

**International Bereavement Education Conference** Bereavement in the modern world: Kindness in the chaos

# Parallel Session Descriptions

### 11:35 Parallel Sessions

**1. Help Researchers from the University of Glasgow Develop a Bereavement Toolkit for Care Home Staff Professor Bridget Johnston**, Clinical Professor of Nursing and Palliative Care, University of Glasgow and NHS Greater Glasgow & Clyde and **Dr Maria Drummond**, Post Doctoral Research Associate, University of Glasgow

This project aims to develop and evaluate a toolkit that will be used by care home staff to support bereaved family members, friends and other residents following the death of a resident. This project uses a co-design approach with patient and public involvement and engagement (PPIE) weaved throughout. This means that key stakeholders are heavily involved in the project.

There are three phases to this project, the first being focus groups with care home staff from across Scotland. We will hear about current approaches to caring for family members, friends and other residents following the death of a resident.

Attendees of the parallel session are invited to participate in a PPIE activity. They will give feedback on focus group data and the toolkit. This will be an opportunity to learn about the importance of PPIE and caring for people who are bereaved.

### **Objectives:**

The primary objective of the session is to demonstrate meaningful PPIE in research using the development of a bereavement toolkit as a working example.

The secondary objectives of the session are:

- To enable better understanding of the co-design methodology.
- To share best practice in care home-related bereavement support.

Participants will:

- Learn about co-designed research projects.
- Learn about what patient and public involvement and engagement can add to research.
- Gain a better understanding of current bereavement support best practice.
- Be able to contribute to an active research project.
- Be able to influence future bereavement practice in care homes.

### 2. "Your Child has Died" - Using simulation training to improve care for bereaved families

Gill Burton, Acting Executive Director, Scottish Cot Death Trust

Professionals that respond to a sudden unexpected child death often find the procedures that surround this complex and can find the emotional and psychological needs of families challenging to support. From the research, bereaved parents state that their greatest needs are time and privacy with their child after death, transparency and information about their child's death and appropriate emotional support (Garstang et al, 2014). As such, provision of training which allows staff opportunities to implement guidelines and protocols in safe and non-judgemental environments and to practice communication and support skills are perceived as highly beneficial. This session will take attendees through simulation training as an important method of experiential learning for staff. We will cover the evidence base for the efficacy of simulation training, the requirements to rollout simulation training, and specific benefits which staff report to this kind of training in terms of impact analysis from two pilots which have been run across NHS Lanark and NHS Fife.

- Outline of the current background to SUDI deaths in Scotland.
- Why simulation training helps families AND helps staff.
- Awareness of SUDI protocols and procedures across agencies.
- Requirements to run SUDI simulation events.
- Needs and perceptions of professionals across statutory agencies and how to meet these.
- Doing the debrief facilitating worthwhile debrief sessions.
- Keeping Parent Lived Experience at the heart of care and processes.

### 3. Bereavement Following a Sudden Cardiac Death

**Helena Davison**, Clinical Nurse Specialist and Co-ordinator for Sudden Cardiac Death and OOHCA, Inherited Cardiac Conditions West of Scotland, NHS Greater Glasgow & Clyde and **Lisa Hay,** Registered Genetic Cunsellor, NHS Greater Glasgow & Clyde

This session will discuss the current project in the WoS Inherited Cardiac Conditions Service to improve the pathway for families following a Sudden Cardiac Death (SCD). One of the key aspects of this project is to improve psychological and bereavement support for families in Scotland affected by SCD.

The news of a sudden death is traumatic, and creates very strong emotions including anger and disbelief. We know from patient experience that we are not doing enough and continue to hear from families across Scotland that have had a challenging journey to get to the right services at the right time.

We will discuss the purpose of the co-ordinator role within the SCD care pathway and improving immediate emotional and psychological support. The session will demonstrate how the care co-ordinator role and ICS can help family's access essential resources. Other presenters will cover discussion of autopsy results and aftercare.

#### **Objectives:**

This presentation should improve awareness and knowledge of healthcare professionals managing and caring for families following a SUD/SCD. Demonstrating how the the use of integrated care pathways, can improve early identification and communication.

As part of this project we will review the evidence for bereavement support following SUD/SCD and gather feedback from families to gain knowledge of lived experience to design a service that meets their needs.

# 4. My Grief My Way: the development of an online bereavement support package integrating Acceptance and Commitment Training and grief theories

**David Gillanders**, Senior Lecturer in Clinical Psychology and **Anne Finucane**, Senior Marie Curie Research Fellow, University of Edinburgh

This session describes the development and evaluation of My Grief My Way (MGMW). MGMW is an online support package that uses Acceptance and Commitment Training (ACT) to help people to grieve effectively. MGMW uses video stories of people's grief. It also uses video, worksheets and audio exercises to nurture psychological skills for grieving in a healthy way.

Nature imagery, poetry and metaphor are used to enhance engagement. MGMW can be used as pure self-help, or guided self-help with a volunteer.

