AIIHPC

All Ireland Institute of
Hospice and Palliative Care

Report of the Community Learning Project

To identify and evaluate community learning needs in the context of Palliative Care and propose key components of an electronic learning package and supporting materials for local communities on the island of Ireland

All Ireland Institute of Hospice and Palliative Care
Report of the Community Learning Project

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EXECUTIVE SUMMARY

Background to and Outline of the Project

The purpose of the Palliative Care Community Learning Project was to identify and evaluate community learning needs in the context of palliative care and propose key components of learning resource for local communities on the island of Ireland. It was undertaken by principal researchers from The Carers Association with the support and cooperation of Carers Trust NI. The aim of the research, conducted in two distinct phases, was to produce recommendations for learning resources and delivery mechanisms. Recommendations are also made for content tailored to local communities and family carers.

Phase 1

Phase 1 comprised discussions with members of the community from various parts of the island of Ireland who also had experienced of palliative care due to their role as a family carers. A series of focus groups took place in the Republic of Ireland and the Northern Ireland, and attendees were invited to identify their needs related to improving their knowledge on issues related to information and/or training in palliative care, and to suggest how these needs might be addressed, including the use of online resources. The focus groups were supplemented by a series of seven one-on-one interviews conducted with healthcare professionals and palliative care recipients, who similarly shared their experiences of the palliative process and made recommendations regarding content for learning resources.

Phase 2

Phase 2 built on the information gathered from the focus groups and interviews. A working group was assembled which met three times for day-long sessions in which issues and suggestions arising from Phase 1 were discussed and further refined into recommendations for learning resources. The working group considered the use of the existing Palliative Hub Learning Platform (platform) and Adult and Public Palliative Hub (Hub) what could be successfully incorporated into an online Hub and Learning Platform and what suggestions might be rejected. Other existing international resources were also examined and reflected upon, which informed the final recommendations. As well as content, the formatting and presentation of a Hub were discussed, as were potential delivery mechanisms for informational or educational material. The final recommendations detailed below

under the headings of Adult and Public Palliative Hub, Delivery Mechanisms and Learning Platform Resources were a product of this process of refinement of material from the original focus groups.

ADULT AND PUBLIC PALLIATIVE HUB: RECOMMENDATIONS

Recommendations regarding content of the Hub were divided into those for the general public and those specifically aimed at individuals involved in the palliative care process, whether as carers or care recipients.

General Public

1. Palliative Care characterisation

The first main objective of the Adult and Public Palliative Hub should be to correct the common misperceptions about palliative care: first, that it is applied only toward the very end of life; and second, that it is synonymous with late-stage cancer care. The Hub will wish to convey the broader nature of palliative care, and the fact that its focus is on the quality of life of the care recipient. Specific recommendations are provided in the report. It is further recommended for Consortium Members from the wider palliative care community that, there be a harmonising of vocabulary and of definitions used in communications, literature and websites – for example, in the uses and definition of terms such as 'life-limiting illness'.

2. Hospice Care

A corollary to educating the public about the broad nature of palliative care is to provide accurate information on the nature of hospice care and the range of services it provides – correcting the impression that admission to a hospice occurs only at the very end of life, and that the sole function of a hospice is to provide for a comfortable death. It should be explained that hospice care can entail temporary admission for symptom management.

3. Attitudes towards Care Recipients and Carers

Members of the public accessing the Hub who are not involved in palliative care directly will, in most cases, know somebody involved in the process as either a carer or care recipient. With this in mind, in addition to general information, some material addressing the psychosocial aspects of care which can involve the larger social circle of carers and care recipients would be appropriate – what support one can offer, for example, or material on broaching the issue of palliative care.

Care Recipients and Carers

4. Available Services

A list, effectively a directory, of available services and supports for carers and care recipients was proposed by the Working Group. This would include information on, for example, Housing Adaptation Grants and Mobility Allowance Grants, but also information on which professionals might be involved in the palliative care process.

5. Rights and Entitlements

Details of what entitlements are available – for example, Carer's Allowance, Carer's Benefit, Respite Care Grant, Domiciliary Care Allowance, etc., can be dealt with through signposting to existing sites (e.g., welfare.ie, Citizens' Information, nidirect.gov.uk, or carersireland.org), but should be easily accessible and prominently displayed. While these existing sites will cover specifics, general, introductory information could be included on the Hub.

6. List of Symptoms and Symptom Management

A recommendation that came through the Working Group was for information on specific symptoms of illnesses and their treatment. Listing and describing symptoms is a matter of having people be aware of and so expect them; also information on how to manage them.

7. Question Checklist

A checklist of questions for carers or care recipients for putting either to a GP or to social workers in hospitals where patients might be admitted having suffered an episode of ill-health was identified as a valuable resource. These questions might cover subjects such as care in the home and available supports, as well as symptoms associated with specific conditions.

8. Glossary of Terms

A glossary of terms relating to palliative care was a recommended feature, with the qualifications that it be expansive (without being unnecessarily so, e.g., providing definitions of 'vomit', as the Australian Palliative Care Online Course glossary does) and that its language be nontechnical and accessible to laypersons.

9. Training and Support

Signposting to courses open to family carers for practical or further professional training will be an essential part of the Hub.

10. Peer Support Services

Engagement with peer support services – for example, carers groups or illness-specific support groups – is for many crucial in coming to terms with the palliative care process, and information on such supports ought to be easily attainable for visitors to the Hub.

11. Communication

The Hub, it was suggested ought to address the issues of communication – general advice such as that provided by the Canadian Virtual Hospice on talking to a parent was well received by the Working Group, and its potential benefits for those new to the palliative care process acknowledged.

12. Self-Care

The issue of carer burnout was to the fore in many focus groups. The importance of avoiding burnout and combating isolation through maintaining social connections was stressed, and material offering advice on managing it ought to be incorporated into the Hub.

13. Planning for Death

Issues surrounding the practical preparations for death have been adequately addressed on other sites (for example that of the Irish Hospice Foundation or Northern Ireland Hospice), and should be linked from the Hub.

14. Post-Death and Bereavement, Practicalities

It was suggested in focus groups and Working Group sessions that the Hub should address in some way the aftermath of the palliative care process for the carer. Matters surrounding post-death would include information on the grieving process, relating to friends and relatives of the deceased as well as other carers; whom to approach about counselling; practicalities such as organising funerals; wills and probate.

DELIVERY MECHANISMS

Delivery mechanisms for informational content were considered, and some recommendations put forward by the Working Group are listed below:

1. Interactive Component, Structure and Presentation

It was noted that interactive components tend to aid learning and recall of information by engaging the user. Incorporation of such components (into the Adult and Public Palliative Hub or the Learning Platform) was viewed as a positive by Working Group participants. Also discussed and recommended was the use of 'hover text' or 'mouse-over' for providing immediate definitions. It was further noted that some of the international resources examined were poorly formatted for Smartphones, and it was recommended that the AIIHPC in formatting the Hub be cognisant of this issue.

2. "Asked and Answered"

A prominent feature of the Canadian Virtual Hospice website – whereby a panel of experts archive answers to frequently asked questions – this was very well received by Working Group participants, and a comparable feature on the Adult and Public Palliative Hub was strongly recommended.

3. Discussion Forums

Moderated discussion forums, common on other sites and a feature of some of those examined in the Working Group sessions, were considered. The opinion of participants was strongly against incorporating such forums, as they must be maintained and moderated constantly, there is generally a surfeit of contributions through which one must go to get to useful information, and inactive threads tend to give a sense of general of desuetude or obsolescence to a site.

4. Offline Resources

Members of the focus groups highlighted the fact that many family carers were not regularly online, and suggested that hardcopy resources ought to be made available. The Working Group however demurred on this point, acknowledging that the content of an online Hub could not possibly be adequately reproduced in a hardcopy format of manageable size. One recommendation in this regard was to have all informational pages on the Hub easily printable. The content of any supporting or supplementary materials will naturally have to be deferred until after the launch of the Hub, and their content and channels of distribution will be a matter for AIIHPC consortium members.

LEARNING PLATFORM RESOURCES: RECOMMENDATIONS

The projected Palliative Hub will include elements of the Learning Platform aimed at family carers. The following suggestions as to content are in some cases developed from and considered a complement to those for the Adult and Public Palliative Hub, and in others are suggested via comparison with or adaptation from other existing international resources.

1. General Education about Palliative Care

General, interactive tools should be developed to educate the general public about palliative care and to counter common misperceptions about the process. Preliminary knowledge tests (such as the pre-test for the open palliative care course at Stanford University, or a Hospice IQ quiz developed by the HPH Hospice site) allow users to gauge how well their perceptions of palliative care tune with its realities. A 'Palliative Care Primer' quiz could be developed which served as an interactive guide for the layperson explaining the holistic nature of palliative care, and its physical, emotional, psychological, social and spiritual aspects.

2. An Interactive Component Detailing Illness Pathways

Typical illness pathways need to be part of education about palliative care. Greater discussion via interactive learning of the stages in typical illness disease pathways, as well as the types of illnesses for which palliative care is required, would better equip users with knowledge and aid them in managing expectations about an illness.

3. Public Awareness of and Attitudes to Care Recipients and Carers

Supplementary to Adult and Public Palliative Hub, Recommendation 3 above, develop a component for the general public addressing the questions of the realities of the palliative process and of how they can best support either a recipient of palliative care or a family carer. Some short video presentations could also be considered for the purposes of illustrating typical scenarios and advising on "dos and don'ts".

4. Pain and Other Symptom Management

An interactive learning tool dealing with pain and symptom management could valuably supplement the informational component suggested for the Adult and Public Palliative Hub (Recommendation 6 above). Helpful and highly regarded video suites relating to general patient care have been

produced, and the AIIHPC might consider tailoring such a suite to the typical problems and symptoms associated with the palliative care process.

