End of Life Aid Skills for Everyone in Scotland

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Abstract: Families, friends and communities have an important role to play in providing informal support when someone is faced with deteriorating health, caring responsibilities, death or bereavement. However, people can lack the confidence, skills and opportunities to offer this support. Public education is an example of a public health approach to palliative care that can help to develop individual skills and knowledge relating to these issues. In Scotland, the Scottish Partnership for Palliative Care (SPPC) has developed a new public education course called End of Life Aid Skills for Everyone (EASE) which aims to enable people to be more comfortable and confident supporting family/community members with issues they face during dying, death and bereavement. The aim was to design a course that imparts knowledge and skills while supporting development of social networks and avoids presenting professionals as the sole repository of expertise in the area of caring, dying and grieving. The intention was also to establish a sustainable delivery model that didn’t rely too heavily on busy palliative care specialists and which had the potential to bring the course to a diversity of communities. This article outlines the development of the EASE course, from conception to delivery.

Keywords: compassionate communities, death literacy, health-promoting palliative care, public education, public health palliative care

Introduction

When someone is facing serious illness, caring responsibilities, death or bereavement, support from family, neighbours, colleagues and communities can help people to cope. However, various factors can prevent people from offering informal support to others, for example, cultural norms (‘I don’t want to intrude’), lack of confidence (‘what if I say the wrong thing?’) or lack of opportunity (‘I’ve never spoken to my neighbour’).

There are also actions that individuals themselves can take to improve their experiences and assert more influence over their situation, for example, making plans and asking for help. But many people don’t realise that they have any control.

This lack of knowledge, experience, confidence and opportunity can cause problems and communities, families and friends can feel disempowered from fulfilling an essential role providing support to people who are ill, dying or bereaved.

Developing personal skills is one of the modes of action identified in the Ottawa Charter for Health Promotion, which provides a valuable framework for conceptualising and organising public health approaches to living with serious illness, dying and bereavement. Public education is one approach to developing personal skills and comes in many guises, with a range of aims, target audiences and delivery methods.

The modes of action within the Ottawa Charter can be mutually supportive. Public education and the development of personal skills is an important aspect of strengthening the mode of community action. This is not just because community
members may become better informed as a result of education. Rather in addition, depending on the approach adopted, public education has the potential to create and strengthen relationships and networks.

Public education courses about death, dying, loss and care
Recent years have seen an increase in the availability of courses for the general public relating to some aspect of death, dying, loss and care, and the positive response to these courses indicates that there is an appetite for education courses on these subjects. Although the potential sensitivity of the subject matter may bring particular challenges and considerations for course designers, indications are that there is nothing intrinsically off-putting about the subject matter and that people can find these courses useful and interesting.

However, Noonan et al. point out that public education courses can also have unintended consequences:

because death education programmes are typically not designed to mobilize networks or create social action they may actually promote compliance with the dominant medical approach by reinforcing the primacy of professional knowledge. As such these traditional models of education rarely recognize, mobilize or develop the existing knowledge within communities.

This article outlines how the development and delivery of the End of Life Aid Skills for Everyone (EASE) course has sought to recognise the potential to build and strengthen networks and relationships, alongside the primary aim of building individual skills and capacity.

Vision
Before beginning work on the development of the course itself, a small working group came together to consider the overall purpose and vision for the new course. Members of the working group gave their time voluntarily and brought with them experience of and expertise in course development, education, chaplaincy, bereavement support, general practice and palliative care nursing. Together the group identified the following key elements that would later set the scene for the design of the course.

Aims
The overarching aim of the course would be to enable people to be more comfortable and confident supporting family/community members with issues they face during dying, death and bereavement.

More specifically, the course would aim to enable people to:

- Be better equipped to provide informal support to friends, family and community members dealing with death, dying and bereavement.
- Find it easier to deal with these issues when they have to face them themselves.
- Know where to find further information and support in relation to these issues.

Target audience
The course would be aimed at anyone who wants to be able to support someone with issues they face relating to death, dying and bereavement. This was seen as likely to include

- People who are caring for family or friends whose health is deteriorating and who are likely to die.
- People who expect to soon be caring for family or friends experiencing declining
health and who are likely to be approaching the end of life.
- People who might not currently have caring responsibilities but who wish to be equipped to provide basic support for friends, family or community members who are either approaching the end of life or who are supporting someone who is.

The course is not aimed at children because that would likely require a different pedagogical approach, but it was agreed that there should be nothing within the course that would be intrinsically unsuitable for children.