This session will introduce delegates to ACT and the MGMW website. The process of development, volunteer training and evaluation using mixed methods will also be described. Data collection and analysis will be completed by late summer 2024. Initial analysis suggests a high level of engagement, acceptability and feasibility of MGMW. Implications for increasing access to evidence-based support for people after bereavement will be discussed.

- 1. Participants will learn about ACT as a novel form of CBT that incorporates acceptance and mindfulness practices with values and behaviour change principles.
- 2. Understand how the ACT model and techniques can support other theoretical approaches such as dual process theory and continuing bonds.
- 3. Understand elements of mixed method treatment development studies such as patient and public involvement, logic models, rapid review, engagement with creative processes as a vehicle for the dissemination of psychological technology, cycles of user testing and mixed method evaluation.

### 5. Bereavement in the Workplace: responding to the death of a colleague

Lynne Innes, Lead for Spiritual Staff Care & Wellbeing, NHS Fife

As individuals, teams and managers we may naturally feel apprehensive about responding to the death of a colleague. This session will provide an opportunity to learn about a new series of recently developed learning resources by the NES Bereavement Education Programme team.

The session will aim to enhance the preparedness of health and social care staff in responding to the death of a colleague in a compassionate and supportive way.

### **Objectives:**

- 1. Appraise how health and social care staff, teams and managers respond to bereavement in the workplace and the differing impacts.
- 2. Apply greater confidence in providing support to and communicating with people bereaved by the death of a colleague.
- 3. Recognise the effects that responding to a bereavement in the workplace may have on us and apply this knowledge to describe how to support colleagues and teams to look after themselves and others.
- 4. Appreciate that having compassion and looking after ourselves is just as important as looking after others when we are bereaved.

### **15:20 Parallel Sessions**

# 6. Sing for Happiness: Understanding how singing in groups can improve mood and overall wellbeing

Samir Savant, Chief Executive, St George's Bristol and Kat Branch, Head of Centre for Music, UWE Bristol

Whilst participation in shared leisure activities is already recognised as a way of supporting people's mental health, there is increasing evidence that singing in groups may provide particular social and emotional benefits to participants. The emotional catharsis, deep feeling of connection to others and sense of meaning and empowerment that singing with others generates offers a safe, non-pharmacological and sustainable intervention for people experiencing negative affective states including bereavement.

This unusual and engaging session will demonstrate how group singing can improve social and psychological wellbeing, sharing the early findings of the first iteration of Sing for Happiness: the largest UK group singing study to date that was open to all members of the public (rather than those with a specific health concern) many of whom had never sung before and/or believed they 'could not sing'. These results will be contextualised into existing research about group singing and bereavement alongside the project founder's own journey of bereavement and singing, including suggestions about how clinicians can apply this knowledge.

### Objectives:

- 1. To understand the effect of group singing on mood and wellbeing.
- 2. To understand how the effects of group singing can help people experiencing bereavement.

3. To increase confidence in supporting bereaved people to access shared activities like group singing as part of the process of coping with and processing grief.

Please note you won't be asked to sing as part of the session.

## 7. Learning Kindness through Literature: prospects and limitations in the UK and Australia

**Dr Tamarin Norwood,** Leverhulme Early Career Research Fellow, Loughborough University, **Dr Emily Crosse,** Senior Clinical Teaching Fellow, University of Warwick, **Sara Ormes,** Undergraduate Student, Warwick Medical School, **Dr Katharine Gillett,** Practising Midwife and Lecturer in Midwifery, Newcastle School of Nursing and Midwifery Australia and **Professor John Boulton,** Emeritus Professor and Conjoint Professor, School of Medicine and Public Health, University of Newcastle

This paper presents two parallel qualitative studies – at Warwick Medical School (UK) and Newcastle School of Nursing and Midwifery (Australia) – measuring the impact of reading a literary account of bereavement upon trainee doctors and midwives. Our data, collected through focus groups and questionnaires (with long-term follow-up planned), indicate that literary accounts such as grief memoirs can expose healthcare professionals to lived experiences of grief more effectively than brief clinical encounters or other modes of teaching and learning.

It is by now well-established that integrating the arts and humanities into medical education can foster compassion, but in practice, such initiatives can be inefficient or ineffective, with impact difficult to quantify. Our studies address these limitations by identifying characteristics of literary writing most effective in 'teaching' kindness, empathy and ethical or moral experience; factors that can impede this mode of learning; and how to evidence changed behaviours and beliefs.

### **Objectives:**

- to share news of an effective pedagogical method for developing skills of kindness and empathy in trainee health and social care professionals, where time and resources are stretched;
- to share some worked examples of this method in practice, so delegates can try it themselves;
- to indicate how the same method can offer support for health and social care professionals who are themselves experiencing grief and bereavement.