5. Self-Care Checklist

Complementing the recommended informational material on the importance of self-care in the Adult and Public Palliative Hub (Recommendation 12), an interactive component containing practical instruction on self-care could be developed. The checklist would help those at risk of 'carer burnout' to self-identify as such, and should include appropriate advice on countering it or signposting for additional supports.

6. Dealing with anger and frustration and other common problems

A suite of videos aimed at family carers dealing with common palliative care scenarios would be welcome. It could be modelled on existing resources produced by the HSE or Stanford University, which are described and linked to in the report. The dramatization of scenarios which will be faced by most palliative care recipients and carers would serve an instructional purpose.

7. End of Life and a Good Death

Videos dealing with the issue of facing death, and helping oneself or someone else to accept it with equanimity can serve to emphasise the holistic nature of palliative care right up to the point when it becomes end-of-life care. The content of such videos can be developed in consultation with AIIHPC Consortium Members.

8. Palliative Care Scenarios

The Palliative Care Scenarios were found to be helpful in encouraging reflection on personal situations and highlighting issues involved in palliative care and, with further development, something similar could be incorporated into the Hub as a learning resource. The positive response to them in focus groups highlighted a preference for an element of engagement or storytelling in accessing information.

BACKGROUND TO AND OUTLINE OF THE PROJECT

The purpose of the Palliative Care Community Learning Project was to identify and evaluate community learning needs in the context of palliative care and propose key components of an learning resources for local communities on the island of Ireland.

The project was commissioned by the All Ireland Institute of Hospice and Palliative Care (AIIHPC). AIIHPC was formally established in October 2010, following a successful bid by the Consortium Members to secure funding for the organisation. AIIHPC reflects a broad range of expertise in the service delivery, academic preparation for and management of hospice and palliative care across the island of Ireland. Consortium Members and their organisations are experts in palliative care service planning and delivery, education and training, research and policy analysis. Through its collaborative approach, AIIHPC promotes strategic, evidence-based contributions to the policy/practice environment, North and South and, through a collaborative and comprehensive approach, delivers a better experience for patients and their families. The significant bulk of funding was from Atlantic Philanthropies, with further funding provided by the Health Research Board, the Irish Cancer Society, the Irish Hospice Foundation, the Public Health Agency and Consortium Members.

Tenders were invited for a programme of research to deliver recommendations to meet community learning needs in the content of palliative care and identify the most appropriate delivery mechanisms to meet these learning needs. The successful tender was from The Carers Association with the cooperation and support of Carers Trust Northern Ireland. The principal researchers were Diarmaid O'Sullivan and Paul O'Mahoney of The Carers Association.

The project was outlined as comprising two distinct phases. From the beginning the structure of the project aimed to ensure that all recommendations were "Carer-proofed", that is, that they had taken account of and taken shape in response to the experience of family carers or palliative care recipients.

Phase 1 comprised of discussions with members of the community from various parts of the island of Ireland who also had experienced of palliative care due to their role as a family carers. Carers were identified as an ideal cohort for the research, for having gone through the process of gathering information on palliative care and being in a position to advise on what knowledge gaps existed; the intention was to capture the carers' personal experience. Five Focus groups took place: three in the Republic of Ireland and two in Northern Ireland. In addition, seven one-to-one interviews were

conducted—six with healthcare professionals involved in different aspects of palliative care, and one with a palliative care recipient. The goal of the interviews was to take account of professional expertise and advice in final recommendations, and to gain from the perspective of an individual who had themselves, gone through the palliative care process. The principal researchers worked with Carers Trust NI in Northern Ireland and The Carers Association in the Republic of Ireland to coordinate the meetings; these organisations sourced participants for the focus groups and facilitated access to healthcare professionals and care recipients.

Phase 2 involved the assembly of a Working Group consisting of five family carers with experience providing palliative care, including four who had taken part in Phase 1 focus groups. This Working Group met three times in September 2014 for extensive, in-depth sessions, which facilitated the further processing of information and recommendations from the focus groups, and discussion of content and delivery mechanisms for the Hub. The Working Group also benefitted from the input of Anne Jacob, a coordinator of QQI Level 5 Training in Palliative Care from The Carers Association, and that of Karen Charnley from AIIHPC.

The progress of each phase is outlined in greater detail below.

PHASE 1

Focus Groups and Interviews

Five Focus groups met between July and August 2014; dates and locations of the focus groups were:

1. 09/07/14 (ROI) – Eastern Region
2. 15/07/14 (ROI) – Eastern Region
3. 01/08/14 (NI x 2) – Northern Region
4. 13/08/14 (ROI) - Mid West Region

Six one-to-one interviews with healthcare professionals, and one with a palliative care recipient, were conducted in the same period; the dates and locations were:

1. 15/07/14 Nurse in Cancer Support Centre (ROI)
2. 17/07/14 Respite Care Worker (ROI)
3. 23/07/14 Public Health Nurse (ROI)
4. 31/07/14 Senior Social Worker (Hospital) (NI)
5. 31/07/14 Palliative Care Recipient (NI)
6. 14/08/14 Nurse in Home Care Team (ROI)
7. 18/08/14 Senior Social Worker (Hospice) (NI)

Both the interviews and the focus groups followed the same format, described below. Participants, having had the purpose of the project explained to them, signed a consent form. Recordings of group sessions and interviews were made for the principal researchers' benefit, which are to be destroyed on completion of the project, and all contributors were guaranteed anonymity.

Structure of the Discussions

The settled-on focus of the discussion was the empowerment of family carers in a palliative care scenario; for this reason, the question of what constitutes empowerment formed the focus of the opening exercises.

The first exercise was a simple warm-up and introduction: participants are asked to 'unpack' the term 'empowerment', through suggesting words they would associate with a position of empowerment. This ensured a broad scope for the discussion, and aimed to get participants thinking in quite general terms, rather than immediately addressing the subject of caring. Issues raised in relation to suggested terms served as prompts for later questions. Having established a number of

terms associated with empowerment, participants were asked to refine the exercise and to suggest what, in their opinion, characterised an empowered carer and empowered care recipient.

The central exercise of the session focused on discussion of three Palliative Care Scenarios. These studies were designed as vignettes which illustrated aspects of three different palliative care pathways. (Those represented were based on a threefold division of pathways popular in the literature, each pathway exemplified by a particular illness: cancer, COPD and dementia.)[1] The scenarios were used in the first instance to facilitate a general and open discussion of issues surrounding palliative care, an approach considered preferable to asking participants to share directly their palliative care experience and thereby risking making them feel exposed or vulnerable. Participants could comment in general terms, or choose to respond to the scenarios with reference to their own experiences, which they frequently did. The different scenarios also encouraged discussion of different aspects of palliative care: for example, different illness trajectories, or problems specific to an illness as well as general issues surrounding obstacles encountered by both family carers and Care recipients. The Palliative Care Scenarios used are contained in Appendix 4.

Finally, participants were invited to share anything from their experiences with palliative care which they would wish to share with those new to the care process. In this stage, participants in the focus groups tended to feel comfortable enough in discussing their own experiences that they often elaborated on the specific difficulties they faced, and detailed the kind of information which, in retrospect, would have been very beneficial to them when first embarking on the care process (see Discussion Guide, Appendix 1).

Some Results of the Discussions

The factors which discussions identified as empowering a carer or care recipient can be reduced to three general categories: control, knowledge and support. These were suggested in the opening exercise by all groups. Other discussed factors - the maintenance of dignity or independence, comfort of the care recipient, the confidence and competence of the carer, or the avoidance of burnout – were typically discussed as dependent on these primary three. The three categories are naturally interrelated and reciprocally reinforcing: supports can be pursued and accessed only where they are known about; medical, social and other supports were often cited as the primary source of a carer's practical knowledge; and a feeling of control is possible only where the carer and care

[1] http://openi.nlm.nih.gov/detailedresult.php?img=2528206_copd0301-11-02&req=4 (accessed Oct. 2014)

recipient both feel the facts of the situation are known to them and they are not isolated or unsupported in dealing with it.

Discussions around the Palliative Care Scenarios tended to address both practicalities of the situation presented and their emotional or psychosocial aspects. Issues raised ranged from general remarks about wellbeing, available support or advised courses of action to specific observations based on aspects of the scenario, for example the situation and dynamic of a family.

Those categories to which one can reduce factors associated with empowerment traversed the two related areas of practical and psychosocial aspects of palliative care. Taking these discussions together with those in which the groups were invited to suggest advice for persons new to the caring process, allowed the researchers to isolate and present issues or points of interest to the subsequently assembled Working Group. Results from the focus groups and one-to-one interviews informed Phase 2 of the project. It was noticeable that there were not significant differences in responses or suggestions from focus groups in Northern Ireland and the Republic of Ireland. The input of palliative care professionals in both regions was helpful in bringing clarity about the operation of health services and where problems might lie, and particularly in emphasising aspects of the dying process such as spiritual concerns or reconciliation, and for frank discussions of what can or ought not to be expected of many carers caring for those with life-limiting illnesses.

PHASE 2

Working Group

The Working Group comprised five family carers, coordinated by the two principal researchers. The group met three times. East Leinster was chosen as a convenient location for meetings. Over the course of the Working Group's three sessions, the identified problems and knowledge gaps from the Focus groups were examined, along with suggested advice and potential delivery mechanisms, in order to refine the final recommendations for the content and form of the online Hub. The dates of the sessions were:

Session 1: 04/09/14

Session 2: 16/09/14

Session 3: 25/09/14

Session 1: 04/09/14

The first Working Group session began by recapping material from focus groups and issues raised by healthcare professionals, and laid the groundwork for the processing of information through to the final recommendations. As well as facilitating discussion about the content of recommendations, the researchers sought preliminary feedback in order to get an initial sense of how the participants thought an online Hub could best respond to carers' knowledge needs. Many of the problems facing family carers discussed in the focus groups came up again in the Working Group, with a greater focus on how these problems might be addressed in an online Hub.

