CDAS conference 2023: Innovation at the End of Life
3 & 4 May 2023

Welcome to the 2023 CDAS Conference, two full days of stimulating talks and discussion from academics, policy makers and practitioners from around the world. We are delighted you can join us.

The theme for the Conference this year is 'Innovation at the end of life'. Pushing boundaries and being creative has been at the heart of CDAS's activities since its inception in 2005 and we are looking forward to learning about what has changed, what is changing, and what will change, over the next two days.

In case you missed it, the Conference this year is also going to contribute towards a special issue of Mortality, to coincide with the Centre's 20th anniversary in 2025. The call for papers for the special issue is on our webpage and in the newsletter, with a deadline later in May. If you would like to submit your paper to the special issue, please make sure to send your abstract to us by the 22nd May.

Thank you to everyone who has worked behind the scenes to put the conference together (especially Rachel Willis and Madeleine Freeborn), everyone who is presenting and chairing, and to our two keynote speakers Dr Ruth Penfold-Mounce and Professor Darcy Harris. Make sure to join us on the evening of 3rd May (BST) for either a writing workshop led by the CDAS Writing Initiative Team, or an In Conversation with Caitlin Doughty. Finally, we cannot wait to be part of the live recording for The Death Studies Podcast with our very own Professor Tony Walter; make sure to be there on day two to hear what the most preeminent death studies scholar of his generation has to say about all things death and dying.

It promises to be an engaging and lively couple of days ahead. We hope you enjoy it!

Reading the Schedule
To help you decide which sessions you would like to attend, we have colour coded the types of engagement.
- Blue - paper sessions you'll need to come ready listen and ask questions
- Green - panels you can expect cameras on and a willingness to take part in discussions
- Pink - workshops and interactive you can expect cameras on and a willingness to take part in discussions
- Yellow - keynotes we'll all be together to listen to our two fantastic keynote speakers and ask questions after their presentations

Any questions, please get in touch with the conference organising team via CDAS@bath.ac.uk.

	Paper sessions
	Panel sessions
	Workshops/interactive sessions
	Keynote

Tickets are available via our shop here.
If you have any issues with ticket affordability please get in touch using the above email address.

Day 1 - 3rd May			
9-10am	Welcome and Keynote - Walking amongst the Dead: learning on the move - Ruth Penfold-Mounce		
10.10 - 11.10	1a. Contemporary African Responses to the Aftermath of death: developments and decolonising challenges - Jane McCarthy	1b. Innovation in body disposal from the producer and user perspective: what will drive change? - Kate Woodthorpe	
11.10-11.30	Break		
11.30-1.00pm	2a. Evolving theory, concepts and practice	2b. Mediated death	2c. History and Culture I
	Non-Buddhist Butsudan and the evolving Kuyo Practices in Japan - Hui Lok Hang	Death Image Transformed by Technology: The Theme of Evolution, Risk and Immortality- Adem Sagir	The 2003 Burial Act and Innovations on Death and Disposal in Finland - Ilona Kemppainen
	Rethinking the deaths of detained patients - Carly Speed	Digital necromany: users' perceptions of digital afterlife and posthumous communication technologies - Tal Morse	"When I'm dead I want to…": Cases in history of medics, dissection, agency of the corpse and informed consent - Sue Jones
	Algorithmic Hauntings: pregnancy loss and grief in online social media - Paul Ord	Necropolitics, Ageism and Naturalization of the Pandemic - Norichika Horie	Building a system that works: Disaster victim identification after the 1949 Noronic Ship Fire - Vicki Daniel
	Dinosaurs Are Only Alive in Erupting Volcanos Because They Are Already Dead': Young Children's Creative Accounts about Death - Zhaoxi Zheng	The Online Immortality Industry and the contemporary mediation of mortality - Paula Kiel	
1-2pm	Lunch		
2-3pm	3a. Place and time	3b. End of life planning and care	3c. Education
	The impact of Covid-19 pandemic on hospices: A cross-cutting thematic analysis of patient, carer, staff and senior manager experiences - John MacArtney	Kashi Labh Mukti Bhawan: An Indigenous Hospice Providing End- of - Life Care for Salvation - Veenat Arora	Can You Hear Me? I Can Hear You Now: Building a Blended Learning Interdisciplinary Module on Loss, Death and Grief for RUN EU Students - Jennifer Moran Stritch

