Southern Health and Social Care Trust

Quality Care - for you, with you

Palliative Care in partnership

The Heart of Living and Dying

A facilitator's guide for health and social care professionals

A group process contributing to a public health approach to advance care planning

The Heart of Living and Dying

A facilitator's guide for health and social care professionals

A group process contributing to a public health approach to advance care planning

"If you choose to use this guide, we would like to hear how you found it. Please do contact us at 028 37 560592 and let us know. Or for any other enquiries relating to "The Heart Of Living and Dying" contact Deirdre.mckenna@southerntrust.hscni.net

Foreword

The Heart of Living and Dying

Social work has always concerned itself with the whole person and with seeing people in their social context; their family and their communities. At its core Social Work espouses the values of person centred care, respect, dignity and empowerment of the people who come into contact with health and social care services. This is no less so in the very challenging world of palliative care where those accessing the service are faced with the sometimes shocking reality of their own mortality. Communicating effectively in these circumstances is vital and enabling others to consider and articulate what is important to them has been shown to enhance quality of life and peace of mind.

This publication offers health and social care professionals a safe and comprehensive guide to facilitating these conversations with their groups, communities and service users: conversations which all of us could participate in and benefit from.

We are delighted that this initiative has been developed by Deirdre McKenna the Social Worker within in the Community Specialist Palliative Care Team in the Southern Trust. In recognition of Deirdre's work on the *"Heart of Living and Dying"* she was awarded the Social Worker of the year in Adult Services Northern Ireland (2018)

We hope this will make a valuable contribution to our citizen's health and well-being and encourage health and social care professionals to participate in these conversations including what matters to them in their living and dying.

Mr Paul Morgan
Executive Director of Social Work

Mrs Melanie McClements
Director Older People Primary Care

January 2019

1.0 Introduction

The Heart of Living and Dying: a group process contributing to a public health approach to advance care planning.

Thank you for your interest in The Heart of Living and Dying initiative. No one likes to think about dying or death, never mind talk about it but it is important to talk more openly to the people that matter to us about what we would like them to know, and do, in the event of serious illness or death. In more formal terms, this type of conversation is often called Advance Care Planning and is usually only offered to people who are facing a serious life limiting illness.

Through The Heart of Living and Dying we try to bring advance care planning into the public domain, thus enabling anyone, not only those who are ill, to participate in this gentle, supported conversation about what matters to them in living and dying and then begin to plan ahead. By so doing, we hope it encourages people who are well, to think forward and explore their goals, hopes, concerns, or fears regarding that time in their life when, for whatever reason, dying is brought into sharper focus.

I wrote this facilitator's guide to help you plan and hold this type of conversation with your group and it describes the steps for you to take as the group's overall facilitator.

Some of you might be interested in additional information about advance care planning, public health approaches to wellbeing or the role of Arts in health and well-being so, at the end of the guide, some references and links are included which you may find of interest. Facilitating The Heart of Living and Dying conversation itself does not require reference to these links.

In our experience of hosting these conversations in the Southern Health and Social Care Trust, people can speak openly and freely about important matters when they feel comfortable and invited to do so. This guide will help you create that comfortable space as well as guide you in your facilitation.

If you choose to use this guide, we would like to hear how you found it.
Please do contact us at 028 37 560592 and let us know.
Or for any other enquiries relating to "The Heart Of Living and Dying" contact Deirdre.mckenna@southerntrust.hscni.net.

Deirdre McKenna
Specialist Palliative Care Social Worker, SHSCT

2.0 Background

In May 2017 to mark Dying Matters Awareness Week the Southern Health and Social Care Trust (SHSCT) ran a series of events called The Heart of Living and Dying. These events offered the general public the opportunity to engage in an Advance Care Planning conversation. The Heart of Living and Dying is a two hour group process which has been designed by Deirdre McKenna, the SHSCT Community Specialist Palliative Care Social Worker. These events were planned and delivered jointly by staff from the SHSCT, Southern Area Hospice Services and Arts Care.

These events were widely advertised across social media, newspapers, church bulletins and flyers so as to raise awareness amongst the public of the opportunity to join in a conversation about what matters to them in their living and their dying.

What participants have said:

"I found it to be a very powerful and empowering experience. Reaching to the core, the actual heart of living and dying, was an emotional experience but one which was so enlightening and indeed motivating."

"It was so good to share experiences both within the smaller groups and the larger groups, we need to talk more openly about what matters to me."