**Ethos**
Health and social care professionals, funeral directors and other professionals play an essential and valuable role in supporting people with illness, dying and bereavement. However, within Scottish society, the medicalisation and institutionalisation of death and dying has contributed to the marginalisation of the lay/family role, and one of the motivations behind establishing the EASE course was the desire to empower the experience and expertise that lies in families and communities.

With this in mind, the working group was clear that the course should validate and recognise experience brought by the course participants themselves and not perpetuate the perception of doctors and nurses as the main ‘experts’ in this field. It was agreed that the course should not be ‘taught’, but rather ‘facilitated’, and that the Course Facilitators should not set themselves up as ‘experts’. The primary role of an EASE Course Facilitator would be to create a welcoming environment, facilitate group discussion, move the course along and ensure the course content is covered.

**Embracing diversity**
The SPPC is a national organisation that aims to serve the whole of Scotland. It was therefore important to create a course that could be of use to people from a diversity of backgrounds and experiences. There was a recognition that the make-up of the working group (mainly white, middle-class, middle-aged) presented challenges to this aim, but also that the work had to begin somewhere. Bearing in mind that real sustained efforts to encourage and support diversity would be required throughout the course of the project, the group set out to design a course that:
- Supported a range of learning styles.
- Could be delivered by facilitators from a range of backgrounds and experiences, for their own communities.
- Included opportunities for course participants to share experiences.

It was recognised that the course would therefore need to be structured in a way that has the potential to engage all kinds of audiences, and efforts made to find ways of making the course appealing, relevant and accessible to disadvantaged and excluded communities.

**Format and content**
There was endless scope for discussion about the best structure for the course – whether it should be delivered in a lunch-break, a day, a weekend, or over several weeks; and various conjecture relating to what kind of commitment potential course participants were likely to be able to make. In a sense there is no one right way to structure such a course – different structures are likely to appeal to different people, and have different advantages and disadvantages – and various different preferences were expressed by the working group.

After much discussion, it was agreed that the course should consist of four modules, each lasting around 2h. This should allow for flexibility with regard to how the course can be delivered. For example, people might wish to deliver the course as 2h per week for 4 weeks, or 2 modules over a morning/afternoon, or 4 modules over a weekend. Choosing this structure does not preclude further variations being developed in future, for example, creating a shorter introductory module, or of adding additional modules on other topics.

Similarly, there was a huge scope for discussion about exactly what content should be covered in the course. This to an extent would be determined by the structure – what could be covered in four 2h modules? Choices would have to be made about exactly what content to cover, and it was
agreed to do further exploratory work by reading relevant literature and finding out what people wanted to know (see below).

**Delivery model**

The SPPC aimed to establish a sustainable delivery model that would empower communities and not rely heavily on busy (and scarce) palliative care or other healthcare professionals. It aimed to do this by developing a network of local facilitators with a shared belief in this work, who are keen to support their local communities to become more connected and supportive around death, dying and bereavement.

SPPC would support these facilitators by providing them with the necessary training and resources to run EASE courses in their local area.

Based on the experiences of members of the working group, it was agreed that Course Facilitators should always work in pairs – so that there was always someone available to provide support if a participant became upset and also so that facilitators always had the support of a trusted colleague should they themselves feel in need of emotional support.

It was agreed that a group of around 15 people would work well for discussion and not be too big.

To become a Course Facilitator for the course, interested volunteers would have to complete a process of familiarisation with the course and its facilitation and become accredited by SPPC.

The plan was to develop an accompanying course leader manual/resource that could enable the course to be run by a broad range of people who might bring a variety of different relevant knowledge, skills and experience. Although facilitation skills would be essential, a background in end-of-life issues would not.

**Designing the course**

**Literature review**

A brief informal literature review was undertaken to get an indication of what topic areas were potentially of interest for a course of this kind. Areas highlighted by the literature included planning ahead; information about palliative care; the importance of a holistic approach; how to care for yourself if you’re a carer; the dying process; pain and symptom management; what to do after a death; bereavement; communication; and where to go for more information and support. Details of the literature included in the miniature literature review can be found in the Bibliography after the Reference section at the end of the article.

**Survey**

The literature review mainly provided insights into the views of professionals and professional organisations, and it was important to get the views of members of the public directly. A short questionnaire was designed, with the aim of finding out what people wanted to know about caring for someone at the end of life, to inform the design of the course.

A total of 208 responses were received. 80% (167) of responses were from people who had experience of informally supporting someone facing the end of life. 20% (42) of responses came from people who had never provided this kind of support.