Delegates will gain the following knowledge and skills:

- How and why to introduce literature, poetry and the arts into the curriculum.
- How to avoid common pitfalls and limitations when bringing the arts into healthcare training.
- How to make a case for such interventions in terms of funding, policy and the REF.
- How to identify and integrate the different kinds of expertise brought by scholars and practitioners of healthcare and the arts.

# 8. Developing a bereavement competency framework. An evidence base for an eLearning resource for bereavement service providers in the community

Amanda Roberts, National Bereavement Development Manager, Irish Hospice Foundation

The <u>Framework for Adult Bereavement Care</u>, based on the public health approach, suggests that people who experience bereavement have needs ranging from acknowledgement and compassion at Level 1 (all bereaved people) to specialist therapeutic support at Level 4 (minority of bereaved people). The framework also identifies supports/services appropriate to meet each level of need and the corresponding knowledge/skills for those providing support. However, there are no agreed standards for bereavement care services in Ireland, nor agreed competencies for service providers at any level of care.

The first phase of the project aimed to develop a CORE Competence Framework for bereavement service providers working at Level 2. A literature review of competence in bereavement care and aligned areas was conducted. The findings from this review informed a two-round eDelphi survey which was used to develop the competence framework. In the second phase, this framework was used to inform the development of an eLearning training resource for bereavement service providers.

- Outline the rigour and robust methodology used to develop the CORE competence framework for Bereavement Service provider working at Level 2 of the <u>Framework for Adult Bereavement Care</u>. (Service providers at Level 2 provide emotional and/or practical support to those who have been bereaved. The support is provided most commonly by a bereavement support volunteer or in the context of a person's professional role).
- Show how the framework provides a way to standardise the knowledge, skills and attributes expected of a service provider at Level 2.
- Describe the value of the framework, to both national and international bereavement service provider organisations', who seek to develop training for their level 2 service providers.
- Introduce the eLearning programme which provides an introductory level learning to each of the five competence domains outlined in the Competence Framework.

This project was funded by The Wheel's Training Links Programme and led by Irish Hospice Foundation in collaboration with a training network of Level 2 service providers across Ireland.

**9. Supporting Difficult Conversations around Bereavement and Grief and the Importance of Self-Care Donna Hastings,** Head of Patient and Family Support, Senior Clinical Team and **Jade Finlayson,** Child and Families Lead Practitioner, St Columba's Hospice Care

# 10. A Right Delayed is a Right Denied: the role of bereavement support in a proposed right to palliative care in Scotland

Ellie Wagstaff, Senior Policy Manager, Marie Curie

By 2040 up to 10,000 more people will need palliative support each year, including bereavement support. This growing demand comes as the cost of living with a terminal illness is increasing and the costs of delivering palliative support are also rising rapidly.

A large proportion of people die without some or all of the palliative support they need despite the fact 90% of people who die in Scotland each year would benefit from it. This unmet need leads to poorer physical and mental health, and financial outcomes for terminally ill people, their families, and carers, including unmet bereavement need.

A <u>legal right to palliative care</u> would work towards eliminating this unmet need, by people of all ages living with terminal illness(es) residing in Scotland having equitable access to the palliative support which is right for them, when they need it - including bereavement support.

The session will explore and engage attendees in discussion around:

- Opportunities and/or challenges a right to palliative care would bring to addressing unmet bereavement needs.
- If and how bereavement should be defined as part of a right to palliative care.
- Funding infrastructure required to deliver bereavement support as part of a right to palliative care.
- Responsibility and accountability for the delivery, implementation, and measurement of a right to palliative care.

Attendees can expect to gain knowledge on:

- The proposal for a right to palliative care in Scotland and impact on physical and mental health outcomes.
- The role of bereavement support in a right to palliative care.

# 11. Informal & Peer-Led Bereavement Support: applying findings of a systematic review to health and social care

**Dr Daniel Knights**, GP and Cambridge Clinical Research Fellow, University of Cambridge and **Dr James Robb**, Academic Clinical Fellow Palliative Medicine

The majority of bereaved individuals do not require specialist bereavement care, but find informal support from peers to be most helpful. However, understanding of how to harness these forms of support most effectively remains limited. This workshop will present the findings of a major systematic review into the evidence for impact of informal and peer-led bereavement support interventions, incorporating studies of peer-support groups, one-to-one peer support, social media usage, online forums and self-administered writing tools amongst others. The review also looked for evidence around interface of informal support interventions with health and social care, but very little was found. This session will therefore seek to gather the collective views and experience of workshop participants to develop recommendations for how health and social care could best tailor their services and signpost effectively to these forms of support.

### **Objectives:**

- To present the findings of a major systematic review of the impact of informal and peer-led bereavement support interventions.
- This in turn will equip participants with the knowledge of what is evidence-based and therefore may be more confidently recommended in professional practice.
- This session will also aim to provide participants with the skills to integrate effective tailored signposting and advice around informal support into their own bereavement support provision.
- Participants will also have the opportunity to share their views and recommendations on application of the systematic review findings to bereavement support practice in health and social care.