"It was interesting to reflect on what matters to me as a person and not as a patients advocate. This was a positive reflection as if something is important to me it is important to consider these issues in relation to my patient's needs."

"My first reaction was this is of great importance to me. I asked myself have I ever really given much thought to it. For me it was a very pleasant enlightening experience - the openness of sharing in the group very encouraging."

"Very difficult subject that you want to put off, culture of N Ireland/don't talk/ stiff upper lip, it is very important that next of kin know what you want."

"The value of such a beautifully facilitated event cannot be overstated. The follow up memento serves as a gentle reminder to make my wishes known and a genuine appreciation for my participation. Thank you."

3.0 Preparation

Purpose

It's important to be very clear about what you intend to do, why you intend to do it and how you intend to do it. Find a simple, clear sentence which describes what your *Purpose* is. For The Heart of Living and Dying, the purpose is to enable people to gather together to talk about what matters to them in their living and their dying and to begin to think about planning ahead.

A clearly defined purpose helps the facilitator to maintain her/his focus as well as the focus of the group. It provides a reference point for those times when people initiate discussion about unrelated issues, or have gone off track. To bring the conversation back to The Heart of Living and Dying the participants can be gently reminded of the overall purpose agreed at the beginning of the session.

Room set up

The tables and chairs are arranged in a café style. Each table accommodates only six or seven participants. This promotes a greater level of participation since people can hear each other more easily and feel more able to contribute to the conversation in this small group.

The room has a flip chart or notice board, which can be referred to as the "jottings board" upon which participants will be invited, at various times during the process, to post their thoughts on what matters to them.

Each table has water, pens, glasses, sweets and fruit along with some sticky notepaper for those all-important participants' thoughts or doodles. The act of doodling in itself may help some participants clarify their thinking or manage any anxiety about the nature of the conversations.

Tea and coffee is available in the room and people are encouraged to help themselves as and when they need a top up. Again, this adds to a level of informality which may help some people feel more comfortable. Getting up and refreshing their tea or coffee may allow some people take a breather from the conversation, get up, move around and then return to their seat.

4.0 The actual session

The two hour event begins with the facilitator welcoming the participants and delivering a very short PowerPoint presentation.

In our culture, as in most cultures, “welcome” is very important and it is good to pay attention to it here as people gather for this event. This is your first opportunity to demonstrate that people will be safe here, will be taken care of and will be treated with respect. This is your opportunity to set a warm, caring, informal and attentive tone. Some people may have come along alone, some may be anxious or nervous about the event and some people may have wandered into your event by mistake! This is an informal welcome which you and those assisting you need to attend to, introducing yourself, shaking hands as people come in, showing them to the tea and coffee, general chit chat and offering them to take a seat at one of the tables.

Slides

This presentation consists of 7 slides. Slides 1-5 are used at the beginning and slides 6 and 7 are used to conclude the event. The slides describe the purpose, the outline of the 2 hour session and the group agreements or ground rules for participation and provide the reassurances some participants may need about the nature of the event. These slides and the script are included in appendices 2 and 3.

In addition, having this very short slideshow allows people settle into the room, gives them a focus during which they can relax and attend to any discomfort they might have particularly if sitting among people they don’t know.

Staff at the tables

Each of the tables has a staff member present to help guide the conversation in the smaller groups. The event moves from whole group conversation to small group table talk and back to whole group conversation. Some conversation prompts may be offered to stimulate thinking and speaking if required. The staff members at each table offer a guide, specifically they keep a focus on the purpose and to the group agreements. A role description for the staff member at each table is included in appendix 4.

After the first or second round of small group conversation, participants are encouraged to jot down key words or phrases on sticky notepaper and place them on the jottings board or flip chart. During these short breaks, participants are encouraged to help themselves to more tea or coffee and to read over the jottings board. This serves to encourage participants as they recognize the commonality among strangers in what actually matters to people. This encouragement helps participants risk a little more of themselves and really begin speaking from their heart.

The artist

The visual artist and/or poet attending the event has a "listening" role in that she listens to the heart of what is being said and notices the mood/emotions of the participants. The artist then reflects what they have seen and heard in either a piece of visual art or a poem.