Results reiterated the topic areas derived from the informal literature review and brought to light some additional areas that people wanted to know more about:

- How to navigate the health and social care landscape in Scotland.
- Information that would help them advocate for someone they were caring for.
- Information that would help them be more prepared, for example, issues that commonly arise towards the end of life, when to ask for help, and what to expect when someone has a particular condition.

**Learning outcomes**

Based on the findings of the survey and literature review, the following learning outcomes were developed:
Course topics

The aim was to develop a course that mapped to Level 4 of the Scottish Credit and Qualifications Framework. The ELDeR framework was used to facilitate a structured and systematic approach to course design. Based on the learning outcomes, the following topic outlines were initially developed for the four modules.

Module 1: An introduction to death in Scotland
- Different illnesses and trajectories of decline and where to get more information about these.
- Roles of different professionals and institutions.
- Rights and roles of individuals and carers. For example, what rights people have to access support or to refuse medical intervention, and the role of carers in advocating/making decisions.
- Expectations about symptoms, available support and navigating the system.
- Growing confidence and comfort in talking about death.

Module 2: Serious illness and frailty
- Some common situations in which individuals and families can find themselves when someone is seriously ill.
- The different things that people might find important towards the end of life – both medical and none medical – what is important to you? And that this can be different for different people.
- Communication skills – being self-aware if you are trying to support someone else.
- Planning ahead (including practical, medical and legal matters).
- Emotional issues that can affect someone who is dying.
- Emotional support and ‘being with’ someone who is dying.

Module 3: Realities of caring and dying
- Bodily changes towards the end of life.
- Common treatment and medications.
- Practical support a friend or family member can provide.
• Practical aspects of what to do after a death including funerals.

Module 4: Caring for the carer

• Issues that can affect carers.
• Where carers can get information/help and support.
• Supporting a carer as a friend, neighbour or colleague.
• Bereavement
• Self-care: how to look after yourself if you’re a carer.

Course materials
Course resources were developed on the above topics, with the aim being to use a variety of different types of activities that would appeal to a variety of learning styles. The creation of films and handouts allowed specialist and clinical topics to be covered credibly and consistently. Materials included the following:

• Short films where specialists share experience, information and knowledge on a range of topics.
• Group activities that enabled participants to work together and learn from each other.
• Written resources that people could take home and refer to at their leisure.
• Discussion groups to enable personal growth and reflection.

Some films and resources were sourced from the Internet; most were developed by SPPC bespoke for the EASE course.

The following resources were also developed to enable facilitators to confidently lead the course:

• A detailed course facilitator manual.
• PowerPoint slides to guide participants through the various aspects of the course.

COVID-19 and the development of EASE ONLINE

By March 2020, preparations were underway to begin delivering the EASE course in different locations across Scotland. However, it quickly became clear that the COVID-19 pandemic would prevent delivery of face-to-face courses for the foreseeable future.

Although the pandemic made it much harder to deliver EASE courses, it actually increased the need for such courses to be made available quickly. There was a need to develop a full online
version of the course which fulfilled the aims, vision and learning outcomes of the original EASE course, but which could be undertaken without face-to-face contact.

From the outset it was clear that this course couldn’t simply be put on a website, or delivered in a 2 h zoom session. There were several considerations to take into account, including:

- People would be undertaking the course at home, potentially alone and without access to their usual support networks. There was the need to ensure people felt supported as they addressed material that can be quite sensitive and emotional.
- Course content shouldn’t rely too heavily on reading ability in the absence of face-to-face facilitators.
- The original course was largely about interaction and group discussion – how could this be replicated while everyone was in separate locations?
- The need to create a course that would be engaging in the absence of group discussions.
- The need to meet the aims of the original course but in a virtual environment, including encouraging a sense of comfort and community among course participants.

Moodle was chosen as an online learning platform that could provide all the functionality the new ONLINE EASE course would require, including online group discussion forums, interactive quizzes, a modular structure and links to films.

A new course was built, taking advantage of the Moodle website functionality and designed to meet the original learning outcomes, but be sensitive to the virtual environment. The structure was altered slightly to achieve a balance of different types of activities each week. Additional films were made, and group discussion activities were adapted to become interactive self-reflection activities or topics for online forum discussions. Weekly hour-long zoom sessions were designed, to complement the Moodle sessions and bring course participants together as a community.

An expert in online learning at Edinburgh University was consulted and provided extremely positive feedback on the draft course. Learning was also gained from SPPC’s speedy development (in response to covid) of an online introduction to End of Life Issues for redeployed staff.