It was agreed that there was low awareness among the public that palliative care is most effective with early intervention in the illness pathway. This led to the following question being raised: Even with better information available, how does one recognise or assess when one can or should access it?

The issue of raising palliative care awareness is necessarily tied up with the problematic issue of how to advise those in a vulnerable position. There are stages in the progression of an illness, and both parties, carer and care recipient – as one participant put it – may offer resistance to accepting the facts of the situation. For the recipient to accept care can be a cause of deep anxiety – a feeling that they have in some way capitulated. This is true of many types of care, but is exacerbated in the case of palliative care (and this is in part due to the mistaken assumptions among the public about palliative care dealing only with the last stages of life). Furthermore, the decline of a patient's health involves a sequence of losses, each of which may prompt a cycle of grieving; and the grieving process may be of different type or duration for different people. On the subject of grieving, it was emphasised that the Hub should address in some way the aftermath of the palliative care process for the carer – grieving, supports, counselling, and pragmatics such as wills, funerals, and advance care directives.

This primary difficulty of the misperception of palliative care was also related to the difficulty in identifying when care should be sought – a patient must have a good idea of what the various elements of palliative care entail in order to seek early intervention. Popularisation of the understanding of illnesses as "life-limiting" rather than "terminal", it was suggested, would go some way toward normalising palliative care in the public mind.

Early intervention was connected to the need to take stock of family resources – an early understanding and communication of what is going on, and where things are going; adaptability was an integral part of the process; both carer and care recipient have to adapt to a changing role. Palliative care is a *holistic* process – a journey, which takes cognisance of the physical, psychosocial and "spiritual" aspects of the individual.

Particularly noted was the importance, in any project promoting the awareness of a caring process, of drawing emphatic attention to the issue of carer burnout – it is almost inevitable where no supports or respite help is sought, and can lead to decline in mental health, social isolation, fatigue and depression.

In the light of these discussions, it was stressed by participants that presentation of the Hub is crucial: non-carers and family carers accessing the site must know immediately they are in an entirely trustworthy and professional place – in this regard it was suggested simply that, for example, logos from associate members ought to be prominently displayed in headings or sidebars.

Session 2: 16/09/14

Anne Jacob of The Carers Association addressed the second session Working Group until lunchtime, focussing on which carers and care recipients face in a presentation based on her QQI Level 5 Course on Palliative Care. General issues dealt with in the training were examined, with a focus on what would be appropriate to carry over into an online Hub. The course emphasised that palliative care was aimed at improving the quality of life of the care recipient: at maintaining dignity, self-esteem, privacy and respect, and a good quality of life retaining as much independence as possible. The presentation also dealt explicitly with other common issues, such as body image, which had not directly emerged in the focus groups; with treatments of symptoms by anxiety-relieving exercises; and extensively with the acceptance of death: with preparing for and achieving as far as possible "a good death", and with bereavement and grieving.

Schemata and graphics used in the course were well received by some members of the group. An example was the representation of palliative care aims – "Affirms Life"; "Promotes Quality of Life"; "Treats the Person"; "Supports the Family"— as branches of a tree. Some of the Group members were drawn to the image as they felt it offered a visual way of counteracting or moderating the impression of palliative care as concerned solely with managing decline, or a way of creating the impression that physical decline or difficulty could be compatible with growth in other respects.

Another example was the schema of the "Five Pillars" of palliative care – its focus on the physical, emotional, psychological, social and spiritual aspects of the person. Some felt the design – particularly as a shortcut to encapsulating the holistic nature of palliative care – could feed into a launching platform for information on the Hub. Attending to and reflecting on visual impressions and matters of presentation helped when focusing further on the issue of incorporating material into an online Hub. (See Appendix 6 for Image.)

The second half of the session discussed delivery mechanisms. In advance of the second session, the researchers had sent participants links to two websites and asked them to engage with certain features: the interactive Australian Palliative Care Guidelines Training programme, and features of the Canadian Virtual Hospice site.[2] Participants considered what was possible or appropriate for a one-way delivery system; whether features could transfer smoothly to an Irish context; the structure of sites for ease of access and navigation; and drawbacks or limitations of online tools. Suggestions concerning delivery mechanisms are dealt with in Section 5 below.

Session 3: 25/09/14

In the third Working Group session, Karen Charnley of the AIIHPC gave a presentation on the work and funding of the Institute, discussing the upcoming, inaugural Palliative Care Week (6th – 11th Oct. 2014) and the goals of the Hub. Group participants had the opportunity to discuss aspects of the Hub, and to view test versions of the Children's and Young People's Palliative Hub and the Learning Platform.

In the final afternoon session, the principal researchers presented to the Working Group with potential recommendations derived from the sessions; this facilitated a final "proofing" process and afforded carers the opportunity to make any further suggestions or to query the inclusion of any recommendation, and to do so with some intimation of the layout and hosting-potential of the Hub. A late suggestion offered on this occasion, which was received enthusiastically by other participants, was for the Professional, Academic and Research Palliative Hub and Learning Platform to link to the Adult and Public Palliative Hub in a way that encourages those engaged professionally in palliative care to get a sense of what family carers entering into the caring process might feel and experience.

[2] http://www.palliativecareonline.com/ (APC);
http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx (CVH) (accessed Oct. 2014)

The recommendations in Section 4 below grew out of the focus groups and were refined and proofed through the Working Group sessions. Some background to each recommendation, relating to knowledge gaps identified during the research process, is included. The recommendations are divided into those for the general public and those aimed more specifically at care recipients and carers.

ADULT AND PUBLIC PALLIATIVE HUB: RECOMMENDATIONS

The recommendations for the content of the online Hub reflect the suggestions of the carers who took part in focus groups and the Working Group. The separation of recommendations into those for the general public and those for palliative care recipients or their carers, itself reflects the opinion of group participants that the hub must serve a dual function and its structure therefore ought to be tiered. The tiered recommendations do not of course reflect an order of priority, only a move from the more general to the particular. The fact is that the majority of those consulting the Hub will have some immediately personally relevant reason for doing so: they will be directly involved in the palliative care process in some capacity, or will know somebody who is caring or receiving palliative care and will therefore be indirectly affected by and concerned with it. Dividing the recommendations simply reflects the different time and energy likely to be expended by people in these differing positions. A member of the public only indirectly concerned with palliative care will want general, immediately accessible and easily digestible information. Those directly involved in the palliative process will have broader and deeper concerns. Accordingly, the division of the recommendations reflects what should be aimed at the general public and so be "front and centre" or immediately accessible – and this includes recommendations, deriving from carers' testimonies, about how to approach a person undergoing palliative care – and what on the other hand can belong to another, deeper "level" of the Hub, and what one can reasonably expect concerned parties to do some "digging" for.

General Public

1. Palliative Care characterisation

The first main objective of the Adult and Public Palliative Hub should be to correct the common misperceptions about palliative care: first, that it is applied only toward the very end of life; and second, that it is synonymous with late-stage cancer care. The Hub will wish to convey the broader nature of palliative care, and the fact that its focus is on quality of life of the care recipient.

This emphasis is provided in the Palliative Care Week leaflets and posters and is clearly integral to AIIHPC's project of raising awareness of palliative care. Participants in the Working Group and prior focus groups agreed that this concern ought to be very much "front and centre" in the Adult and Public Palliative Hub. At the second Working Group session, Anne Jacob emphasised these aspects, remarking for example on what is at stake in palliative care: "it's about living until you die, not waiting for death"; or that: "palliative care affirms life, it doesn't hasten death". Speaking of the ideal initial reaction to the site of family carers or others seeking information on palliative care, the Working Group said the feeling should be: "This is for me; this is a place for me."

More concrete recommendations from the Group in this regard included:

- A listing and discussion of illnesses for which palliative care is commonly provided
- Prominence of the term "life-limiting illness" for reasons of clarity and accuracy as well as being a means of avoidance of "terminal illness"
- Some indication or discussion of illness pathways, and of how early palliative care intervention is most effective (the Working Group queried whether concrete guideline recommendations of any kind could be given in relation to specific illnesses)
- The importance of emphasising that their refusal of forms of care does not mean refusing palliative care – for example, declining aggressive or invasive chemotherapy with low odds of success does not entail refusing pain and symptom management or the psychosocial supports which the palliative care process offers
- In line with the broader nature of palliative care being emphasised, an explanation of how palliative care constitutes an ongoing process. A palliative care recipient often experiences continual, sometimes staggered loss: loss of mobility, fitness, continence, independence, opportunity to travel; also, financial loss and narrowing of a social circle. These are the realities of a care recipient's situation, and palliative care can offer support, medical or non-medical, in dealing with each stage.
- There was some dissatisfaction expressed with available definitions of palliative care or related terms; it was felt for example that "life-limiting" should be substituted for "life-threatening" in the standard WHO definition; while with the Irish Hospice Foundation's definition of a "life-limiting illness" in its 'Palliative Care for All' report (2008) as "Any illness where there is no reasonable hope of cure and from which the person will die", it was felt (in the words of participants) that a more accurate rendering would be "...and which will

contribute to the person's death"—often an illness such as dementia, Parkinson's or MND will contribute to but not directly cause death.

It is recommended for Consortium Members from the wider palliative care community that there be a harmonising of vocabulary and of definitions used in communications, literature and websites – for example, in the uses and definition of terms such as 'life-limiting illness'. This is one of the ways – minor in any given instance but cumulatively effective – in which professionals can take the lead in addressing common misperceptions about palliative care (this would naturally require agreed-upon definitions for major terms among member associations).