This artwork offers an invaluable addition to the entire experience for 2 reasons:

1. **It is a keepsake of the person's conversation and experience.**
2. **It serves as a prompt to the participant to revisit the conversation with family members or others important to them.**

The use of art has an important role in transforming capacity to cope with bereavement and open up a healthier public conversation about death. *(Westminster report 2017).*

5.0 Facilitation

Each Heart of Living and Dying event is facilitated by someone with advanced facilitation skills and experience of group work. This enables the facilitator to attend to the two key aspects of facilitation, firstly the task at hand i.e. the purpose, and secondly, the actual group process itself: the relationships in the group. The facilitator needs to be attentive to the pace of the conversation at the small tables, the mood among participants, the comfort and safety of those gathered, and be competent enough to make an effective intervention in the event of for example the group going off topic or one participant dominating the conversation, or the staff member at a table having difficulties guiding the small group.

While a very informal style is maintained throughout to encourage participants relax into conversation, staff remain very much on alert and vigilant for any signs of distress or difficulty among participants. Given the nature of these conversations, people may become tearful or distressed at times which can be attended to in the small group. However, we would consider it best practice to have enough staff present that should someone become so distressed they needed to step out of the room for a short time, a staff member is available to accompany them and offer support.

A 2 hour session will typically allow for 4 rounds of small group conversation. These rounds may be interspersed with a check in by the facilitator with the whole group or by allowing participants to post on the 'jottings board' or by a comfort break.

Endings

How the two hour session ends is as important as any other aspect of the process. The facilitator needs to manage the endings with the same high level of skill and attention in order to fulfil her duty of care to the people who have gathered and participated in the conversation. In our experience of facilitating these conversations, participants do speak from their hearts and in doing so share at quite a profound level. People do not usually speak in group settings about dying or about hopes or fears regarding future care. So this is a very different type of conversation for participants to be having. Good endings ensure participants are able to leave the session feeling grounded, and re oriented back into what is, for them, their more usual level of relating and being.

After the last round of table conversation the facilitator invites from the whole group 1 or 2 people to share some of their personal responses. This is an invitation to the group and it is important to ensure no participant feels pressured to speak.

People may be reluctant to speak out in the whole group so the facilitator needs to remain assured, patient and be gently encouraging of those gathered.

When a few people have shared, the facilitator draws the session towards conclusion by firstly inviting participants to use a word or phrase to describe their experience of the 2 hour session.

Following this short feedback session the facilitator introduces slides 6 and 7 which includes a thanks for coming, signposts to support services and offers copies of a booklet such as “Your Life Your Choices” (available from Macmillan.org). These two slides also remind participants to do something restful and gentle for themselves in order to soften the tiredness they may feel following the conversation experience.

Staff debriefs

The final tasks of the facilitator when the session has ended and the participants have left is to provide those other staff present with an opportunity to debrief. The nature of these conversations may trigger personal experiences of death and dying and this emotional impact needs to be attended to.

The facilitator will also collect all of the sticky notepaper on the jottings board or any scribbles left at the small tables since these may be someone’s very personal thoughts or feelings.

Following the first series of The Heart of Living and Dying hosted in May 2017 the jottings were re worked into a word cloud which expressed in truly visual terms what the participants considered “mattered to them”. The visual is included on the front cover of this guide and is used in all subsequent advertising and promotion of The Heart of Living and Dying.

6.0 Feedback/Evaluation

An evaluation form is sent out to participants along with the art piece, typically 6 to 8 weeks after the event itself. This short evaluation template is included in the appendix 5. Those evaluations completed and returned have consistently provided positive feedback and encouragement to continue hosting The Heart of Living and Dying conversations.

A more robust evaluation of this initiative, through a university based research module is planned for 2019.

7.0 Some things to look out for!

We strongly recommend that you attend one of these Heart of Living and Dying conversations as a participant before taking on the role of Facilitator. Because the facilitator has thought about these questions and had the personal involvement in the conversation, she/he will feel more comfortable facilitating a group in which the discussions centre on death and dying. This will also serve as a good safeguard for the group.

Give a full briefing to staff and artists who are helping to facilitate this work. Ensure all are clear on both task and process.

Some people may arrive thinking they are attending "training". Address this misunderstanding early on and clarify purpose encouraging all participants to speak only for themselves and experience the process of speaking personally.

It is also important the facilitator is able to follow the rhythm of the group and be able to adapt and adjust accordingly. She/he may find one table is ahead or behind another; this can happen so just engage the faster group with a new prompt!

Maintain a high level of vigilance throughout for any signs of distress and respond appropriately. Tears can be expected so don't worry about that just ensure the person has the support she or he needs either inside the room or outside of it.