By signing up for EASE ONLINE, participants become part of a small group of around 10 others working through the course at the same time. It takes around 3 h per week, for 4 weeks, to complete the course.

**Building a network of EASE ONLINE facilitators**

The online EASE course was piloted in January–February 2021, with participants with an interest in becoming EASE facilitators in future.

Two pairs of newly accredited facilitators from the February cohort went on to deliver local EASE courses in June 2021 (Prince & Princess of Wales Hospice) and August 2021 (North Berwick Compassionate Community).

Initial indications are that the delivery model has the potential to work well. Feedback is being sought to refine and improve the process for supporting people to become EASE facilitators and run courses in their local areas. Plans are underway to run further EASE facilitator sessions, and in time to recruit a diversity of facilitators from a wide variety of communities. Funding is being sought to speed up and scale up the development and spread of the course.

**Evaluation**

Evaluation of the course has been built in to the EASE online Moodle course, through ‘pre-’ and ‘post-’ course questionnaires, asking people to ‘strongly agree’, ‘agree’, ‘neither agree nor disagree’, ‘disagree’ or ‘strongly disagree’ with the following statements (which were designed to correspond to the learning outcomes):

- I am aware of the common patterns of how people die in Scotland.
- I understand the roles different professionals and institutions play in supporting individuals and their families and carers towards the end of life.
- I feel confident taking part in discussions relating to death, dying and bereavement.
- I am aware of how people can plan to prepare for the end of life, and where I can get further information about this.
I am aware of some of the emotional responses someone who is dying might experience.

I am aware of how individuals and carers can have an influence on what happens when someone is dying.

I feel able to talk with people I know about planning ahead for the end of life.

I am aware of the common bodily changes that people often go through in the last days of life.

I know about the kind of treatments, equipment and medications that are commonly used by healthcare staff towards the end of someone’s life.

I feel able to offer practical support which will make a positive difference to someone who is dying.

I feel able to talk with and listen to someone who is dying in a way that will make a positive difference.

I am aware of some of the emotional and physical responses people can experience when caring for someone who is dying.

I am aware of some of the responses people can have to bereavement.

I feel able to offer practical support which will make a positive difference to someone who is supporting someone who is dying.

I feel able to talk with and listen to someone who is caring or who is bereaved in a way that will make a positive difference.

I can recognise when I need help and know how to access different kinds of help, information and support (relating to death, dying and bereavement).

Overall, I would feel comfortable and confident supporting people I know with issues they face during dying, death and bereavement.

The course also has weekly opportunities for participants to provide feedback on how they feel about the course, so course facilitators can respond in real time. SPPC plans to request permission to contact EASE participants a few years after they have completed the course, to find out whether the course is making a difference to them in the long term.

Although too early to be able to reflect meaningfully on the feedback from the course feedback questionnaires, indications from the pilots and from online course participants are overwhelmingly positive.

Online course
Facilitator Feedback:

the combination of film clips, written information, discussion board questions, and live facilitated conversations helped all 11 participants become more confident and comfortable in thinking and talking about dying, death and bereavement, which then helped them feel more confident and comfortable about the prospect of supporting themselves and others in their personal network with issues they may face at the end-of-life.

The EASE course has provided a unique opportunity for North Berwick Compassionate community volunteers to explore issues around death, dying and grief together as a group. It has helped to ensure that our compassionate neighbour volunteers are prepared and confident to engage in community conversations and offer support.

Participant Feedback:

I was struck by how quickly the group came together and the ease and openness that developed. The use of breakout rooms really helped and I liked having the opportunity to meet with everyone in smaller groups. The work between sessions was a good balance between information/video/personal reflection and in defined chunks, so you could take your time through the week to complete it.

The whole of Module 4 was beautifully and comprehensively crafted. I picked up some really useful (not EASE-specific) resources for our own work in Compassionate Communities, and for my own personal development. Thank you.

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The questions for the forum were well thought out and good follow ups to the course material presented. They were always very thought provoking and interesting and made me address issues and ideas I hadn’t previously and would probably not have if the course had not asked me to provide a written response. I also liked the signalling when the content may be upsetting, and the way that the course practice what it preached. For example, if you don’t feel able to watch this it’s ok, or take a break before watching video 2, or have a friend to speak to afterwards. Also, Caroline and Libby were
really great facilitators. They exuded warmth and professionalism and created and held a safe space for the discussions. I also like that they sometimes contributed to the forum discussions with their own personal experiences.