2. Hospice Care

A corollary to educating the public about the broad nature of palliative care is to provide accurate information on the nature of hospice care and the range of services it provides. Even those with a broader conception of palliative care are often under the impression that admission to a hospice occurs only at the very end of life, and that the sole function of a hospice is to provide for a comfortable death. It should be explained that hospices are not only for end-of-life care, but admissions can entail temporary admission for symptom management (not precluding multiple, irregular admissions), or the beginning of a process of palliative rehabilitation. Discussion or description of the in-hospice management of temporary illnesses or episodes can be supplemented by discussion of palliative rehabilitation, including the transitional or outpatient facilities available, for example in Our Lady's Hospice and Care Services, Dublin or Northern Ireland Hospice, Belfast.

3. Attitudes towards Carers and Care Recipients

Members of the public accessing the site who are not involved in palliative care directly will, in most cases, know somebody involved in the process as either a carer or care recipient. With this in mind, in addition to general information, some material addressing the psychosocial aspects of care which can involve the larger social circle of carers and care recipients would be appropriate. The focus group discussions brought to the fore the importance of attitudes of this wider circle toward those involved in palliative care, and how they can help. There may be a tendency, quite understandable, to "walk on eggshells" around someone involved in palliative care; and avoidance of the subject, which may be felt as an "elephant in the room", tends often to lead into avoidance of contact with the care recipient, either to avoid an uncomfortable situation, to "give them space", or out of worry of making some misstep in relation to them.

It was emphasised that practical advice on these matters for those who know care recipients or carers would be something participants in the focus groups would advocate for. Some common examples of such practical advice, which emerged repeatedly throughout focus groups in both the Republic of Ireland and Northern Ireland, include:

- The carer and care recipient remain individuals throughout the caring process. They should not be "lumped together" or considered as a single entity. Some participants recalled instances of people speaking to a carer in the presence of a care recipient about matters concerning the latter.
- Both also remain the person they were before the palliative process. Just as they should not be considered a single entity, neither should they be defined by their role or situation as "full-time carer" or "patient" or "sick person" on the other.
- Friends or acquaintances should be aware – that is, advised – of the supportive role to be played by the extended social circle. This may be in offering to give the carer a break for an afternoon, or simply in continuing to call around and maintain the ordinary routines that give shape and meaning to people's lives.

In this respect, in the second Working Group session, Anne Jacob introduced and discussed the "Five Pillars" of Palliative Care, each representing one aspect of the caring process – the *Physical; Emotional; Psychological; Social; Spiritual*. This schematisation was well received by the Working Group; and it is immediately notable that four of the five pillars primarily address psychosocial aspects of care. Participants in the Working Group reported that, while their initial concerns in the care process were invariably focused on medical or physical matters, they came to view the psychosocial aspects of care as ultimately more important than the medical. An awareness of this focus on the part of those associated with but not directly involved in palliative care, will encourage them to see how they can support a care recipient or carer.

Care Recipients and Carers

4. Available Services

A list, effectively a directory, of available services and supports for carers and care recipients would be helpful information. This would include information on, for example, Housing Adaptation Grants and Mobility Allowance Grants, but also information on which professionals might be involved in the palliative care process.

What came through strongly in discussions in focus groups was that carers can have very different experiences in their interactions with different healthcare professionals. Some reported excellent experiences with GPs, others with Public Health Nurses or Social Workers, while some found their chemist especially helpful—others found that in their case, for example, if not holding a medical card, a Public Health Nurse was not accessible.

A description of the role of each professional potentially involved in palliative care (in Northern Ireland and Republic of Ireland) –would provide helpful information in ascertaining what kind of services carers and care recipients might seek to access. Examples of such professionals would include the GP, Specialist Palliative Care teams, Public Health Nurse or District Nurse, Social Worker and Occupational Therapist.

5. Rights and Entitlements

Details of what entitlements are available – for example, Carer's Allowance, Carer's Benefit, Respite Care Grant, Domiciliary Care Allowance, etc., can be dealt with through signposting to existing sites (e.g., welfare.ie, Citizens' Information, nidirect.gov.uk, or carersireland.org), but should be easily accessible and prominently displayed. While these existing sites will cover specifics, general, introductory information could be included on the Hub. With respect to entitlements, opinion coming through the focus groups and Working Group sessions was very much in agreement that honesty about what can be accessed, about "the realities, not the formalities" of the care system, was essential. All participants noted they would advise those new to the palliative care process to manage their expectations. Examples of the realities situations should be clarified including that a person may have no statutory entitlements to many services (e.g. Housing Adaptation Grants or Mobility Allowance Grants in Republic of Ireland or Disabled Facilities Grant in Northern Ireland). Also in order to modify a house one may have to apply for planning permission, which can be a unforeseen cause of delays.

6. List of Symptoms and Symptom Management

A recommendation that came through the Working Group was information on specific symptoms of illnesses and their treatment. Listing and describing symptoms is a matter of having people be aware of and so expect them; also information on how to manage them. The Canadian Virtual Hospice

provides such a list and information on management – including dry/sore mouth; breathlessness; swallowing difficulties; constipation; diarrhoea; pain; nausea and vomiting; fatigue.[3]

It was discussed in the second Working Group session with Anne Jacob that alternative treatments can be productive – e.g. massage relieves anxiety which may be a cause of breathlessness. It was noted that depression is a specific symptom of some neurological diseases, as well as a side-effect of some drugs, and hallucinations an occasional effect of Parkinson's Disease. Such information on management or alleviation of symptoms was identified as of value to carers and care recipients.

Linked to discussion of symptoms was the importance of keeping an eye on bodily functions and seeing them as something to be managed, perhaps through keeping a record. Managing diet, for example, can alleviate constipation (which unchecked can lead to great pain and to hospitalisation). Participants in the Working Group felt such information and suggestions might be included for the benefit of those new to palliative care.

7. Question Checklist

Discussions in the original focus groups strongly support this recommendation, which it was felt would go some way toward remedying a sense of disempowerment often reported by care recipients or carers in the face of a dearth of information and their being uncertain of themselves in interaction with medical professionals.

A Checklist of Questions for Care Recipients or Carers for putting either to a GP or Social Workers in hospitals where patients might be admitted having suffered an episode of ill-health was identified as a valuable resource. The questions might cover subjects such as care in the home and available supports, as well as symptoms associated with conditions.

In discussions during Working Group sessions, the practical value of such a resource from both an informational and economic point of view was emphasised. With a checklist, carers will be aware of issues they ought to be raising which they would otherwise have no reason to consider or insufficient experience to address. Being provided with a checklist can also minimise visits to a GP, which one carer in the Working Group noted can in the Republic of Ireland cost €50 – €60 each time. The unconsidered costs of treatment and care tend to mount up – for example, hospital parking by

[3] http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Symptoms.aspx (accessed Oct. 2014)

the day can be expensive. If a patient is hoping to get through an illness, they do not want to be left with substantially depleted finances, and this possibility will be a cause of great anxiety during the care process.

The Carers Association is calling for a "transfer of care protocol" as an element of the discharge of a patient and transition from institutional to home care. Some carers in the focus groups were emphatic on this point, even advising that a carer refuse to accept a patient's discharge until the home has been inspected and equipped for their home care. The realities of a carer taking on all the duties previously discharged by an entire care team were often not appreciated. Some participants reported the impression of reluctance on the part of members of the health service voluntarily to provide information on available supports. Those who reported this seemed to feel that it was a resource management strategy. This was certainly not a universal experience, however, and for other carers the health service was their primary avenue to services and supports.

Carers suggested questions for a GP (e.g. about appropriate services for a care pathway) should be outlined in advance via a checklist following a specific diagnosis: Would ***x*** be of benefit? Is it available? What does it cost? It will save trips to the GP if one knows what questions to ask at the earliest stage.

A carefully drafted question checklist could do two complementary things: it would give carers or care recipients a degree of control in the early stages of the care process, when they often feel rather at sea and vulnerable, and would also suggest to them other service providers who may take *professional* responsibility for medical aspects of palliative care, something which alleviates some of the burden of care. One palliative care patient adopted the strategy of handing over everything to the medical experts. They did not research illness-specific information outside of what health care professionals told them: "I didn't read a single leaflet or book!" This strategy worked for them and they could focus on living their life.

8. Glossary of Terms

A glossary of terms related to palliative care was one of the features of the Australian Palliative Care (APC) course. The APC glossary was perhaps overly expansive – including technical definitions of vomiting, for example, as "expulsion of the contents of the stomach". The value of a select glossary would lie not alone in explanation, however, but also in making certain terms less alarming. A good example is the syringe driver for subcutaneous injection – apart from the rather alarming term itself,

one of the professionals interviewed noted that the syringe driver is associated by many who understand what it is with end-of-life treatment. Knowing that this is simply an injection under the skin rather than into the vein, and something commonly self-administered by diabetics, somewhat disarms the term. (The HSE Palliative Care glossary could serve as a starting point – it was well received when run by the Working Group as a follow-up. However, some of the explanations were deemed to be too technical in nature for the lay person and that the list of terms should be extended to include such things as the subcutaneous injection.)

9. Training and Support

Signposting to courses open to family carers for practical or further professional training will be an essential part of the Hub.

