Network Recording Declaration

During this ECHO session discussions will be recorded so that people who cannot attend will be able to benefit at another time. Filming is regarded as ‘personal data’ under the Data Protection Act 2018 General Data Protection Regulations (GDPR), under that law we need you to be aware that:

• This Data will be stored with password protection on the internet.
• This Data will be available for as long as your network continues to meet and will then be taken down from the internet and either stored securely at the Superhub or deleted.

Your ongoing participation in this ECHO session is assumed to imply your agreement to the use of your data in this way.

If you are NOT willing for your data to be used in this way, please LEAVE the session at this point.
## Agenda

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<tr>
<th>Time</th>
<th>Item</th>
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<tr>
<td>10:30</td>
<td><strong>Introduction and call for papers</strong></td>
<td>Craig Duncan, Interim Chief Executive Officer, Hospice UK</td>
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<tr>
<td>10:35</td>
<td><strong>Hospice UK Bereavement Project, Mind the grief gap</strong></td>
<td>Anita Hayes, Head of Clinical Leadership, Hospice UK</td>
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<tr>
<td>10:50</td>
<td>Questions &amp; Group Discussion</td>
<td>All</td>
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<tr>
<td>10:55</td>
<td><strong>Practice example: Bereavement hubs</strong></td>
<td>Suzann Chantrill, Bereavement volunteer support/enabler, LOROS hospice</td>
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<tr>
<td>11:05</td>
<td>Questions and Group Discussion</td>
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<td>11:10</td>
<td><strong>Dying Matters Awareness week</strong></td>
<td>Sarah West, Director of Campaigns and Communications</td>
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<tr>
<td>11:25</td>
<td>Questions and Group Discussion</td>
<td>All</td>
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<tr>
<td>11:30</td>
<td>Close</td>
<td>Craig Duncan, Interim Chief Executive Officer, Hospice UK</td>
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</table>
Mind the Gap: the Hospice UK Bereavement QI project

Anita Hayes  Head of Clinical Leadership  Hospice UK

27 April 2022
Two years ago ....

Mar 2020

Nov 2020

Full lockdown

Partial lockdown

www.hospiceuk.org
Programme aims: to ‘extend’ reach and improve access

• Reaching out to people who were previously unknown to the hospice
• Enabling a system change to create virtual delivery models
• Ensuring hospice staff had the necessary skills and confidence to provide the required support virtually

Participating hospices rapidly prototyped models of virtual bereavement support
Virtual bereavement support during the pandemic: poll
The bereavement project

Hospice UK Team
Cat Sullivan
Amber Morgan

Reference Group

www.hospiceuk.org
“UK faces a post-pandemic bereavement crisis and lasting legacy of grief”

Lucy Selman (2021) University of Bristol, Press release 15 06 2021
“I felt slightly overwhelmed with the grief within the room, but also a sense of relief that we were amongst people who truly understood the loss we all feel.”

“.. I wasn’t sure how the group would work through Zoom. It worked okay though.”

“great help to those who attend and us as an organisation in terms of the support we can offer. A great joint venture with sharing of expertise and skills. We hope very much we can continue to support carers in this way.” Attendee from the carer support organisation.

The programme’s reach during the six month piloting phase

At least 273 people who were bereaved received direct virtual support from hospice staff or volunteers.

Technology skills gained
At least 38 hospice staff and 74 volunteers developed their confidence and skills in using technology to provide different forms of virtual support.

187 people in communities gained greater skills and knowledge about supporting people who are bereaved.

Perceived confidence of service users’ ability to use video conferencing has risen by 24%.

Social media and website information
Website communication reached over 2,500.

Partnership working
One hospice connected to 250 care homes.
Others’ connections included primary schools, premiership football club, carer support organisations.

Social media adverts extended reach further e.g. one hospice had a collective reach of 55,000 with two targeted adverts.

Dissemination of learning
Over 200 individuals accessed the programme learning via the Hospice UK website (April 21 to Oct 21).

Bereavement skills gained
At least 52 hospice staff developed their skills in bereavement support.

Three ECHO™ community of practice sessions reaching 30 hospices.

71 hospice volunteers developed their skills in bereavement support.
Collective learning

- A wide range of bereavement support models appear to work well in a virtual environment
- Skills developed mainly for people experiencing unexpected death
- Also skills in trauma and grief in children & recognising traumatic grief in adults
- Referrals for bereavement support during the pandemic did not rise as anticipated
- Upskilling providers and the bereaved in the use of ICT and video conferencing should not be underestimated.
Learn to “trust the process”

Virtual working is just another mechanism to connect people together

“Trust the process, a reminder rather than a learning that human connection is the key element to support and healing.”

it is clear the pandemic has created a step-change in use of virtual support and virtual working.
Meeting the gap: system

Seek out those in need

Central coordination

Capacity and capability

www.hospiceuk.org
Meeting the gap: education and skills

Practice development/ Building Capability

- Children's and adult’s needs
- Diversity of need in communities
- Greater numbers
- ‘Non hospice’ bereaved people
- Nature of the different bereavement e.g. sudden
- Boundaries
- Onward referral
- Online space considerations
Meeting the gap is a combination of both ...skills and system ... as partners saw the benefits, they reach out more.

Reaching out with success needs a combination of factors:

- **Counsellor is able to meet needs and understand clients life [skills]**
- **Practical working relationships with people already working with the client group [system]**

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**Counselling for people who are homeless**

A number of factors enabled this project to provide 62 sessions to seven people who were homeless despite a number of challenges.