Trust the group: once people settle in allow them explore these issues and talk freely.

"the facilitation is so important and how the facilitator is able to read the group is vital. People will come to this for different reasons. It does help when the facilitator is able to balance and blend care, compassion and humour." (participant comment)

8.0 Rationale for developing this process

Public health approaches to palliative care recognise that dying, death and bereavement are inevitable parts of human experience and are not primarily medical events in isolation (National Palliative and End of Life care Partnership 2015).

The Heart of Living and Dying contributes to a public health approach to Advance Care Planning (ACP).

"Advance care planning is an on-going process of discussion between the person, those close to them and their health care professionals focusing on the person's wishes and preferences for their care as they approach the end of their life" (Public Health Agency, unpublished but forthcoming, 2018). Advance care planning is one of the four palliative and end of life care priorities identified by the Regional Palliative Care Programme Board in Northern Ireland.

According to Preston et al (2011).

> *"The timing of ACP is a highly individualised concept reflecting the different stages of acceptance of illness experienced by patients. It would appear that appropriate timing poses a particularly unique challenge" pg135*

The issue of timing might be addressed by promoting a public health approach to ACP. This approach enables people consider and plan ahead for their future health care needs while they are well thus taking the conversation out of the context of serious ill health. This reflects the aim of The Heart of Living and Dying which is offered by the SHSCT.

According to the National Palliative and End of Life care Partnership (2015) people are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

And at the same time, research shows, that Health and Social Care Professionals have difficulty discussing end of life. Age UK (2013) state that
"HCPs find it difficult to discuss end of life issues and death with patients" (pg11)

Nursing students report difficulties in dealing with death (Sadala and da Silva, 2009; Parry, 2011; Edo-Gual et al, 2014; Strang et al, 2014). They often feel emotionally unprepared to care for dying patients (White and Coyne, 2011).

The Heart of Living and Dying addresses this issue of "timing" in that it takes advance care planning out of the context of ill health and into the general population. Where health and social care professionals participate in the conversation themselves, they report a greater ease in speaking about death and dying. This helps address HCPs discomfort or lack of confidence in this area.

Appendix 1

Planning group

Deirdre McKenna: *Specialist Palliative Care Social Worker SHSCT*
Aileen Mulligan: *Palliative Care Lead SHSCT*
Anne Coyle: *Bereavement Coordinator SHSCT*
Neil Gillan: *User Involvement SHSCT*
Gwen Stevenson: *Arts Care Artist*
Fiona Robinson: *Senior Social Worker Southern Area Hospice*
Members of the Community Specialist Palliative Care Team SHSCT

Appendix 2

Facilitator's script for PowerPoint presentation

Slide 1

My name and role and it's my pleasure to welcome you on behalf of the Southern Trust and our partners for these events, SAHS and Arts Care, to this conversation about living and dying, (replace these organisations for your own).

Slide 2

Our purpose is very simple, in one sense, to have a conversation about what matters to us in our living and our dying, yet in another sense, this is one of the most profound conversations any of us may take the opportunity to have.

The Heart of Living and Dying is all about "what matters to you". "Heart" is a very different centre from which we speak in this conversation; and it is therefore really important that each one of us, pay attention to how we are as we speak and listen.

Slide 3

As hosts, having issued the invitation to you, we hope to offer you a comfortable, informal, homely space where you can speak safely, comfortably, confidently, freely about what matters to you.

Tea and coffee is available to you throughout this time and please feel free to get yourself the top ups you need.

The nature of our conversation can trigger emotional responses in us and so there are a few staff here who are keeping an eye out for you and if anyone feels the need to step out of the room for a while, then please feel free to do so. When you give yourself a few moments to compose we hope you will feel able to re-join us.

Slide 4

We also have some very general group agreements, (sometimes called ground rules) which we hope will add to this comfortable space for you, and allow you speak from your heart knowing your contribution will be listened to, respected and heard without judgement or criticism.

At each table we have a staff member who will help guide your conversation and keep an eye to our purpose and to these group agreements. We also have little sticky notepaper and pens and we encourage you to use these to doodle or scribble down any thoughts, ideas, insights, feelings on these and we can add them to our "jotting" board for all to see.

We also have with us a Gwen, a visual artist and Alice, a poet (replace these with the names of your own artists). Neither of whom will participate in your conversation, but whose role will be one of "a listening witness" to your conversations at the tables and they will then try to capture the heart of what you say. Art is after all the language of the heart and soul.

