



Improving public awareness of end of life issues among older people in North Lancashire: A peer education approach

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Background

- End of Life Care Strategy (DH 2008)
 - Public Awareness work
 - Dying Matters National Coalition
- Knowledge about public awareness – surveys indicate limited engagement with these issues
- Public health approach
- Previous studies
 - Peer education and older people
 - Understanding older people's perspectives
 - Revisions to educational resources
 - Development and piloting of peer education training



Aims and Objectives

Aim:

- To pilot a locally appropriate peer education programme on end of life issues for older adults;

Objectives

- To design a personal portfolio to hold individually tailored end of life resources and information;
- To undertake public end of life workshops for older members of the general public and their advocates;
- To identify future partnerships for ongoing end of life public awareness work.



Participatory Action Research

- Key principles
 - Working with
 - Incorporating different forms of knowledge
 - People's experiences
 - Practical impact
 - Bringing about a change
 - Both action and review



Approaches to action research

- First person inquiry
 - Looked at our own practice
- Second person inquiry
 - Engaged with others to share practices



User Involvement

- Integral to study
 - Designed and undertaken by Lancaster Peer Education group
 - Comprises members of general public , retired and/or active in working with older adults about issues of learning, plus researcher

Methods

- **Strand 1** (*1st person inquiry*):
Group worked to develop personal end of life information and resources portfolio
- **Strand 2** (*2nd person inquiry*):
Community workshops on end of life issues





Strand 1: Development of personal end of life information and resources portfolio

- Monthly meetings – September 2009 to March 2010 and ongoing
 - Record of meetings - notes
 - Personal reflections

Focus

- Examination of end of life issues faced by group members
 - Identification of appropriate sources of information and resources to address these
 - Review of resources and information
 - Design and development of portfolio to record personal information
- + preparation for community workshops





Strand 2: Development of a community workshop on end of life issues

- Two workshops
 - Older adults
 - Advocates
 - family members, paid care staff and other health and social care professionals and volunteers who support and work with older adults
- Preparation facilitated by external adviser Mary Mattheisen “Cumbria Conversations for Life”



Who attended?

- Older adults contacted via
 - local older and ageing networks (SLP/U3A)
 - personal contact
 - local press
 - NHS North Lancashire
- Advocates
 - via local services eg Alzheimer's Society, Help the Aged, Age Concern, local hospices, cancer support centres, carers' forums, hospitals, social services



Workshop Content

Three sections

- *What are some things to think about?*
- *How to begin planning*
- *How to talk about these issues*