10. Peer Support Services

Engagement with peer support services – for example, carers groups or illness-specific support groups – is for many crucial in coming to terms with the palliative care process, and information on such supports ought to be easily attainable for visitors to the Hub. In this respect one can refer to how participants in the focus groups recounted how they themselves learned about palliative care. Many participants reported being almost totally ignorant of services available: one heard of The Carers Association through their GP, but others became aware of it by chance, usually when they had already been involved in care for some time. They were accordingly unaware of services such as Respite Care and Home Help which would have benefitted them, and they flagged the failure of the health service to inform them of the existence of these services. It was also mentioned that courses on palliative care or other practical courses (Care in the Home, Patient Moving and Handling, etc.) were not something they were aware of. Participants who had done such courses later, when they were no longer caring for a relative – in transitioning to a professional caring role – recognised that they would have been a great help. Apart from the physical practicalities of caring, these courses also helped carers to approach their role with a more confident attitude: e.g. “being assertive without being bossy” – listening to the care recipient but being aware that self-care and assertiveness was important for oneself. It also readied carers to accept outside help, which many participants said was essential: it helps to avoid burnout, and accompanying resentment or despondency that be its consequence.

The advice focus group participants would offer to those in the position they were once in would be to contact their GP and Public Health Nurse as soon as possible. Get the situation assessed by a

professional (P.H. Nurse, Occupational Therapist), and know where to go to have it reassessed if the care recipient's condition deteriorates or a new standard of care is required: be informed about morning help, night help, etc., and what kind of time can be allotted. Even if the carer is currently coping, they should be aware of where to go in the case of further decline of the care recipient. It was noted that often, it is only attending a clinic for something else (effects of a fall, say) which gets a palliative care recipient into the system. Some participants advised keeping a Care Diary with the specific goal of approaching professionals in an informed way, and one had even found use in watching the news or reading newspapers to find out who the head people at relevant departments or associations were. In light of the trial-and-error way in which most people reported becoming aware of entitlements or supports, and the lack of consistency in reportedly effective sources, available leaflets or brochures would help to raise awareness of palliative care supports and services.

11. Communication

An Adult and Public Palliative Hub it was suggested, ought to address the issues of communication – a commonly cited example was the difficulty of talking to children about serious illness, and there are resources available to help families in this respect (organisations such as Macmillan or the Irish Cancer Society offer specific services or advice on the topic). While this specific issue might be dealt with in the Children's and Young People's Palliative Hub, the idea of general advice such as that provided by the Canadian Virtual Hospice on talking to a parent was well received by the Working Group, and its potential benefits for those new to the palliative care process was acknowledged.

12. Self-care

The issue of carer burnout was to the fore in many focus groups. The importance of avoiding burnout and combating isolation through maintaining social connections was stressed, and should be dealt with in the Hub. Much of this material can be dealt with by signposting to existing resources; but again, a brief, general discussion of the need to accept help when it is offered, or to avail of respite care, or about the existence of Carers Resource Centres, will highlight how central the issue is to the care process.

13. Planning for Death

Issues surrounding the practical preparations for death have been adequately addressed on other sites (for example that of the Irish Hospice Foundation or Northern Ireland Hospice), and should be linked to from the Hub. Other issues to cover might include the cost of hospice care; funeral costs;

insurance policies and whether and what they cover in regard to home or hospice care; living wills and/or advance care directives; and life assurance and life insurance.

Anne Jacob also detailed the matter of "achieving a good death", and the questions for an individual to pose in relation to: Where do I wish to die? How? With or among whom? In hospice or at home? Are there people with whom I wish to be reconciled before dying? The Irish Hospice Foundation's 'Think Ahead' initiative was mentioned as an example of a positive and proactive approach end-of-life planning.

14. Post-Death and Bereavement, Practicalities

It was suggested in focus groups and Working Group sessions that the Hub should address in some way the aftermath of the palliative care process for the carer – again, these are issues which can be signposted. Matters surrounding post-death would include information on the grieving process, relating to friends and relatives of the deceased as well as other carers; whom to approach about counselling; practicalities such as organising funerals; wills and probate.

DELIVERY MECHANISMS

The examination of delivery mechanisms in the second Working Group session, and of the test versions of the AIIHPC Hub in the third, facilitated thinking about what kind of mechanisms were both effective and deliverable. The following suggestions arose from discussion:

1. Interactive Component, Structure and Presentation:

It was noted, particularly in relation to the Australian Palliative Care (APC) website, that interactive components served as learning aids: information given in a form which requires engagement is absorbed and retained in a way in which that merely read is not.[4] The APC course and site is described in Appendix 5.

The APC course and website were notably easy to navigate: everything was very readable and immediate, and self-contained; bite-sized information was accessible without leaving one page for another. A particularly welcomed feature for the Working Group was the use of 'hover text' or 'mouse-over'[5] – whereby letting the cursor hover over highlighted terms or phrases gives a captioned definition without having to click on the term link to a glossary.

It was noted in relation to presentation, however – and it is something all website development must now be cognisant of – that the APC course was not very navigable on devices such as a Smartphone. The Canadian Virtual Hospice, in similar fashion, the content and layout of which was praised by all participants as useful and sensitive in its handling of topics, also presented Smartphone problems due to the volume of information being unsuited to smaller screens.

An aspect of presentation which was highlighted by participants, and which bears repeating, is the recommendation that logos of AIIHPC itself as well as consortium members be prominently displayed on the Hub. The Hub should be immediately identifiable by users as a professional and entirely reliable space for accessing information and learning.

[4] http://www.palliativecareonline.com/ (accessed Oct. 2014). The course is as described, but exercises can only be accessed by a registered user.

[5] http://en.wikipedia.org/wiki/Mouseover

2. "Asked and Answered"

The "Asked and Answered" feature on the Canadian Virtual Hospice website was singled out as particularly useful. This is a maintained archive of the most popular or useful questions from users, answers to which can be accessed by any user (the issues covered range, for example, from questions of lack of appetite to a care recipient making racist or otherwise inappropriate remarks in a carer's presence). These answers are provided by a team of professionals, with the disclaimer that they are in no case a substitute, practically or legally, for medical advice. At the second Working Group session, a number of participants found the first answer provided – advice on how to address issues with an elderly father undergoing palliative care – to be sensitively handled and helpful.[6] The feature also constituted an invitation to users to identify knowledge gaps to be filled, and it was strongly recommended that AIIHPC give consideration to a similar feature.

3. Discussion Forums

The Canadian Virtual Hospice and other sites featured discussion forums for users to trade stories or knowledge on issues surrounding palliative care. The Working Group expressed reservations about such a feature, however, on a number of grounds: that it is frequently necessary to "wade through" uninformative or superfluous material in order to find something useful; that such forums must be permanently monitored and moderated (something likely beyond the current resources of the AIIHPC site); and the problem of the "dead thread"—threads which remain active but to which no active user has contributed in a long time tend to give an impression of general desuetude, and affect how visitors view a site as a whole. It was the opinion of the Working Group that maintaining such forums were not necessary.

4. Offline Resources

The issue of complementary offline resources as part of the drive to raise public awareness of palliative care was raised. It was accepted by the Working Group that trying to reproduce what can be done online was simply not possible, and, as far as this element of the project is focused on creating an online tool, designing supplementary or complementary hardcopy materials was outside of its remit. It was noted repeatedly in the original focus groups, however, that many older palliative care recipients and in many cases their carers may not be connected to the internet. In this regard, it

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6 www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support/Asked+Answered/Communication/Communicating+with+the+Patient/My+dad+doesn_t+talk+about+his+illness_+How+can+I+talk+to+him+about+dying_.aspx (Accessed Nov. 2014)

was thought that some brief complementary material could be produced – a leaflet or slim brochure – which gave basic information about palliative care and which also directed readers to the website and encouraged them to have someone help them consult it. Perhaps the most useful way of addressing this is to make each informational page of the Hub easily printable (in the manner of the Citizen's Information website in the Republic of Ireland). Any directly related hardcopy resources will have to be developed after and with reference to the Hub, and can best be created through the collaborative efforts of AIIHPC Consortium Members.

The question remains as to where such leaflets or brochures would best be placed – in GPs' surgeries, for example, or in hospitals and hospices, primary care clinics, and Carers' Resource Centres. It is possible that an adequately constructed Question Checklist (see Section 4.2, Recommendation 7 above) would fulfil many of these informational needs and provide a way to introduce patients and their carers to the concept of palliative care. A Social Worker interviewed also raised the issue of translations for non-English speakers; the Working Group, however, felt that accommodating non-native speakers might well be outside of what would reasonably expected of the Hub.

LEARNING PLATFORM RESOURCES: RECOMMENDATIONS

It was strongly emphasised by participants in the final Working Group session that the Palliative Hub Learning Platform ought to include general, non-professional information and resources for family carers. It was also suggested in the final session that it be possible for and recommended to Professionals to enter the Adult and Public Palliative Hub, as a way of better appreciating where palliative care recipients and family carers are coming from and what they are dealing with. A link from the Professional, Academic and Research Palliative Hub and Palliative Hub Learning Platform to the Adult and Public Palliative Hub was recommended. The following recommendations are in some cases developed from and considered a complement to those for the Adult and Public Palliative Hub, and in others are suggested via comparison with or adaptation from other existing international resources.

1. General Education about Palliative Care

General, interactive tools should be developed to educate the general public about palliative care and to counter common misperceptions about the process. One way to do this is through preliminary knowledge tests which give a user of the Hub an opportunity to test their own

knowledge of (and articulate their own preconceptions about) palliative care (as well as corollary subjects such as hospice care). An example of such a quiz is the 'Hospice IQ Quiz' provided by the HPH Hospice website – a 10-question test which allows a user to evaluate their knowledge of hospice care.[7] This quick quiz also resembles the 'Pre-Test' component of Stanford University's open 'E-Campus' modules on palliative care.[8] These quizzes pose general questions about the nature of palliative or hospice care, including about percentages of a population which receive such care, which want to die at home and which actually do – these could be adapted for an Irish user base. A 'Palliative Care Primer' quiz could be developed which served as an interactive guide for the layperson explaining the holistic nature of palliative care, and its physical, emotional, psychological, social and spiritual aspects. Also to be considered is a short instructional programme offering exercises or questions for the user after each lesson, modelled on the format of the Australian Palliative Care Online Course.