**Face-to-face pilot course**
- ‘I feel the course given was excellent’.
- ‘Very well managed and at all times sensitively handled without losing the focus on sharing the information in each module’.
- ‘The resources are very helpful and a booklet of them all would be great’.
- ‘Very relaxed friendly atmosphere. Non-judgemental’.
- ‘I gained lots of helpful information. I never felt pressured to participate in the discussions. The discussions were very helpful. I met some very nice people’.
- ‘Superb course’.
- ‘Well done and I really hope that this will roll out Scotland wide (I had to do a fair bit of travelling to get to Dundee but feel it was worth it!)’.
- ‘It was well thought out in terms of how each session was structured and how information was presented’.
- ‘I enjoyed it and found it to be well facilitated’.
- ‘Found course very helpful on both emotional and practical level’.

**Ongoing challenges**
So far, the vast majority of course feedback has been extremely positive, indicating the success of an initial design, piloting and revisions process which actively sought and addressed negative feedback.

However, ongoing feedback from course participants and engagement with facilitators has highlighted a number of ongoing challenges. Most of these are related to the virtual nature of the online course:
- A couple of participants have mentioned feeling unsettled after leaving the Zoom group meeting. Facilitators already stay online after the meeting has finished to chat to anyone who wants to talk further, and in response to this further feedback the online course now includes suggestions of optional ‘grounding’ exercises to help bring people to a positive mind-set before leaving the meeting.
- Some people find the online experience less energising than a face-to-face course. (This is a matter of personal preference, and it has also been highlighted that the online course has benefits in terms of flexibility and accessibility.)
- Technical issues and variable Internet signal occasionally mar experiences.

**Discussion**
Work on the EASE course has indicated that there is a real appetite for a course of this kind, as illustrated by the growing waiting list of those interested in doing the course and becoming facilitators.

The delivery model has been successful so far, with several organisations, including hospices, charities and community organisations, interested in becoming EASE facilitators. The willingness of experienced and busy professionals to volunteer their time to support SPPC develop, pilot and revise the course is a perfect illustration of the motivation and energy that exists within Scotland to make this model work. However, it is clear that sustaining this model will require ongoing commitment from the SPPC in order to maintain quality assurance, provide support to facilitators, promote the course more widely and ensure a good experience for participants.

However, the potential of this course is huge. For community groups and local charities, it can provide a ‘way in’ to reach new parts of their community. And reciprocally, the people who come along to the course can gain more than knowledge – they can become connected into wider networks and gain a sense of belonging.

The course values and empowers participants from the outset, involving participants in shaping course experiences, and with the flexibility to respond to the individual needs of each cohort. The ethos of the EASE course is one of peer learning and discussion. Each person who participates in the course brings with them their own unique life experiences – as well as learning from course materials, participants learn from each other.

A priority for the future development and rollout of the course is to ensure it is engaging, useful and accessible to people from a range of backgrounds and demographics. This will require concerted
efforts to involve diverse communities in delivering and developing the course.

EASE online was developed through necessity during the Covid-19 pandemic, but brings with it some advantages over the face-to-face course:

- People undertake most of the course in their own time, meaning that it is more accessible for some people with commitments such as work or caring responsibilities.
- For people living in remote or rural areas, or who find it difficult to leave the house, the online course presents a more accessible option than travelling to a specific location.
- People from various geographic locations can attend the same course, opening up more opportunities for people to attend courses – they don’t have to wait for one in their local area.

However, anecdotally many people have noted that face-to-face meetups provide a sense of connection and warmth that is hard to replicate via video-conferencing, and there is clearly still an important role for the original face-to-face EASE course. It is likely that in future SPPC will experiment with offering some online courses and some face-to-face courses, so people can choose the option that suits them best.

Author contributions
Rebecca M. Patterson: Conceptualization; Data curation; Formal analysis; Methodology; Project administration; Writing – original draft.
Caroline Gibb: Conceptualization; Data curation; Formal analysis; Methodology; Project administration; Writing – review & editing.
Mark A. Hazelwood: Conceptualization; Data curation; Formal analysis; Methodology; Project administration; Writing – review & editing.

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- Good Life, Good Death, Good Grief website (Scottish Partnership for Palliative Care)
- Marie Curie information for family and friends
- Enriching and improving experience framework (NHS Education for Scotland and Scottish Social Services Council)
- The last aid course – A Simple and Effective Concept to Teach the Public about Palliative Care and to Enhance the Public Discussion about Death and Dying (Bollig G and Heller A, Austin Palliative Care, October 2016)

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