

*Thinking and planning ahead:
learning from each other.*

A volunteer training programme about advance care planning

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(On behalf of the peer education project team)

Thanks to...

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- The Burdett Trust for Nursing/ Age UK
- Everyone in the Peer Education Project Team
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Setting the scene

- Changing demography: death at older ages, preceded by uncertainty / chronic disease/ often loss of, or fluctuating capacity
- The potential for 'advance care planning'¹ to aid transitions to palliative care
- Public awareness as a national priority (English End of Life Strategy – DH 2008)
- Many either do not wish or don't know how to talk- need for community initiatives
- Peer education: '*...sharing experiences and learning amongst people with something in common*' (Shiner 1999: 557)
- Peer education may aid attitudinal change at the community level

See:

National End of Life Care Programme (2011) *Capacity, Care Planning and Advance Care Planning: A Guide for Health and Social Care Staff*. NEOLCP: Leicester

Fried TR and Drickamer M. Garnering support for advance care planning. *JAMA*, 2010; 303(3): 269-270

Shiner M (1999) Defining peer education. *Journal of Adolescence*, 22, 555-566

Previous work – peer education training programme

- **Phase II of an action research project: development and implementation of a peer education training intervention to aid end of life care education¹**
- We worked with a core group of older adults already trained as volunteer educators (research partners)
- Developed a 3 day training programme to cover:
 - *Loss/ bereavement*
 - *Group dynamics*
 - *Communication/ listening skills*
 - *Peer education: conceptualising/ planning*
 - *Supporting self and others*
 - *ACP and related issues*
- 32 participants (24 older people, 8 staff)
- We used a range of teaching methods: *role play, narrative exchange, small group discussions, presentations.*

Based on previous research, first started in 2001

1. Seymour JE, Almack K, Kennedy S, and Froggatt K (2011) Peer education for advance care planning: volunteers' perspectives on training and community engagement activities. *Health Expectations*.
2. Clarke A and Seymour JE (2010) 'At the foot of a very long ladder': discussing the end of life with older people and informal caregivers. *Journal of Pain and Symptom Management*, 40(6): 857-869



Based on the principles of 'peer education'

- Peer education provides an alternative, or a complement, to 'expert' led education
- Can strengthen a sense of identity and encourage change by role modelling
- Can range from the structured to very informal
- Works by helping volunteers take 'ownership' of knowledge and use it according to their own purposes¹

¹See: Campbell C, MacPhail C. Peer education, gender and the development of critical consciousness: participatory HIV prevention by South African Youth. *Social Science and Medicine*. 2002; **55**: 331-45.

The community groups

- A 'Crossroads' Cancer and Palliative Team and their Bereavement Support Group –N England
- An umbrella organization comprising several self help groups-Midlands
- An African Caribbean Community Association in a city in Northern England
- A network of lesbian, gay and bisexual (LGB) older people living in various parts of England (London-Scarborough)
- A Seniors Forum in the North East of England.
- Senior Learners Group (NW England)

The volunteers

- 32 people recruited from the preliminary focus group study, sampled via community groups
- 24 'older' people; 8 community care staff
- 22 women, 10 men
- 8 under 55; 8 were 55- 64; 9 were 65-74; 3 were over 75
- 2 black British; 30 white British
- 17 rated their health as either 'excellent' or 'good'; 7 said their health was 'fair' or 'poor'

(not everyone agreed to give demographics)

Evaluation methods

Training

- Personal aims and concerns
- Evaluation forms and 'post it notes' end of each day

4 months

- Postal Questionnaire (24 respondents)

6 months

- Follow up workshop/ focus groups (20 participants)

12 months

- Interviews (12 with 25 participants)

Evaluative model: Äldreväst Sjuhärad (ÄVS) model

Equal access?	<p><i>We were a team. Everyone's views were important and listened to.</i></p> <p><i>There were people with different age ranges, different personal experiences, professional backgrounds, you know, it was a good cross section ... it was nice that people felt comfortable to share their experiences</i></p>
Enhanced awareness?	<p><i>It taught us new skills and reminded us of the importance of listening.</i></p> <p><i>... on a personal note, I too have taken notice of what I've learned from here, and I've made all my arrangements, such as if I have to go</i></p> <p>The majority of those who took part in the training programme reported increased knowledge and awareness</p>
Encourage action?	<p><i>What we've taken from (the course) on the end of life , we plan to incorporate in our work, it's great, absolutely</i></p> <p><i>We're very lucky to have got on that course really, and we just go from strength to strength I hope with it.</i></p>
Enable action?	<p><i>We would like the guide to become available to our peers and others. Some of us now feel confident to educate a group of our peers.</i></p> <p>Many had plans to implement peer education, either working in their communities or within their own family/ friendship groups. At one year, volunteers reported considerable personal impact.</p>

