Supporting carers in end of life care: an introductory programme for support workers and volunteers

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**31 individuals and 13 organisations participating in pilot**

1 Age UK Notts, 2 Rowcroft Hospice, 3 Carers Federation
Background to the project

- Carers have little prior knowledge or training
- Few services provide 24/7 care
- Caring in the context of multiple morbidity or incontinence largely ignored
- Carers have their own needs; they may not feel able to express/address these
- There is almost no research into the practical education needs of carers, or the best way to meet them
Influenced by exploratory qualitative research

A woman in her late 60s reflecting on the impact of caring for her mother, who died of cancer. She looked after her mother more or less single handed for many months:

The GP who was very nice came to see my mother not long before she died, and he looked at me and he said “Oh you do look tired”. I thought yeah. And then he said “Couldn’t you get one of the younger neighbours to sort of spend a night so that you can get a good night’s sleep”. And I just looked at him and said “I am the younger neighbour, my neighbours are in their 80s”. (Bereaved daughter)

A woman in her 70s who needed a replacement hip joint, but delayed admission to hospital because of her husband’s illness:

I put my health needs on hold ... I thought I can’t cope with my husband’s sort of deteriorating condition ... and the possible after effects of the particular surgery I might have had... And obviously tiredness is one of the things that really hits you, and actually after my husband died I just had one illness after another. (Widow)
Our project aims

• To develop and pilot a training programme for volunteers and support workers who help carers providing home based end of life care.

• To develop an associated resource pack to facilitate discussion in each individual case of what support is most appropriate.
The ‘Supporting Carers’ training programme

• Free to use (registration form)
• Seeks to provide volunteers/support workers with basic skills and knowledge to support family carers
• Can be adapted to local needs/context
• Needs research about transfer of learning to/impact on practice
Participatory action research

People affected by an issue produce and use knowledge about it:
• Collaborative
• Acknowledges expertise of different types
• Patient and public involvement (PPI)

Available at www.qualitative-research.net
Training design issues/ imperatives

• A one day introductory course
• Evidence based
  CSNAT (breadth of carer needs explored).
  Learning theory (learners needs considered).
• Concise pre-course reading
  (overview of topic, FAQs).
• Flexibility (for variable use to meet organisation’s own needs).
• Evaluation of the materials (course piloted with different groups).
• ‘Real world’ using case studies and film
• Sustainable/ transferable
  -Training package with full teacher notes
  -Possible to be delivered by anyone with teaching experience- co learning.
Developing the resource pack

43 possible resources identified

• Reviewed by research partners, research team, carer support workers

• Whittled down to 10

• Included in trainee workbook
Developing the training programme

• What needed to be in it?
• Two workshops: 9 people, 3 organisations
• Informed by Carer Support Needs Assessment Tool ©
• Consultation with partner organisation:
  5 days became 4...
  became 2...
  became 1
Substantive content

Topics covered include:

• The principles of supporting
• Diversity of carers’ support needs
• The well-being of supporters
• Need for boundaries and exit strategy
• Resource pack
The principles of supporting

– The supporter is someone who will listen.
– The supporter will have an awareness of the palliative approach to care.
– The supporter appreciates the wider context of ‘caring’ and recognises that carers may have a variety of responsibilities.
– The supporter understands that they are part of a larger team of people involved in supporting the carer and the cared for.
– The supporter will be self-aware of their knowledge and skills.
– The supporter and carer are clear about the supporter’s role and that the relationship is constrained by professional boundaries and contractual obligations.
– Supporters work within the scope of their own organisation’s policies and procedures.
Teaching methods

Varied:
• Quiz
• Discussions
• Case studies
• Small group/paired work
• Scenarios
• Individual planning
• Film clips of ‘real’ carers
Bill Noble - introduction to the training

http://www.nottingham.ac.uk/helm/dev/end_of_life/session_one/page_five.html
<table>
<thead>
<tr>
<th>Session</th>
<th>Title</th>
<th>Duration</th>
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<tbody>
<tr>
<td>1</td>
<td>Introduction and welcome</td>
<td>30 minutes</td>
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<tr>
<td>2</td>
<td>Caring and being cared for</td>
<td>1 hour</td>
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<td></td>
<td><strong>Break</strong></td>
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<tr>
<td>3</td>
<td>Supporting in practice</td>
<td>45 minutes</td>
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<td></td>
<td><strong>Lunch</strong></td>
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<td>4</td>
<td>Being a safe supporter</td>
<td>1 hour</td>
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<td></td>
<td><strong>Break</strong></td>
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<tr>
<td>5</td>
<td>The principles of supporting</td>
<td>30 minutes</td>
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<tr>
<td>6</td>
<td>Boundaries and exit strategies</td>
<td>30 minutes</td>
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<td></td>
<td><strong>Break</strong></td>
<td></td>
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<tr>
<td>7</td>
<td>Ongoing learning and development</td>
<td>45 minutes</td>
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Testing the programme

- **3 pilots**: 2 in Nottingham, 1 in Torquay
- **Trainees**: 31 people from 13 organisations
- **Trainers**: 4 people from 3 organisations
- **Rewrites and reviews** by Nottingham team
- **Critical readers** reviewed the final product, which was then produced as an ‘RLO’ (reusable learning object)
Evaluation

Pilot one

Pilot two

Pilot three

- The course has been interesting
- The course has been informative
- Ability to contribute to activities
- The course was the right length
- There was enough time allowed for each session
- Improved understanding of the subject matter
- The course was easy to understand
- There was enough time allowed for each session
- The workbook is clear and easy to understand

Stongly agree
Agree
Disagree
Stongly Disagree
Comments from trainees

What did you enjoy most:

‘Film clips, made the day real’ (Pilot 1)
‘Meeting other professionals and hearing their experiences and difficulties’ (Pilot 2)
‘Working together and feedback’ (Pilot 3)
‘I expected it to be depressing but it wasn’t’ (Pilot 2)

What did you enjoy least:

‘Would have liked more time to discuss – sometimes felt a little rushed’ (Pilot 1)
‘Struggled with understanding some of the language of the principles’ (Pilot 2)
‘Nothing, everything was great!’ (Pilot 3)
Role of research partners within the project

- Felt valued and safe
- We brought different experiences
- We brought how it felt to be a carer
- We had the opportunity for reflection
- The Video clips.
Since release online in Sept 2015…. 

• The programme has been accessed by 289 individuals from 108 organisations 

• We have submitted an outline bid for research about transfer of learning to practice:
  
  • How do trainers and organisations make use of the programme? 
  • What value do organisational stakeholders perceive as coming from the programme? 
  • How do trainees experience the training programme? 
  • What are the mechanisms by which the transfer of learning takes place from training programme to trainees’ work with family carers? 
  • What is the reported/potential impact on carers and patients of this transfer of learning and can hypotheses be developed about patient/carer outcomes for further study?
Thank you for listening!