2. An Interactive Component Detailing Illness Pathways

The standard graph showing the three different types of illness trajectory elicited a lukewarm response from carers.[9] Greater discussion via interactive learning of the stages in typical pathways, as well as the types of illnesses for which palliative care is received, would better equip users with knowledge and aid them in managing expectations about an illness. This type of interactive tool forms one section of the third module in the Australian Palliative Care Online Course.

3. Public Awareness of and Attitudes to Carers and Care Recipients

There is a need to develop a component for the general public addressing the questions of the realities of the palliative care process and of how they can best support either a recipient of palliative care or a family carer. This could take the form of a presentation on issues surrounding the palliative process and incorporate elements concerning attitudes toward carers and care recipients discussed in Recommendation 3 above. Some short video presentations could be considered for the purposes of illustrating typical scenarios and advising on "dos and don'ts". A comparable suite of videos has been produced by NCPOP dramatising scenarios faced by older people and offering

[7] http://www.hph-hospice.org/hospice-iq-quiz (Nov. 2014)
[8] http://palliative.stanford.edu/ (Nov. 2014)
[9] The three common illness trajectories are exemplified by cancer, organ failure and dementia, illustrated here:
http://www.mywhatever.com/cifwriter/library/commonsense/graphics/fig_1_2_large.jpg (Jan. 2015)

advice, which handle the relevant issues in a clear and sensitive way.[10] This type of work could be replicated with palliative care scenarios.

4. Pain and Other Symptom Management

An interactive learning tool dealing with pain and symptom management could valuably supplement the informational component suggested for the Adult and Public Palliative Hub (Recommendation 6 above). Instruction concerning pain management makes up one of the sections of Module 2 of the Australian Palliative Care Online Course. A developed suite of videos dealing with symptom management, and tailored to typical issues in palliative patients, would be a valuable resource. Such a suite has been created from an original Hungarian project, and its success was such that EU funding has made the videos available in multiple languages one the 'Webnurse' website. Webnurse is a suite of videos offering demonstrations of various acts involved in caring for a patient at home or in a nursing environment, and would be a valuable learning tool for carers. Subjects covered include, e.g., turning a patient in a bed, wound dressing, bed making, preventing pressure ulcers, and hair, eye and nail care. A link to the site from the Adult and Public Palliative Hub or Learning Platform is recommended, but the AIIHPC may choose to develop its own similar suite of demonstrative videos to extend the topics covered.[11]

5. Self-Care Checklist

Complementing the recommended informational material on the importance of self-care in the Adult and Public Palliative Hub (Recommendation 12 above), an interactive component containing practical instruction on self-care could be developed. The subject of self-care forms one of the sections ('Carer Strain') within Module 2 of the Australian Palliative Care Online Course. In addition to such a component, a self-care checklist should be created; as a questionnaire which can be printed off, this could form part of the Learning Platform or be incorporated into the Adult and Public Palliative Hub. The checklist would help those at risk of 'carer burnout' to self-identify as such, and should include appropriate advice on countering it or signposting for additional supports. An existing and very useful guide from the US-based Healthinaging site could be adapted.[12] A project

[10] www.keepcontrol.ie (not yet live; due to go live 11 Dec. 2014, videos were shared with principal researchers in advance)

[11] http://www.webnurse.eu/ (Nov. 2014)

[12] http://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/self-assessment.aspx (Nov. 2014)

('Keep Me Well') has also been piloted in Cork City encouraging family carers to keep a care diary in a secure online form.[13]

6. Dealing with anger and frustration and other common problems

Stanford University's Palliative Care E-Campus Course includes a useful video concerning how best to engage with an angry or frustrated patient – showing both the wrong way of doing so and the recommended manner of engagement for clinicians.[14] This course is clinical in nature and oriented entirely toward healthcare professionals. A similar suite of videos aimed at family carers dealing with common palliative care scenarios would be welcome. It might be modelled on the HSE's highly-regarded videos on elder abuse commissioned for an 'Open Your Eyes' awareness-raising campaign (without the negative atmosphere of those videos).[15] The dramatisation of scenarios which will be faced by most palliative care recipients and carers would serve an instructional purpose.

7. End of life and a Good Death

Videos dealing with the issue of facing death, and helping oneself or someone else to accept it with equanimity can serve to emphasise the holistic nature of palliative care right up to the point when it becomes end-of-life care. These might take the form of interviews with professionals or recipients of palliative care, and can deal with matters of reconciliation, spirituality or acceptance which complement the physical or medical side of palliative care such as pain management. The content of such videos can be developed in consultation with AIIHPC Consortium Members.

8. Palliative Care Scenarios

The Palliative Care Scenarios were found to be helpful in encouraging reflection on personal situations and highlighting issues involved in palliative care and, with further development, something similar could be incorporated into the Hub as a learning resource. There would be some difficulty involved in framing the scenarios – used as part of the focus groups, they served a definite function, focusing conversation; and they were framed in terms of reflection on the empowerment of carer and care recipient – but development of an exercise based around them should be

[13] www.keepmewell.info (Nov. 2014; requires login)

[14] http://palliative.stanford.edu/overview-of-palliative-care/case-1-james-benton/part-1-introduction/ (Nov. 2014); http://palliative.stanford.edu/overview-of-palliative-care/case-1-james-benton/case-1-part-2/ (Nov. 2014)

[15] http://www.youtube.com/watch?v=KNCYv1g64xI; http://www.youtube.com/watch?v=9TU6fkCgV3I (Nov. 2014)

considered. The scenarios present vignettes which facilitate discussion rather than presenting information, or personal or professional advice; as such, they differ from Testimonials such as are offered on the Children's and Young People's Palliative Hub. Their usefulness was emphasised by participants in focus groups and healthcare professionals; but given the reservations about including discussion forums in the Hub, whether they can be integrated as part of a Learning Platform is an open question. While they may not in themselves be transferable directly to the Hub, the positive response to them in focus groups highlighted a preference for an element of engagement or storytelling in accessing information. The Working Group felt the same was true of the Charlie – Edna – Moira case study in the Australian Palliative Care Course (described in Appendix 5).

APPENDIX 1: FOCUS GROUP DISCUSSION GUIDE

FOCUS GROUP GUIDE

OPENING

To begin I'd like to thank you all for coming today we really appreciate your time and input into this study. Before I briefly explain the goals of this research and the proposed format for our discussion this morning, it might be useful to introduce ourselves. For those of you that don't know me already, my name is Diarmaid O'Sullivan, and I am the Campaigns and Research manager with The Carers Association. This is Paul O'Mahoney who is a research assistant with the Carers Association and who is working with me on this study. The study is funded by the All Ireland Institute for Hospice and Palliative Care (AIIHPC) who through collaboration in the Republic of Ireland and Northern Ireland aims to deliver a better hospice and palliative care experience for patients and their families.
Perhaps you could briefly introduce yourselves to each other by stating your name and, if you wish, the caring role you have performed or are performing?

The overall aim of this piece of research is to identify components for a learning package aimed at those wishing to learn about Palliative Care. We're hoping to draw on your experience of palliative care to suggest learning components that will ***empower*** care recipients and Family Carers to have as positive a palliative care experience as possible. For that reason we'll be discussing issues of empowerment as well as drawing on your experience of the palliative care process.
This focus group today is part of a two phase research process. In the first phase we will conduct focus groups and interviews with Family Carers and Health Care Professionals in the Republic of Ireland and Northern Ireland. The goal of these discussions is to learn from your experiences of palliative care and to identify important supports; sources of advice; knowledge acquisition; and coping skills. In the second phase a working group of Family Carers will be supported and empowered to come to strong recommendations about specific components for a Palliative Care Learning Package.

The format for the discussion today will be structured quite loosely around the a number themes: what is empowerment?; What is palliative care?; Case studies of Palliative Care; your experience; and achieving empowerment. With your permission I would like to record the discussion as this will assist myself and Paul in our analysis and will ensure that our representation of the discussion is accurate and reflects what is actually said today. Your confidentiality outside of this discussion is guaranteed by the research team – your name will not appear in the final report or in any subsequent publications. Also, I'd just like to remind you to be conscious that we try and have one person speaking at a time – if only just for the sake of the recording.

WHAT IS EMPOWERMENT?

Main Question/Task:

We will start off with a general discussion of empowerment. Working with the person sitting next to you discuss the particular attributes that you associate with empowerment and make note of key words, phrases or characteristics that are coming up in the discussion. Note that this initial discussion pertains to the topic of empowerment in general and does not have to be specific to palliative care recipients or caring roles.
Prompts/Follow-up:

- List the words on flip-chart
- Are there any more words that you think should be added here?
- Are there any words that you think don't describe an aspect of empowerment or you wish to query?

- Is there any way that these words could be categorised or brought together under headings or themes?

PALLIATIVE CARE AND EMPOWERMENT

Main Question/Task:

With this broad understanding of the attributes of empowerment we will consider how concepts of empowerment might relate to palliative care. Make note of key words, phrases or characteristics that are coming up in the discussion.

Prompts/Questions

- How might the notion of empowerment change before and after experience of Palliative Care?
- What strengths can people exhibit through the Palliative Care process?
    - Care Recipients and Family Carers
- Is empowerment different for the care recipient and their family/friends who care for them?
- **Describe an empowered Palliative Care Recipient?**
- **Describe an empowered Family Carer?**

CASE STUDIES OF PALLIATIVE CARE

Main Question/Task:

Having come to some understanding of how empowerment might relate to the experience of palliative care we are now going to focus upon the role of empowerment and disempowerment in case studies of palliative care experience. Read each case vignette in turn. While reading these cases perhaps think about what challenges that person is facing

- What are your initial responses to this case?
- Who is vulnerable and who is empowered in this situation?
- What are the sources of disempowerment for the individual at the centre of this case?
- What is the dynamic?
- What are the differences between this individual and the empowered person described earlier?
- What are the key attributes of empowerment which are required in this situation? Can these attributes be categorised? (Personal attributes, Environmental attributes, Social/cultural attributes)

ACHIEVING EMPOWERMENT

We now turn to thinking about strategies for empowering people through the palliative care process. In the context of each of those case studies how could the person at the centre of the case be empowered to take control of their situation?