*... on a personal note, I too have taken notice of what I've learned from here, and I've made all my arrangements, such is if I have to go. As I progressively get worse I might later on, hopefully a lot later on, have to go in a home because I don't have next of kin. And I have been out to talk, write down exactly what I want to know, [how] I want it done, so that for me has been a good thing as well, because I wouldn't known nothing about it had I not comehere All I've got to do now is grow old gracefully **(older woman, six months after the programme).***

Outcomes: examples of volunteer educators' activities 1-2 years after training:

- Information and awareness raising events organised to encourage people to discuss advance care planning
- PCT funding to develop a resource portfolio
- Comic Relief funding for range of activities including awareness-raising for service providers delivering end of life care for older lesbians and gay men
- Articles written in local newsletters and newspapers.
- Those well embedded in a community group more likely to report success
- Some found it difficult in spite of efforts.
- Some had become ill or been bereaved: this stopped engagement, at least temporarily.

Two case studies

- *Older LGB group*

- began with their local support group, their friends and relatives
- extended to regional activities
- in 2010/11 won lottery funding to continue
- gained support from national and local agencies

- *Seniors forum*

- reported success in engaging at local level, because of direction of national policy
- then began to network nationally

Critical factors supporting peer education for ACP

- Social identity
- Critical consciousness
- Social capital

See: Campbell C, MacPhail C. Peer education, gender and the development of critical consciousness: participatory HIV prevention by South African Youth. *Social Science and Medicine*. 2002; **55**: 331-45.

Freire P. *The Pedagogy of the Oppressed*. London: Penguin, 1970/1993a

Seymour JE, Almack K, Kennedy S, and Froggatt K (2011) Peer education for advance care planning: volunteers' perspectives on training and community engagement activities. *Health Expectations*.

Social capital / social identity in action....

- *I'll be quite frank, I certainly wouldn't have got as involved as I am if I hadn't have done it (the training). ... after the last training day we had a meeting we said well okay we'll go and meet these people and see what they're doing ... So we went and saw the hospice. We went and saw the PCT [Primary Health Care Trust]. We went and saw the Council. ... We literally pressed our PCT to get an (end-of-life care) strategy together ..; we said ...we're going to hold an information day and we will invite them to come and talk. So it pressurised them into having to have something ready **(Older volunteer, male, 12 months after the programme)**.*

And for a staff volunteer....

Before it always felt like a major topic, you know Oh how am I going to raise this? ... it [has] made it seem like something more natural to talk about, not to feel so awkward about discussing end-of-life matters and decisions ... so that was really helpful (Female staff volunteer, 12 months after the programme).

Limitations

- A self-selected group of volunteers
- The evaluation of the programme depends on self-report data
- We don't know how peer education activities are received by peers (except anedotally)
- We need some more funding to study outcomes of peer education in communities

Aims of the revised training programme:

- To provide a means of raising public, user and professional awareness of ACP issues
- To enable dissemination of key messages via peer networks
- To provide **freely available package for use by facilitators in** community groups/ health and social care
- **Can be accessed from:**

<http://www.endoflifecareforadults.nhs.uk/education-and-training/acp-for-volunteers>

Training Programme Objectives

- To enable sharing and development of understanding of key issues in advance care planning
- To develop understanding of what volunteer education means and how individuals can work as volunteer educators
- To enhance awareness of issues about loss and communication and how these influence volunteer education
- To enable participants to facilitate volunteer group or one to one discussions about advance care planning
- To enable participants to identify and use appropriate resources to provide information about advance care planning to others



What's in the training programme?