Structure

- Personal stories
- Facilitated table discussions
- Feedback and wrap up

Ethical Considerations

- Consent
- Confidentiality
- Distress

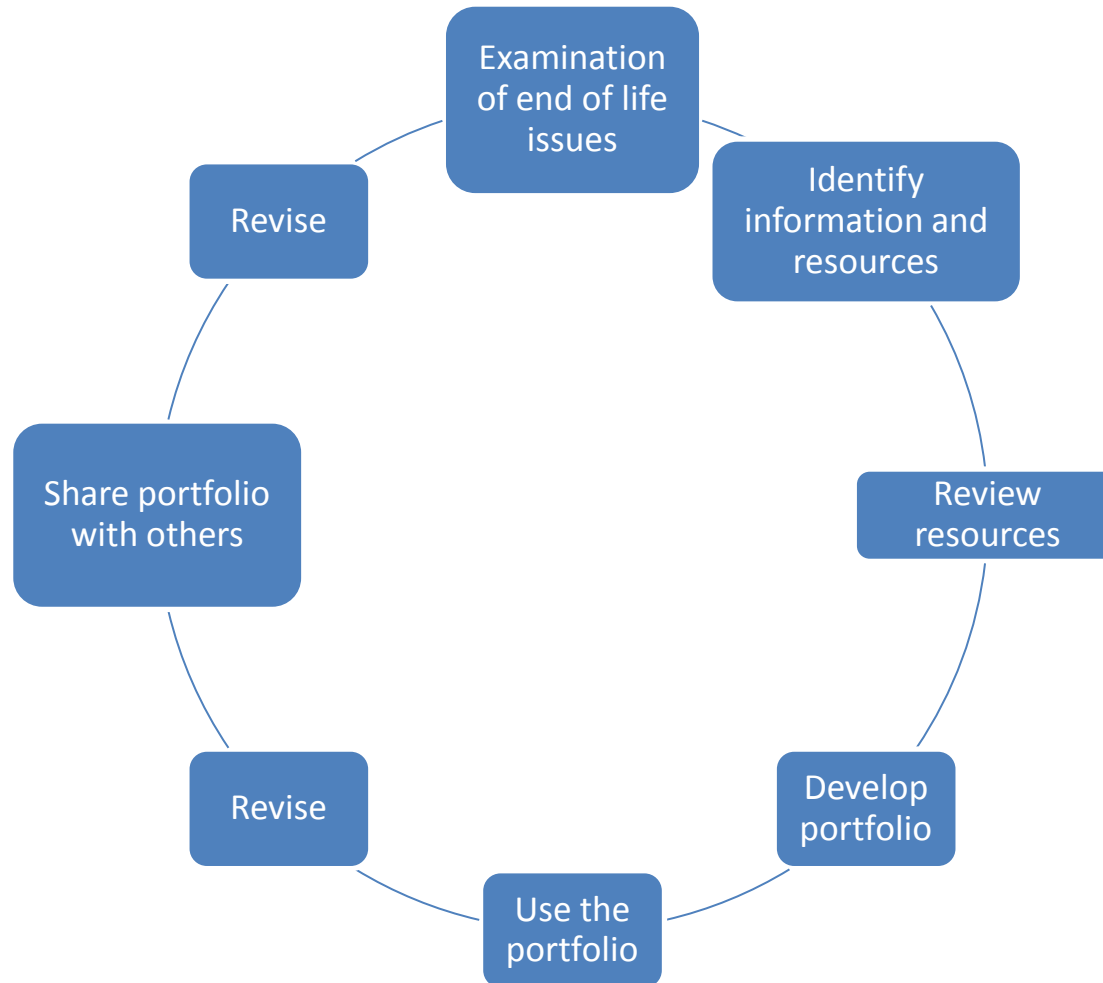


Findings

- Portfolio development
- Community Workshops



Process of portfolio development





A BIT OF HEAVEN FOR THE FEM? Journal of Palliative Care, 2009

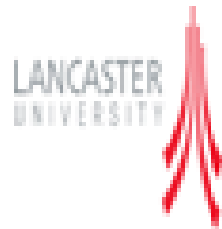


Looking to the Future

Creating a Personal Portfolio

Peer Education Group, International Observatory on End of Life Care, Lancaster University

April 2010





Looking to the Future portfolio

- Introduction to the Portfolio
- Who am I?
- Personal Details
- Life Contacts
- Health Information
- Important Documents
- How I want to be cared for now and in the future
- Anticipating Future Changes
- After I Die
- Further Information
- Resources
- Background

Design

- Loose leaf
- Sections can be omitted, completed and amended as required
- Electronic or hard copy
- NB. Not a legal document





Portfolio evaluation

- 8 workshop participants sent feedback.
- Overall positively reviewed
 - Clarity
 - Comprehensive
 - Identified as useful
- Helpful suggestions regarding format and content

Concerns

- Ensuring someone knows about it
- Safety of information
- Access to resources for people without *web* access
- Too much to address at once
- Different views re some sections eg ‘Who am I?’





Filling this in provides a useful focus to begin thinking of important issues

For anyone just starting to think about these issues I think it could be overwhelming

I have already begun this work for myself but will change to this format because it is clearer and more inclusive than my own

It has really spurred me on to talk to my parents about this

It's tiring trawling through all this stuff

Workshops

- Attended by 35 participants
- Workshop 1 – 21 participants
 - 18 women; 3 men
- Age
 - All participants were over 55 years old,
 - 17 (85%) over 65 years old
 - 7 (35%) over 75 years old
- Health status
 - 14 (76%) participants' health good, very good or excellent;
 - 7(24%) health was fair





- Workshop 2 – 14 participants
- 11 women; 3 men
- (1 older women)
- Hospital, hospice, care home and voluntary sector backgrounds
- Nurses, doctors, social workers

Evaluation

- Recognition of shared concerns
- Importance of doing this work
- Identification of practical ways to plan and talk to others
- Importance of timing





Issues raised

- Frameworks for advanced care planning
- Local resources
- Communication
- General information



Discussion (1)

- Public awareness work
 - Interest and need
 - Emotional work
- Portfolio
 - How to develop further
 - How to best communicate about it

Discussion (2)

- Community workshops
 - How to reach a broader population of older people
 - Are other ways of presenting these issues needed?
 - Going to people
 - Small group work
 - 1:1



Where next?

- Further engagement with PCT
 - Links with other regional initiatives – Conversations for Life
 - Series workshops 1x2 months
- Two part sessions
- External expert speakers
 - Discussions around portfolio development



Conclusion

- Met our aims and objectives
 - Piloted a local peer education initiative
 - Design a personal portfolio
 - Undertaken public end of life workshops
 - Identified future partnerships and further work