- How could person at centre of the case be empowered to take control of their situation?
- What information would assist them?
- What advice/coping mechanisms would be of benefit?
- What services should they be aware of?
- What skills would be of benefit to acquire?
- What conversations do they need to have?

LEARNING FROM YOUR EXPERIENCE OF PALLIATIVE CARE

In our final theme we move from considering these case studies to your own experience of Palliative Care and ask the question; what do Family Carers and Care Recipients new to the process need to understand about Palliative Care?

- Reflecting on when Palliative Care first became necessary what expectations did you have of Palliative Care? Was there a difference between your expectation of Palliative Care and reality?
- Looking back, which supports, advice or coping mechanisms were most useful to you? How did you come across this information or advice?
- What was your biggest fear following a diagnosis and how did you deal with this? We're you supported to have these discussions or is it something you worked out on your own?
- Were there methods of coping, information or supports and services that you found useful but would have been good to have been aware of earlier in the process?
- How did you find out about illness-specific information?

CLOSING

I want to thank you again for coming today and for contributing to such a rich and enlightening discussion. You have given myself and Paul a lot to think about, our next task it to try to represent this discussion as accurately as possible through a written descriptive account or summary.

This account will be used by the working group to develop a working definition of empowerment as well as to identify components for a Palliative Care learning tool.

Finally, if you have any more thoughts about this topic which come to your mind over the next few days/weeks please do not hesitate to contact me or to add them to the summary document.

APPENDIX 2: FOCUS GROUP CONSENT FORM

Consent Form

Palliative Care Community Learning Project
You are being invited to take part in a research study. Before you decide whether to participate it is important that you read the following information carefully and take time to decide. It is important for you to understand why the research is being done and what it will involve. Please ask if there is anything that is not clear to you or if you would like more information.

Who is undertaking the research?
This research is being undertaken by The Carers Association and is funded by the All Island Institute for Hospice and Palliative Care.

Why is this research being undertaken?
In order for the public to benefit from Palliative Care, it is important they understand it and its benefits for supporting the quality of life of people with life limiting conditions. People's understanding can be enhanced through education. However, the education needs of local communities in respect of palliative care are not well understood and are often overlooked.

Why is this research being undertaken?
This research hopes to explore your experience of Palliative Care so that we can make recommendations for a learning package and support materials which will be available online and offline.
Ultimately, this research will feed into the creation of a learning tool so that those new to Palliative Care can learn all they need to about the process. Your experiences will be vital in ensuring that the recommendations we make are relevant and reflect the reality of Palliative Care on the Island of Ireland.

Why have I been selected to take part in this study?
You have been asked to participate in this study because we would like to learn from your experience of palliative care and what you think is important for empowering Care Recipients and Family Carers through the Palliative Care process.
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I consent to interviews being audio-taped.

What happens during the discussion
The session will last between 2-3 hours and will be facilitated by a member of The Carers Association research team. You will be facilitated in a discussion about empowerment and to explore what Family Carers and Care Recipients new to the process need to understand about Palliative Care. With your permission, the discussion will be audio-recorded. You will not be asked to disclose any information that you feel uncomfortable with. Your contribution will be made anonymous in all reports and the recordings will be destroyed when the project ends.

Consent to Participate

I confirm that I have read and understand the description of the study above and have had the opportunity to ask questions.

1. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
2. I agree to allow the researcher to audio record the discussion. I understand that these recordings will be destroyed within 12 months of the study's completion.
3. I give permission for anonymised data in the form of transcripts to be presented in research reports
4. I agree to take part in the above study.

_____	__/__/2014	_____
Participant (Print)	Date	Signature
I believe that the participant has a clear understanding and appreciation of the information necessary to provide informed consent to participate in this study		
Diarmaid O'Sullivan	__/__/2014	_____
Researcher (Print)	Date	Signature

Contact details for further information

If you have any further questions or if you would like any further information please feel free to contact lead researcher Diarmaid O'Sullivan (Tel: + 353 (0) 86 8099446, Email: dosullivan@carersireland.com) Research and Campaigns Manager, The Carers Association, Smithfield Business Centre, The Distillers Building, New Church St, Smithfield, Dublin 7

APPENDIX 3: INTERVIEW GUIDE

INTERVIEW GUIDE: HEALTH CARE PROFESSIONALS

OPENING

To begin I'd like to thank you for your time and input into this study. My name is Diarmaid O'Sullivan, and I am the Campaigns and Research manager with The Carers Association. The study is funded by the All Ireland Institute for Hospice and Palliative Care (AIIHPC) who through collaboration in the Republic of Ireland and Northern Ireland aim to deliver a better hospice and palliative care experience for patients and their families.

The overall aim of this piece of research is to identify components for a learning package aimed at those wishing to learn about Palliative Care. We're hoping to draw on your professional expertise and experience of palliative care to suggest learning components that will empower care recipients and Family Carers to have as positive a palliative care experience as possible.
This interview today is part of a two phase research process. In the first phase we are conducting focus groups with Family Carers and interviews with Health Care Professionals in the Republic of Ireland and Northern Ireland. The goal of these discussions is to learn from your experiences of palliative care and to identify important supports; sources of advice; knowledge acquisition; and coping skills. In the second phase a working group of Family Carers will be supported and empowered to come to strong recommendations about specific components for a Palliative Care Learning Package.

The format for the discussion today will be structured quite loosely around the a number themes: Empowerment and Palliative Care; Case studies of Palliative Care; your experience; and achieving empowerment. With your permission I would like to record the discussion as this will assist our analysis and will ensure that our representation of the discussion is accurate and reflects what is actually said today. Your confidentiality outside of this discussion is guaranteed – your name will not appear in the final report or in any subsequent publications.

EMPOWERMENT AND PALLIATIVE CARE

The overall aim of this piece of research is to identify components for a learning package aimed at those wishing to learn about Palliative Care. This research will suggest learning components that will ***empower*** care recipients and Family Carers to have as positive a palliative care experience as possible. We've started our discussion Family Carers by discussing **empowerment** so that the recommendations we come to are as holistic as possible; so that they include advice about health supports but also about social, psychological and emotional supports too.

- What words, phrases or characteristics do you associate with **empowerment** (in general not necessarily specific to palliative care or caring roles)
- What strengths can people exhibit through the Palliative Care process?
    - Care Recipients and Family Carers
- **Could you describe an empowered Palliative Care Recipient?**
- **Could you describe an empowered Family Carer?**
- Is empowerment different for the care recipient and their family/friends who care for them?
- How might notions of empowerment change before and during the palliative care process?

CASE STUDIES OF PALLIATIVE CARE

Main Question/Task:

Having discussed how empowerment might relate to the experience of palliative care we are now going to focus upon the role of empowerment and disempowerment in case studies of palliative care experience. Read each case vignette in turn. While reading these cases perhaps think about what challenges that person is facing

- What are your initial responses to this case?
- Who is vulnerable and who is empowered in this situation?
- What are the sources of disempowerment for the individual at the centre of this case?
- What are the differences between this individual and the empowered person described earlier?

ACHIEVING EMPOWERMENT

We now turn to thinking about strategies for empowering people through the palliative care process. In the context of each of those case studies how could the person at the centre of the case be empowered to take control of their situation?

- How could person at centre of the case be empowered to take control of their situation?
- What information would assist them?
- What advice/coping mechanisms would be of benefit?
- What services should they be aware of?
- What skills would be of benefit to acquire?
- What conversations do they need to have?

LEARNING FROM YOUR EXPERIENCE OF PALLIATIVE CARE

In our final theme we move from considering these case studies to your own professional experience of Palliative Care and ask the question; what do Family Carers and Care Recipients new to the process need to understand about Palliative Care?

- What advice do you give to Family Carers and Care Recipients new to palliative care?
- Are there any myths you have to set right? How do you do this?
- Do people have expectations of the palliative care process that differ from reality? How do you deal with this?
- Which supports, advice or coping mechanisms do you recommend? Are there particular resources (books, leaflets, websites, organisations) that you recommend?
- What is the biggest fear that Family Carers and Care Recipients have following a diagnosis? How to you suggest they deal with this?
- Were there methods of coping, information or supports and services that you found useful but would have been good to have been aware of earlier in the process?
- How do you recommend people to find out about illness-specific information?

CLOSING

I want to thank you again for your time and your contribution to this piece of research. You have given us a lot to think about, our next task it to try to represent this discussion as accurately as possible through a written descriptive account or summary.

Your contribution along with those of other Health Care Professionals and interviews from Focus Groups will be used to identify key components for a Palliative Care learning tool.

Finally, if you have any more thoughts about this topic which come to your mind over the next few days/weeks please do not hesitate to contact me.

APPENDIX 4: PALLIATIVE CARE SCENARIOS

PALLIATIVE CARE SCENARIO 1: KAY

Kay is an 80 year-old widow. She has three children: her 50 year-old daughter Millie lives close by with her family and looks after many of Kay's everyday needs. Kay has two more adult children, a son and daughter, Conor and Rebecca, who do not live locally and who more seldom visit. Recently, Kay has shown increasingly frequent signs of forgetfulness, and Millie suspects the early symptoms of dementia. She is anxious about her mother's condition, but also about how and with whom she should broach the issue – with her mother, her siblings or healthcare officials. The matter is complicated because Kay has always had reservations about hospitals and is uncomfortable dealing with healthcare workers. In particular, Millie fears that Kay will jump to the conclusion that Millie hopes to have her moved into residential care, and so discussing the issue with her will be extremely difficult. At the same time, she knows that she is not equipped herself to diagnose the onset of dementia, and is unsure of how her concerns about her mother's condition might be confirmed or allayed.