Just before the end of our conversations, Alice will recite for us a poem reflecting back to us what she has heard us say. And Gwen will take away her impression of the conversations and create a piece of art reflecting this.

Slide 5

So this is how we will work together during this time.

A very fluid movement or rhythm of whole group work and small group table conversations. You will be invited at times to speak but no one will be forced to or put upon, so please don't worry about that.

So, let me check in with you at this point, how are you as you sit here ready for this conversation?

(take some verbal responses)

Then invite people to turn into their tables and begin by introducing themselves and saying what brought them here.

At the end of the two hour session, go back to slideshow and use the concluding slides to attend to some business bits at the end.

Slide 6 and 7

Conclusion: gathering in: inviting from whole group

"Would anyone like to give us a sense of how you found the experience?"

(take some verbal responses)

We have a few leaflets available with contact numbers of organisations who provide advice and support should anyone feel they need to talk about any issues that may have arisen following this experience. Please feel free to take one.

Your Life Your Choices: please also feel free to take one of these booklets with you if you feel you would like to continue this conversation with someone at home or in your family.

Thank you for joining us in this conversation; for having the courage to come and talk about what matters to you in living and dying. Hold yourselves gently as you go and be very compassionate to yourself for having taken the time to consider these weighty matters.

For anyone who would like copies of the art and/or poem, if you leave your contact details with us now we will send the finished pieces to you as a memento of this event.

Finally, we would welcome some indication from you as to how this experience was for you and to this end we invite you, as you leave, to take a bead, button, stone and place it in one of the 3 jars at the door indicating how you found this experience.

And if anyone feels they would like to offer a fuller feedback or evaluation you can contact our Line Manager to do so.

Appendix 3

PowerPoint presentation – slides

Appendix 4

Role description for staff member at each table.

Your task is essentially to help people talk and help the others listen.

Welcome people in small group and ask them to introduce themselves.

Explain you are there to guide conversation and keep an eye on "purpose" and on "group agreements".

Explain you are not making notes or keeping a record of the conversation.

Explain the use of "post its" if people want to joint down their thoughts, insights, and stick on "jottings" board.

Invite people to answer "why did you come to this session?" and allow each one time to answer, encouraging them to elaborate as appropriate. This initial enquiry may well enable people to begin talking about what matters to them. i.e get into the heart of the sessions purpose".

Maintain a very "light touch" facilitation style, staying out of the way of the conversation as much as possible and only gently drawing attention to purpose or group agreements if these are being neglected. Use all of your lovely listening skills throughout this session.

Use additional "prompts" only when conversation feels like it has dried up and the group needs another wee prompt (be careful these don't produce a question answer type situation).

There are no experts in the group, each person is speaking personally about what matters to her/him. This is not about giving advice, arguing, etc.

Some additional prompts should you need them

What's really important to me in life is.....

Some of my happiest memories, as I reflect back on my life are.....

During the really hard times in my life, what sustained me was.....

When I think ahead to a time when I am less well, I would worry about.....

I think people close to me would worry about.....If I became really unwell

Some things that give me strength or courage are.....

When I think ahead about my own normal dying I.....

How do I want to be remembered.....

(there is no particular order on these. Please use according to your feel of the where the group is at.)

Appendix 5

Post Event Evaluation Template

1 When you reflected on the experience of talking about what matters to you in living and dying, what were your thoughts?

2 Following your participation in the conversation, did you speak to anyone at home about what matters to you in living and dying?

3 Would you encourage others to participate in a conversation like "The Heart of Living and Dying"?

4 Have you any advice/suggestions about how we can improve on the experience or encourage others to join in?

5 Any other comments?

Appendix 6

References.