One enabler was counsellor's skills and approach:

"The counsellor was a trauma informed integrative counsellor, with additional online training. In particular, they offered flexibility, working with a chaotic group and not enforcing rigid appointments. Sessions had 30 minutes booked free afterwards to allow for late attendees, or those who may turn up early. This group do not wait! In the main they offered a single session model of working, always with the offer of more sessions when needed, but aimed at making use of each individual contact in case it was the only contact."  

Hospice Project Lead.

Another enabler was the ability of the hospice staff to develop close and practical working relationship with other agencies. This helped practical support for clients in some of the arrangements (access to a private space for counselling, printing materials, ICT, etc).

The hospice found they needed to have clear boundary management as they did not accept Tier 4 referrals.

The project has received additional 12 months funding from the Local Authority.

"It's given me the new version of me. It's given me confidence, a new lease of life. You have helped me find myself. I feel proud of myself."

Client Feedback
Rapid prototyping using Quality Improvement

Quality Improvement Tools

Model for improvement
Plan Do Study Act
Developed by Langley et al

30-60-90 action planning

Measurement for improvement

Driver Diagram

Sustainability tool
Recommendations

Build capacity and capability in bereavement support (all levels)

Blended approach – retain and build skills developed with virtual working and support

Hospice leading and working with new partners and new communities will enable equity and new innovation

Partnership working … connect to geography … based on an understanding of needs … with strategic leadership

Building capacity and capability in quality improvement methods

Community of practice: ECHO™ helpful virtual model
Sharing plans and ideas for next steps

please use chat to share ideas and concerns
Bereavement collaboration ECHO and Community of Practice

Registration link
https://tinyurl.com/59swda5s
Bereavement resources

www.hospiceuk.org/professionals/bereavement-project-resources-toolkit
Thank you
Practice example: Bereavement hubs

Suzann Chantrill, Bereavement volunteer support/enabler, LOROS hospice
Dying Matters Awareness Week 2022
From 2 – 6 May 2022.

With your support, our mission is to help people to talk about dying and grief, and plan for the end of life.

But if the healthcare system isn’t set up to deliver on those wishes, then people may not be dying in a good place.

Building on the work we did together in 2021, looking at what it means to be #InAGoodPlace when we die.
Three areas of activity

- Supporting events and activities around the country
- Sharing stories, and encouraging people to share their experiences
- Encouraging people to take action by writing to their MP
Supporting events

• Aiming for 200 events nationally (162 last year)

• Events can be registered and promoted via our website. Please flag to your networks!

• Templates are available on our website for your materials

www.hospiceuk.org
Supporting events

Featured events

Here are just some of the highlights we're looking forward to during Dying Matters Awareness Week!

- **Listening and Having Tender Conversations**
  - Wythnos Ymwybyddio Arf Byw Nawr: Dying Matters Awareness Week

- **Creating a death literate society in Northern Ireland**
  - Thursday 5 May 2022
  - 9.15am-10.45am
  - Online

- **There's no place like home? End of life Conference**
Supporting events

- New for this year - partnering with Libraries Connected to support events in libraries

Kathryn Mannix’s
Five books to help us think about dying, death and grief

*Granpa* by John Burningham

A picture book for younger children (and all of us) remembering happy times with Granpa, now that he has died and his chair is empty. A great way to engage in family discussion about the death of a person we love.

*Dear Life* by Rachel Carke

A palliative care doctor reflects on her work, on how dying can be made bearable, and the importance of talking about death realistically.

*Waiting for the Last Bus* by Richard Holloway

A wise and humble exploration of older age, and the approach of life’s end. How should we face our own mortality? Warm, kind and gentle.

*Grief is the Thing with Feathers* by Max Porter

A fictional blend of poetry and prose describing the grief of a widower and his young sons following the death of their mother. A beautiful and validating exploration of grieving, laced with wry humour, suitable for teens, young adults and grown-ups.

*Grief Works* by Julia Samuel

Using stories from her practice, an experienced grief therapist talks us through the pain and challenge of grief and offers tools that all of us can use to help us cope with bereavement.

Kathryn Mannix is the author of *With the End in Mind*, a collection of stories to show us how people live the last part of their lives, described by readers as surprisingly uplifting.

Dying Matters is a campaign run by Hospice UK.
On Tuesday 3 May at 4.30pm. Free & Online

Dying to talk
finding new ways to talk about death and grief

Simon Blake  Jude Kelly  Rankin  Rubina Khalid
Storytelling

• Sharing stories pushes change – for people and as a society

• Film with Maureen Anderson, telling her story about when her parents died at home during the pandemic

• Numerous other storytellers in the build up to and throughout the week

www.hospiceuk.org
Pushing for change

• We’ve been campaigning with some success on the issue of excess deaths at home and are mobilising the Dying Matters community on this issue.

• We are calling for deaths at home to be in the UK COVID inquiry. Support from nearly 50 Parliamentarians, lots of partner organisations, and coverage in Times, ‘I’, C4 News, Sunday Express, Politico, Press Association.

• We will launch a ‘write to your MP’ action on this issue too.
What you can do

Promote Dying Matters Awareness Week and ask people to:

- Join the Dying Matters community (17k)
- Encourage anyone you know who is organising an event to register it on our website
- Encourage people to write to their MP when that action goes live
- Join us on Tuesday 3rd May at 4.30pm for Dying To Talk

See Hospice UK Dying Matters website and social media channels on how to get involved
Next Session:

Topic: Commissioning in England

Date: 25 May 2022

Time: 10:30 – 11:30
Before you go…

https://www.surveymonkey.co.uk/r/Innovation27-04