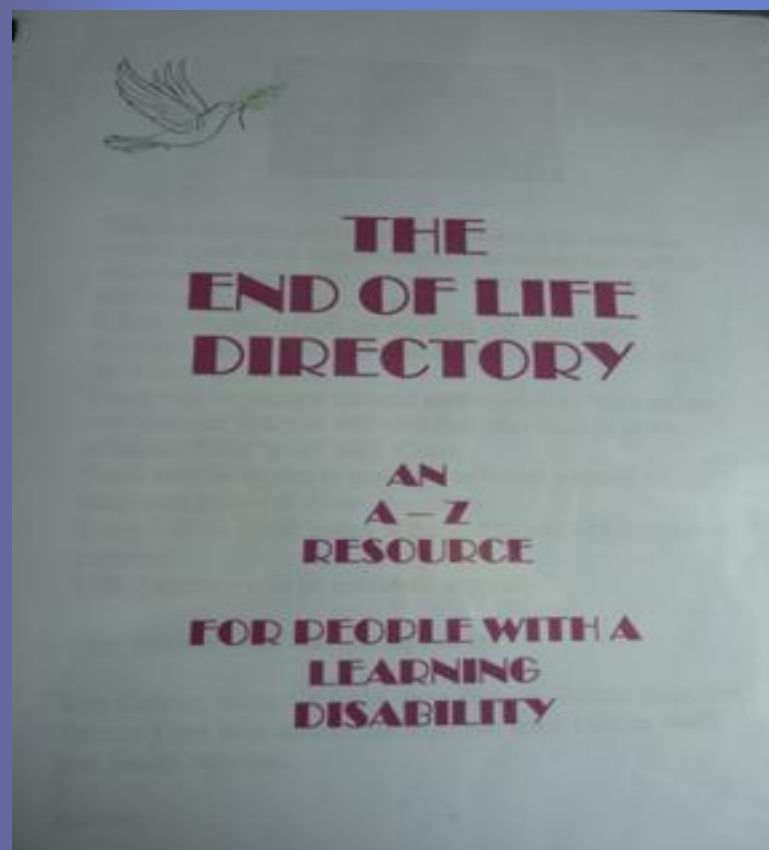




Why a key staff group with manager in a 'one-off' session?

- Approach identified by manager
- Usually a re-active response to a specific issue
- Addresses the immediacy of the situation
- Aims to capture higher numbers of staff
- Either full or half day
- Collaborative approach with CTPLD

Developments in practice managerial group



Examples of developments in practice manager and core group



Makaton, signs, symbols and pictures



An end of life plan

Examples of developments in practice manager and core group



In memory of a young man
who died suddenly



In memory of a resident who
loved cats and jigsaws



In memory of a resident who
loved roses

Developments in practice

Development of a 'hospital pack' containing the individual user's personal information regarding health and end of life wishes

- Improved communication between community and hospital
- Positive comments from GPs & families

A-Z End of Life Care Directory for people with learning disabilities leading to

- A bereavement resource for service users and staff
- Guidelines & policies now in place for palliative care
- Information regarding cultural, religious & ethnic groups
- Bereavement policy written and ratified

Person centred thinking days for staff to develop strategies for managing 'difficult' end of life situations by being proactive rather than reactive

- In one instance this enabled the team to support a client with complex needs to die at home and also enabled them to provide appropriate support to the other clients in the home

Development of 'end of life' tool to aid communication/conversations with clients about their end of life wishes


- Resulted in clear identification of one service user's funeral wishes which has been much appreciated by them and their family



Impact

Service provider choice & relevance of approach used has resulted in:

- Clear evidence of greater understanding of end of life care including development of policies
- Ability to talk with greater confidence and understanding of death & dying
- Topics which would have been taboo now talked about in a more free and informed way



Cultural and organisational changes in practice – hospice & HSCP

- 2 'speed dating' sessions held with over 40 MDT staff attending
- LD link/resource nurse within the IPU
- Increase in LD resources for hospice staff including accessible information
- Education/training for hospice and general health & social care professionals
- Accessible/easy read hospice information for LD service users

Developments in Practice



About Dorothy House Hospice Care

Easy Read



The Dorothy House Day Patient Unit

Easy Read



The Dorothy House In-Patient Unit

Easy Read

We would like to thank Sandra Wells,
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References and further reading

- A Life Like Any Other? *Joint Committee on Human Rights (2008)*
- Death by indifference: Following up the Treat me right! Report. *Mencap (2007)*
- End of Life Care Strategy. *Department of Health (2008)*
- Living and Dying with Dignity. *Mencap (2009)*
- Living Well: thinking and planning for the end of your life . *HSA (June 2010)*
- Healthcare for All. *Independent Inquiry (2008)*
- Person-centred thinking tools at end of life . *HAS (2010)*
- Six Lives. *Ombudsman (2009)*
- The Route to Success: achieving quality end of life care for people with learning disabilities. *National End of Life Care Programme (2011)*
- Todd, S (2005) Surprised endings: the dying of people with learning disabilities in residential services. *International Journal of Palliative Nursing* 11 (2) pp 80-82
- Treat me right! Better healthcare for people with a learning disability. *Mencap (2004)*
- Valuing People Now. *Department of Health (2009)*