Age UK: **End of Life Evidence Review 2013**

All-Party Parliamentary Group on Arts, Health and Wellbeing: Inquiry Report (2017)

**Ambitions for Palliative and End of Life Care:
A national framework for local action 2015-2020**

Edo-Gual, M., Tomás-Sábado, J., Bardallo-Porras, D. and Monforte-Royo, C., 2014. **The impact of death and dying on nursing students: an explanatory model.** *Journal of clinical nursing, 23(23-24), pp.3501-3512.*

Parry, M., 2011. **Student nurses' experience of their first death in clinical practice**. *International Journal of Palliative Nursing, 17(9), pp.448-453.*

Preston, H., Fineberg, I.C., Callagher, P. and Mitchell, D.J. (2012) **The preferred priorities for care document in motor neurone disease:** *Views of bereaved relatives and carers. Palliative medicine, 26 (2), 132-138.*

Public Health Agency (2016) **Advance Care Planning: Operational Guidance for Health & Social Care Staff in Northern Ireland, Belfast** *(unpublished but forthcoming 2018)*

Sadala, M.L.A. and Silva, F.M.D., 2009. **Taking care of terminal patients: nursing student's perspective.** *Revista da Escola de Enfermagem da USP, 43(2), pp.287-294.*

Strang, S., Henoch, I., Danielson, E., Browall, M. and Melin-Johansson, C., 2014. **Communication about existential issues with patients close to death—nurses' reflections on content, process and meaning**. *Psycho-Oncology, 23(5), pp.562-568.*

White, K.R. and Coyne, P.J., 2011, November. **Nurses' perceptions of educational gaps in delivering end-of-life care.** *In Oncology Nursing Forum (Vol. 38, No. 6).*

https://be.macmillan.org.uk/be/p-21065-your-life-and-your-choices-plan-ahead-northern-ireland.aspx

Further Reading.

Ashton, S.E., Roe, B., Jack, B. and McClelland, B. (2016) **End of life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia-A qualitative study**. *Dementia: The International Journal of Social Research and Practice, 15 (5), 958-975.*

All Ireland Institute of Hospice and Palliative Care. (2015) **Let's Talk About Palliative Care Survey Report**

Bollig, G., Gjengedal, E. and Rosland, J.H. (2016) **They know!-Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes.** *Palliative Medicine, 30 (5), 456-470.*

Brown, C. and Lowis, M.J. (2003) **Psychosocial development in the elderly: An investigation into Erikson's ninth stage.** *Journal of Aging Studies, 17 (4), 415-426.*

Candy, B., - Jones, L., - Drake, R., - Leurent, B. and - King, M.- **Interventions for supporting informal caregivers of patients in the terminal phase of a disease.** - *John Wiley & Sons, Ltd. Available from: - http://dx.doi.org/10.1002/14651858.CD007617.pub2*

Coulter, A., - Entwistle, V.A., - Eccles, A., - Ryan, S., - Shepperd, S. and - Perera, R.- **Personalised care planning for adults with chronic or long-term health conditions.** - *John Wiley & Sons, Ltd. Available from: - http://dx.doi.org/10.1002/14651858.CD010523.pub2*

Davidson, S. and Gentry, T. (2013) **End of Life Evidence Review.** *London: Age UK*

DHSSPSNI (2011) **Transforming Your Palliative and End of Life Care,** *Belfast: Health and Social Care Board*

Department of Health and Personal Social Services (NI) (2012) **Improving and Safeguarding Social Wellbeing: A strategy for Social Work in Northern Ireland 2012–2022.**

Department of Health, Social Services and Public Safety (2010) **Living Matters, Dying Matters. A Palliative and End of Life Care Strategy for Adults in Northern Ireland.**

Detering, K.M., Hancock, A.D., Reade, M.C. and Silvester, W. (2010) **The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial.** *BMJ: British Medical Journal, 340 (7751), Sefe.*

Dickinson, C., Bamford, C., Exley, C., Emmett, C., Hughes, J. and Robinson, L. (2013) **Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning.** *International Psychogeriatrics, 25 (12), 2011-2021.*

Fried, T.R., Zenoni, M., Iannone, L., O'Leary, J. and Fenton, B.T. (2017) **Engagement in Advance Care Planning and Surrogates' Knowledge of Patients' Treatment Goals.** *Journal of the American Geriatrics Society*

Heyland, D.K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., Shortt, S., Tranmer, J., Lazar, N., Kutsogiannis, J., Lam, M. and Canadian Researchers End-of-Life Network(CARENET) (2006) **What matters most in end-of-life care: perceptions of seriously ill patients and their family members.** *CMAJ: Canadian Medical Association journal = journal de l'Association medicale canadienne, 174 (5), 627-633.*

Jeong, S.Y., Higgins, I. and McMillan, M. (2011) **Experiences with advance care planning: Older people and family members' perspective.** *International Journal of Older People Nursing, 6 (3), 176-186.*

Macmillan Cancer Support (2018) **Missed Opportunities Advance Care Planning Report**

NHS. (2008) **End of life care. Advance Care Planning: A Guide for Health and Social Care Staff**

National Institute for Health and Clinical Excellence (NICE) (2011) **End of life care for adults Quality standard [QS13**

Reports.