PALLIATIVE CARE SCENARIO 2: DEBORAH

Deborah is a 44 year-old woman who almost a year ago was diagnosed with stage II breast cancer. She lives with her husband Ivan, 44, and their two children, David, 14, and Emmeline, 9. Deborah underwent a course of chemotherapy and responded well to treatment: her most recent biopsy suggests the disease is in remission. Doctors have cautioned the couple to manage their expectations, however, as the remission may well be temporary and this cancer has a high incidence of recurrence. Deborah and Ivan are focused on planning for the future, but Ivan in particular is finding the lack of an 'all-clear' is impacting more on their lives than they would wish; they worry particularly about explaining the situation to their young children, and Ivan finds it especially difficult to face the idea of Deborah's relapsing or her death.

PALLIATIVE CARE SCENARIO 3: THOMAS

Thomas is a 75 year old pensioner, who was diagnosed with Parkinson's disease ten years ago. He is cared for at home by his 72 year-old wife Terri. They have two grown sons who visit frequently. As his mobility decreased, a downstairs room was extended and converted into a bedroom with the aid of a housing adaptation grant. Having led an active life, Thomas's frustrations in the early stages of the disease affected his humour, making him frequently uncooperative and angry. In time he came to accept the new limitations set on his activities. More recently, however, partly as a result of the disease's progression, he has suffered with respiratory complications. These culminated in a recent hospitalisation with breathlessness. This has been a major setback for Thomas. With the prospect of further diminishment of his health, he has become preoccupied with becoming a burden on his family and friends. He has begun saying that he doesn't have much time left, or would be better off dead. Thomas does not want their sons told of his hospitalisation. Terri would prefer to tell them, and fears particularly that Thomas is becoming depressed and frustrated.

APPENDIX 5: DESCRIPTION OF AUSTRALIAN PALLIATIVE CARE ONLINE COURSE

The Australian Palliative Care Guidelines (PCG) online training course

Introduction:
The PCG online (http://www.palliativecareonline.com.au) course is an online education and training package available to assist health workers, including general practitioners, nurses and care workers, to implement the principles of the Guidelines for a Palliative Approach for Aged Care in the Community Setting (COMPAC Guidelines).

The project was developed through collaboration between SilverChain; the Australian Healthcare and Hospitals Association; Just Health Consultants; online educational program providers e3Learning; and Molly Carlile, a healthcare professional who works to raise awareness of palliative care and issues around the dying process, and speaks publicly and maintains a blog under the professional name 'The Deathtalker'.

The course consists of four modules, on successful completion of which a printable certificate of accreditation is provided. Participants have the ability to apply for continued professional development points and recognition of prior learning.

The program is geared toward aged care (designed for care of those with a life-limiting illness and/or approaching final stages of normal ageing process) and aimed at professional healthcare workers; its model could however be adapted to information delivery to a broader and more general audience and beyond the care of the aged.

Outline:
- The Palliative Care Guidelines cover:
- the components of care that should be included when delivering a palliative approach
- clients' care needs
- advance care planning and advance care directives
- physical symptom assessment and management
- psychosocial and spiritual support

Modules focus on four competencies:
CHCPA301B Deliver care services using a palliative approach
CHCPA402B Plan for and provide care services using a palliative approach
CHCCS422B Respond holistically to client issues and refer appropriately
CHCCS426B Provide support and care relating to loss and grief

In support of two skill-sets:
CHC08 Palliative approach skill set – plan and provide care
CHC08 Palliative approach skill set – provide support

Modules:
Module 1: A Palliative Approach to Care (4 sections)
Module 2: Planning and Assessment (15 sections)
Module 3: Providing and Delivering Care to Clients and Carers (6 sections)
Module 4: Deliver a Palliative Approach to Care in the Community Setting (5 sections)
The advised total time for completion of the four modules is 6–8hrs.

Form and Content of the Modules:
Welcome and Objectives: Each module begins with a Welcome and section detailing the Learning Objectives, which are set out clearly in bullet point form.

Information: Each section of a module (the number of sections varies, from 4 in module one to 15 in module 2) contains a number of short, clear pieces of information, which the user can read in their own time before clicking onto the next screen. Sometimes this is a screen where the user clicks on a number of icons in turn to read, for example, about the differing roles of each member of a multidisciplinary team; other times it is simply a set of bullet points. At any point in the module, the user can return to the module's table of contents – there is no time limit on completing individual sections or modules.

A brief sample of sections from across the four modules includes: 'The Assessment and Management of Pain'; 'Advance Care Directives'; 'Genitourinary and Respiratory Symptoms and Fatigue'; 'Pyschosocial and Spiritual Support'; 'Recognising and Managing Stressors'; 'Communication'; 'Grief, Loss and Bereavement'; 'Discussing an Illness Pathway'; 'Culturally Appropriate Care'. The program seeks to be comprehensive in covering issues that arise for carers in a palliative care situation.

Activity: Following on the information screens, activities test the user – unlike the Assessment section, these are not graded, and the user must complete them correctly before the next screen can be accessed or the module completed.

Examples of activities:

- Three members of a multidisciplinary team are shown – a GP, Counsellor and Registered Nurse. A sequence of activities or roles involved in the provision of palliative care is shown, and the user must click and drag each role to match it with the appropriate individual.

- A set of 'notes' containing actions are shown in sequence; each must either be dragged and 'pinned' to a notice board, if relevant to the provision of care, or alternatively, if not relevant or useful, 'dumped' in a wastebasket.

Link to Guidelines: Prior to the final element of any section, a summary and assessment, a link is provided to the relevant section of the extensive Australian Palliative Care Guidelines document (in general, the linked-to information simply reiterates that already provided in a more formalised and extensive way; it is rarely necessary for users to read guidelines to supplement information already given, and this step could easily be discounted in a version of the program adapted to a general audience).

Summary and Assessment: this is the final element of each section, which poses a set of multiple choice questions (varying depending on the length of the section from about 3 to 8). After completing the questions, a mark for the section is awarded. The marks in each section contribute to the user's overall mark/grade in the module. These questions are very easy and serve above all to reinforce essential points of information from the individual section.

Case Studies: A feature of the modules is the use of case studies which typify a situation related to a particular learning area and on which activities are based: for example, the section on palliative care for those with a mental illness uses the case of 'Pat', a woman without family and a history of mental illness, who exhibits difficult behaviour and shows a distrust of males. The section on palliative care for Aboriginal communities introduces 'Joe', and details numerous challenges in administering care based on cultural or community norms. Activities consist of questions to the user as to how best provide care for these individuals.

A major component of the program is a case study which is developed across modules, and which is used to exemplify many situations and issues related to different stages of palliative care. This case study revolves around a family of three:

Charlie is a 78 year-old man who has been caring for his wife, Edna, 75, for the past four years, since Edna was diagnosed with dementia. Edna's condition has deteriorated, but Charlie is still capable of caring for her. As we meet the characters, however, Charlie has been for a chest scan which has shown a mass in his chest; owing to his worsening cough, Charlie suspects the mass is malignant.

The third family member is Charlie and Edna's adult daughter, Moira. She lives with her own family and is only intermittently involved in caring for Edna.

This ongoing case study forms the basis for many of the activities, for example: 'Discussing the Palliative Approach to Charlie's Care'; 'Advanced Care Planning with Charlie and his Family'; 'Managing Charlie's Pain'; and later: 'Helping Charlie at the End of his Life', or 'Supporting Charlie's Family in Bereavement'.

The 'Charlie and Edna' case study involves a video diary component: we are introduced to Claire, carer in the case study scenario (played by Molly Carlile). Each instalment of the video diary takes the user through the various stages of palliative care from diagnosis to death and the family's bereavement, all from the carer's perspective, and deals not only with challenges faced in caring for Charlie and interacting with his family but also in self-care while administering palliative care to another.

A range of issues are addressed through the video diary, e.g., initial difficulties – the carer's becoming gradually comfortable in Charlie and Edna's home, or Charlie's being distracted by Edna in the initial meeting; Charlie's reluctance to discuss his diagnosis with Moira (Claire offers to speak to Moira, which Charlie agrees to eagerly); Moira's difficulty in accepting the diagnosis and the idea of her father's illness and death; Claire's own difficulties, becoming temporarily overwhelmed by the work, and the options available to help her cope – supervision, debriefing or counselling; Charlie's advance care plan and directive, and the provisions it includes for Edna's care after his death, when she will be placed in a residential care home specialising in dementia; Charlie's family's grief after his death and Claire's own, and Moira's guilt at not being able to care for her mother herself.

Completion:
When an individual module is completed, there is a final recap of material in a 'What We've Covered' section, detailing what knowledge should have been acquired and competencies targeted; in addition, there is a multiple-choice Evaluation Questionnaire, asking the participant to rate the module in numerous ways.

The final sections proved either a glossary of terms or references from literature cited in or relevant to the module. If completed successfully, a certificate of accreditation is immediately issued which can be viewed, attached to an email or printed by the user.

On completion of the course, as well as being offered options for further professional development, participants can log in again at any time to refresh their knowledge (though completed assessments cannot be retaken, the questions and how they were originally answered by the respondent – and whether the answer was correct or incorrect – remain accessible).

APPENDIX 6: PALLIATIVE CARE "TREE" IMAGE

Sourced from http://hospiceofrutherford.org/palliative-care