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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• Critical readers from NCPC and the peer education volunteers
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
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 education
- 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**

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 purposes

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? | We were a team. Everyone’s views were important and listened to. 

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 |
| Enhanced awareness? | It taught us new skills and reminded us of the importance of listening. 

… 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 

The majority of those who took part in the training programme reported increased knowledge and awareness |
| Encourage action? | What we’ve taken from (the course) on the end of life, we plan to incorporate in our work, it’s great, absolutely 

We’re very lucky to have got on that course really, and we just go from strength to strength I hope with it. |
| Enable action? | 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. 

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. |
... 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 come ....here 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


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

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

| Break |

**Suggested Timetable - approximately 4 hours + break**

We've suggested a time, but you'll need to factor in time for breaks.
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<tr>
<td>5 Individual expectations</td>
<td>45 minutes</td>
<td>Participants explore and discuss their expectations of training and share their worries about working with peers</td>
<td>Post it notes activity in pairs</td>
<td>Coloured index cards or pieces of paper: two different colours</td>
<td>Participants share their individual expectations and concerns; facilitators gain insight into training needs</td>
</tr>
<tr>
<td>6 The role of a volunteer educator</td>
<td>45 minutes</td>
<td>Clarify what being a peer educator means and the range of activities/modes possible with application to advance care planning</td>
<td>Interactive discussion/participatory exercise</td>
<td>Handout - Section 6, wall charts, pre-prepared cards</td>
<td>Participants understand the range of activities within 'volunteer education' and begin to identify their preferred modes of volunteer education</td>
</tr>
<tr>
<td>7 Feelings about being a volunteer educator</td>
<td>45 minutes</td>
<td>Participants explore feelings about the role of a volunteer educator and identify core values</td>
<td>Small group discussion (3-4 participants)</td>
<td>PowerPoint Slide 1 - Section 7, Handout - Section 7, flip chart, paper and pens</td>
<td>Participants examine their feelings and concerns about volunteer education and articulate key values in the approach</td>
</tr>
<tr>
<td>8 Recap, evaluation and preparation for the next module</td>
<td>15 minutes</td>
<td>Participants recap, evaluate module 1 and receive information about Module 2</td>
<td>Completion of evaluation forms and post it notes. Facilitator provides information</td>
<td>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</td>
<td>Participants have an opportunity recap and to provide feedback on module 1 and receive necessary information about the next module</td>
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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’

• 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