Resource pack includes:

- Guide for trainers – planning the training programme
- Outlines and materials for four 'modules':
 - Guidance notes for delivery of each module
 - Presentations
 - Training activities – guidelines, notes, handouts
 - Evaluation sheets
- Advance care planning resource list

Four flexible modules:

1. **Learning from each other:** understanding peer education
2. **Supporting ourselves and others:** understanding loss, grief and bereavement
3. **Advance care planning:** What it means and how to do it
4. **Putting it into practice:** understanding group dynamics, facilitation of groups and communication skills

Example module 1

Sections	Time needed	Content	Activity	Resources required	Outcome
1 Introductions and practical information	10 minutes	Welcome and brief housekeeping presentation; introduction to facilitators and timetable	Presentation by facilitators	Pre-programme information booklet	Participants feel welcome and comfortable; introduced to the facilitators and timetable; provided with health and safety information
2 Review of objectives for whole training programme	15 minutes	Clarification of the objectives / style of the training programme	Presentation by facilitator; time for questions	PowerPoint Slide 1 - Section 2, Handout with objectives for Module 1	Participants understand the purpose of the training programme and its style
3 Getting to know each other	30-40 minutes depending on numbers (3 minutes each)	Participants have an opportunity to be introduced to each other	Ice breaker exercise in pairs and presentation to whole group	PowerPoint Slide 1 - Section 3	Participants are introduced to other participants and appreciate diversity of the group. Facilitators gain insight into each person's background and understanding of ACP.
4 Ways of working	30 minutes	Participatory exercise to establish ground rules of the training	Whole group exercise and discussion	PowerPoint Slides A, B and C - Section 4, flip chart, pens	Participants develop and agree group norms
Break					

You'll need to factor in time for breaks.
We've suggested a time, but you'll need to be guided by the group.

Booklet

Module **1**
Learning from each other:
Understanding Peer Education

Suggested Timetable - approximately 4 hours + break

Sections	Time needed	Content	Activity	Resources required	Outcome
5 Individual expectations	45 minutes	Participants explore and discuss their expectations of training and share their worries about working with peers	Post it notes activity in pairs	Coloured index cards or pieces of paper: two different colours	Participants share their Individual expectations and concerns; facilitators gain in sight into training needs
6 The role of a volunteer educator	45 minutes - 1 hour	Clarify what being a peer educator means and the range of activities/ modes possible with application to advance care planning	Interactive discussion/ participatory exercise	Handout - Section 6, wall charts, pre-prepared cards	Participants understand the range of activities within 'volunteer education' and begin to identify their preferred modes of volunteer education
7 Feelings about being a volunteer educator	45 minutes	Participants explore feelings about the role of a volunteer educator and identify core values	Small group discussion (3-4 participants)	PowerPoint Slide 1 - Section 7, Handout - Section 7, flip chart, paper and pens	Participants examine their feelings and concerns about volunteer education and articulate key values in the approach
8 Recap, evaluation and preparation for the next module	15 minutes	Participants recap, evaluate module 1 and receive information about Module 2	Completion of evaluation forms and post it notes. Facilitator provides information	Handout - Objectives Module 1, evaluation form (available in appendices), post it notes and pens, contact list of all participants (with their permission), information for Module 2	Participants have an opportunity recap and to provide feedback on module 1 and receive necessary information about the next module

What do we know about use, since publication ?

- We know of use in London, Midlands, Devon
- Facilitators tend to have palliative care backgrounds and are trainers
- They have used the evaluation model/ materials
- Providing valuable insights into what works / how to recruit/ support requirements

‘Participants said they felt like pioneers’ ¹

- Seems to enable difficult questions to be raised in a safe environment: *resuscitation, myths about EOLC, use of painkillers*
- Volunteers do very different things
- Volunteers want to keep meeting and need support
- Programme helpful and can be adapted to local contexts

1. *Facilitator involved in training hospice volunteers, gained co funding with AGED UK to run several courses*

One case study

- London based facilitator
- One course run March 2011, funding for another gained
- Recruited 34 people across 5 boroughs in London. 32 completed the course (aged 17-65).
- Evaluation on-going

Since then

- **Total conversations people have had about end of life = 433**
- **Total conversations specifically about ACP = 234**
- One participant is a volunteer at a GP surgery – GP referred two patients to her
- One participant wrote an article for the national heart failure magazine
- In Haringey, one participant talked to a pensioner group and wrote up an article for their newsletter
- **New funding** to deliver the training to 30 volunteers and for the volunteers to be attached to GP practices

Difficulties, challenges and unanswered questions.....

- Labour intensive
- How to provide on-going support
- Not always easy for volunteers to sustain involvement post-training
- How to enable use of volunteers' input in their organisations/ social groups
- To what extent is monitoring required? (accuracy of what volunteers are saying/ doing)
- Where volunteers have contact with 'patients', issues about confidentiality and insurance need to be addressed
- Cost effectiveness?

Thank you