Horsfall D., Yardley A., Leonard R., Noonan K. & Rosenberg J. (2015) **End of Life at Home: Co-creating an Ecology of Care.** *University of Western Sydney & Cancer Council of NSW.*

Horsfall D., Noonan K., & Leonard R. (2011). **Bringing our dying home: creating community at end of life.** *Research Report. University of Western Sydney & Cancer Council of NSW.*

Creative Health: The Arts for Health and Wellbeing July 2017

Journal Publications.

Abel. J., Walter, T., Carey, L., Rosenberg, J., Noonan, K., Horsfall, D. et al. (2013) **Circles of care: Should community development redefine the practice of palliative care?** *BMJ Supportive & Palliative Care 3: (4) 436-443.*

Abel, J., Bowra, J., Walter, T. and Howarth, G. (2011). **'Compassionate community networks: supporting home dying.'** *BMJ Supportive & Palliative Care 1 (2), pp. 129-133.*

Ashby, M. (2013) **Caring for dying patients is not about prolonging life at all costs.** *BMJ 2013;346:f3027 doi: 10.1136/bmj.f3027*

Conway, S. (2008). **'Public health and palliative care – principles into practice?'** *Critical Public Health, 18 (3), pp. 405-415.*

Haraldsson, E., Clark, P. and Murray, S.A. (2010). **'Health-Promoting Palliative Care arrives in Scotland.'** *European Journal of Palliative Care 17 (3), pp.130-132.*

Horsfall, D., Leonard, R., Noonan, K., & Rosenberg, J. (2013). **Working together–apart: Exploring the relationships between formal and informal care networks for people dying at home.** *Progress in Palliative Care (ISSN: 09699260) Appeared or available online: 25 January 2013. DOI:10.1179/1743291X12Y.0000000047*

Horsfall, D., Noonan, K., Leonard, R. (2012) **Bringing our Dying Home: Creating community at end of life,** *Health Sociology Review 21(4) 373-382.*

Kellehear, A. (2013). **Compassionate communities: End of life care as everyone's responsibility.** *Quarterly Journal of Medicine (UK) 106, 12, pp 1071-1076.*

Kellehear, A. & O'Connor, D. (2008) **Health Promoting Palliative Care: A practice example.** *Critical Public Health (UK) 18, 1, pp 111-115.*

Kellehear, A. (2004). **'Third-wave public health? Compassion, community and end of life care.'** *International Journal of Applied Psychoanalytic Studies, 1(4), pp. 313-323.*

Leonard, R., Horsfall, D., Noonan, K. (2013). **Identifying changes in the support networks of end of life carers using social network analysis,** *BMJ Supportive and Palliative Care, Published Online First December 2013. doi:10.1136/bmjspcare-2012-000257*

Noonan K., Horsfall D., Leonard R., & Rosenberg J.P. (2016). **Developing Death Literacy. Progress in Palliative Care.** *Published on-line first. DOI 10.1080/09699260.2015.1103498*

O'Mara-Eves A, Brunton G, McDaid D, Oliver S, Kavanagh J, Jamal F, et al. (2013) **Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis.** *Public Health Research 1(4).*

Paul, S. and Sallnow, L. (2013) **'Public health approaches to end of life care in the UK: An online survey of palliative care services.'** *BMJ Supportive & Palliative Care, Published Online First doi:10.1136/bmjspcare- 2012-000334.*

Rosenberg J., Horsfall D., Leonard R., & Noonan K. (2015) **Informal caring networks for people at end of life: Building social capital in Australian communities,** *Health Sociology Review, 24:1, 29-37, DOI: 10.1080/14461242.2014.999400*

Rosenberg J., Horsfall D., Leonard R., Noonan K. (2014). **Informal caring networks for people at end of life: building social capital in Australian communities.** *Health Sociology Review. E-View Ahead of Print. doi: 10.5172/hesr.2014.4226*

Rumbold, B., Aoun, S. (2014). **Bereavement and palliative care: A public health perspective.** *Progress in Palliative Care 22(3), 131-135. (If you click on the title you can read it now, for free!).*

Sallnow, L. and Paul, S. (2014) **Understanding community engagement in end of life care: developing conceptual clarity.** *Critical Public Health http://dx.doi.org/10.1080/09581596.2014.909582.*

http://aiihpc.org/wp-content/uploads/2015/02/Briefing-Paper-Public-Health-Approaches-to-Palliative-Care-Nov-2017.pdf

http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf

https://www.palliativecarescotland.org.uk/news/news/new-report-on-public-health-approaches-to-palliative-care/

http://www.phpci.info/

Arts Care

info@artscare.co.uk
artscare.co.uk

Arts Care, founded in 1991, is a unique Arts and Health Charity based in Northern Ireland. In partnership with Health and Social Care Trusts throughout Northern Ireland, Arts Care engages 19 Artists-in-Residence, a team of Northern Ireland Clowndoctors and many project artists who facilitate and co-ordinate participatory workshops and performances. Believing in the benefits of creativity to well-being, Arts Care makes all forms of art accessible to patients, clients, residents and staff in health and social care settings. Arts Care selected Gwen Stevenson and Alice McCullough to work with 'The Heart Of Living & Dying' initiative.

Gwen Stevenson is an award-winning new media and visual artist. She has represented Ireland at Estudio Abierto in Argentina and won the Claremorris Open Prize for Visual Art. She has a socially engaged arts practice working in arts in health and community arts projects across Northern Ireland. Gwen delivers digital art workshops such as community filmmaking, digital story telling, video and stop motion animation. She also delivers traditional art workshops in painting, photography, crafts, textiles and sculpture. Gwen's own practice resides in the intersection between art and technology and on the physical border of Northern Ireland. Her community artwork aspires to make art and creativity accessible to all.

Alice McCullough is a forerunner on the wave of spoken word talent rising in Belfast. Her award-winning poetry performances have captivated audiences, from her 'Alice Fresco' outdoor recitals to her critically acclaimed one-woman show 'Earth to Alice' her work has gained praise and recognition both in her hometown and beyond. Alice's unique way with words has won her a presence on local and international radio with poems commissioned for both television and radio. She has supported talents in poetry, comedy and music including Hollie McNish, Katherine Ryan, Tony Walsh and Lemn Sissay.

(All of the artwork contained in this guide has been created by Gwen Stevenson.)

Alice's poem

Here at the foot of the Mountains of Mournes,
we've come from the comfort of our homes
to this cosy hotel,
and it's beautiful.
Just the drive here this morning would sooth the soul
all sunny, alive and full of Spring,
wee rabbits hopping on the green.
And isn't life a precious thing
when you think about it all.
And I guess that's why we're here today
to stop and think
to have our say
on why life matters
alll the ways we share these precious moments.
Enjoy the cool breeze on a sunny day
the journey
the lessons along the way.
We all want to make the most of it.
We all want to enjoy our time here,
that bit of sun.
But we're not just here to take about life,
not just here to talk about the easy fun stuff,
not just here to have a wee scone,
although the scones help us along.
We're here to talk about what happens when we come to the end of life,
what happens when we need to have those uncomfortable conversations.
It can be difficult, painful even.
But when we gather together
when we share and all these mixed emotions come to the surface,
we begin to speak the language of the heart.
We may not move mountains.
We may not find all the answers
but once we've broken though the silence,
once we've been given permission to talk
about those things we don't often talk about,
it's a good start along this path we all must walk.

A good wee bit of support
to help prepare us and our loved ones for the future.
We hear ourselves in a different form.
We talk about how we'd like to go on living
how we might want to change,
how we might want to rearrange things.
We share all those things that matter most to us
peace of mind, our quality of life, loving and being loved
our family, their safety, health and wellbeing.
We talk about how we'd like to live our lives and
how we might prepare for when we die.
Strange to hear ourselves say these things out loud
strange but good.
Maybe initially we didn't want to go there
but now somehow it feels comfortable.
It's amazing, empowering.
We feel more relaxed when we share these things
and realise we share so many of the same wishes hopes and dreams.
Sometimes you haven't thought about these things until someone asks you.
Sometimes it feels too taboo.
Sometimes you're just too busy
just too on top of things to go under the surface.
But today we took that risk,
spoke from the heart,
shared our emotions,
made connections,
shared the privilege of witnessing real true storytelling
and special moments,
some tears but also laughter
shared together
And I hope we can all go home feeling better for it
gracious and thankful.

Notes

Notes

Southern Health and Social Care Trust

Quality Care - for you, with you

Palliative Care in partnership