Day 1 - 3rd May

	3a. Place and time	3b. End of life planning and care	3c. Education
2-3pm	Biological life, social death and the spaces in between - Glenys Caswell	Conducting virtual Advance Care Planning classrooms: Reflections from Thailand perspective - Thagoon Kanjanopas	Using death literacy to identify the information needs of local communities: a population survey - Alison Llewellyn
	Implementation and evaluation of virtual grief cafés across two national Public Health organisations - Nicola Bowtell	Surrey Child Death Review Team and the Cuddle Cot at Home Service - Nicola Eschbaecher	
3.10-4.10pm	4a. Choosing Light: transforming grief through the practice of mindful photography and reflection on self made images - Jessica Thomas	4b. Redesigning future dead body disposal technologies - John Troyer	4c. Help Texts, a new text based approach to delivering quality bereavement care to hospice families - Melissa Lunardini
4.10-4.30pm	Break		
	5a. Community	5b. Creativity I	
4.30-5.30pm	The Death Positive Movement as Innovative Community - Anne Wilde	Choreographing Death: Negotiating Ambivalence Around Dying through Gift Giving and Narration - Miranda Tuckett	
	Football, men and perinatal death: Uniting a community of loss - Kerry Jones	Replenishing Narratives, Crafting Grief: two innovations in reproductive bereavement support - Tamarin Norwood	
	Upholders of tradition? Innovation and novelty in the promotion of the 18th century undertaking trade - Dan O'Brien	The Harmony In Living And Dying Approach (HILDA) Project – A New Perspective On Death And Dying - Eleni Tsiompanou	
5.30-7pm	Break		
7-8.30pm	6a. Writing for Work and/or writing for the self - the CDAS Writing Initiative	6b. Death - Exciting and New! - Caitlin Doughty and John Troyer	

Day 2 - 4th May

	1a. Relationships we live with	1b. Online II	1c. Planet and people
9-10am	Planting Seeds: facing COVID isolation, motherhood and grief with an online gradening community - Katy McHugh	Impact of the COVID-19 Pandemic on funerals: experience of particpants in the 2020 Dying2Learn MOOC - Deb Rawlings	The media framing of long-distance grief of migrants during the COVID-19 pandemic - Tram Nguyen
	The Importance of the Multi-Species Death Doula - Racheal Harris	Governing Ghostbots - Edina Harbinja	Dead Bodies' Agency and Western Politics: The Women, Life, Freedom Movement in Iran and its International Political Impacts - Hajar Ghorbani
	Bereavement support for in-home dying older adults in urban India - Sayendri Panchadhyayi	Innovation, Online learning and end of life care for people in prolonged disorders of consciousness - Jenny Kitzinger	
10.10 - 11.10	2a. Mourning Italy: rites and spaces for a sustainable experience of death - Giovanni Corbelli	2b. Decolonising the aftermath of death in UK contexts: theoretical approaches, institutional 'constraints' and everyday experiences Jane McCarthy	2c. From voluntary to commissioned: learning innovative end of life doula provision in Leeds Erica Borgstrom
11.10-11.30	Break		
	3a. Creativity II	3b. Support	3c. Post-death
11.30-1.00pm	End-of-Life Narratives. Innovative Ways of Creating Legacies - Zoe Ghyselinck	Unpacking Grief for Children - How could "Therapeutic Toolkit" resources provide support for bereaved children and increase confidence for adults in their interactions with them? - Callie Harrop	Developing a holistic approach to bereavement care across Europe through collaboration across disciplines and country borders - Eva Zsak
	#RIPBozo: memes as ritual practice of contested memory - Anu A. Harju & Johanna Sumiala	Maximising impact through a knowledge to action approach: The Palliative and End of Life Integrated Care System Care Data Packs - Nicola Bowtell	Rethinking 'disposal': making meaning from our processes, rituals and bodies after death - Poppy Mardall

Day 2 - 4th May			
	3a. Creativity II	3b. Support	3c. Post-death
11.30-1.00pm	New Ways of Writing Loss: A Peculiar Case of COVID-19 Obituaries - Pia Bakshi	Evaluating the Implementation of the Dorothy House Hospice Service Transformation - Natasha Bradley	Theoretical innovations in the aftermath of death: extending 'bereavement' paradigms through family and relational perspectives - Jane McCarthy
	Compassionate Acts: Implementing Forum Theatre as a tool to create a compassionate peer structure for bereaved students - Alex Cahill	Saying 'Hello Again', rather than a Long Goodbye - Elizabeth Gilmour and Edith Steffen	Saying 'no' goes against the grain – UK funeral directors' experiences and the complexities of 'choice' during and beyond the COVID-19 pandemic - Jennifer Riley
1-2pm	Lunch		
2-3pm	Keynote - Darcy Harris - Sociopolitical Grief		
3-3.30pm	Break		
3.30-4.30pm	4a. The Death Studies Podcast with Tony Walter - Bethan Michael Fox and Renske Visser		
	5a. Structural inequality	5b. Death Tech	
4.30-5.30pm	Dying at home: Integrating findings from a large-scale Canadian mixed methods study - Laura Funk	Doing User Experience Research in Death Tech: Pain Points and Positives - Kathrina Mazurik	5c. Hear here: where real and fictional death meet - Mel Keiser
	"Bottom Line Blackness": Revising Death Awareness Discourse in light of Black American Activism - Ara Francis	Cultivating Innovative Death Technology - Victoria Haneman	
		In Their Presence: Technologically Mediated Departures - Emily B. Campbell	

<u>Welcome and Keynote</u> - Walking amongst the Dead: Learning on the Move

Ruth Penfold-Mounce, University of York, UK

Mobile methodology has long been adopted in social science as a data collection tool and there is an established industry focused on cemetery and ghost walks as a novel and appealing way to engage interested audiences. However, in the academy and beyond death studies has rarely sought to embrace mobile methods as an opportunity to teach and engage students and broad(er) research audiences. In this keynote I will reflect on why that is the case and draw on my experience of creating a highly successful walk in the city of York, UK, to explore the value and potential that occurs through adopting an innovative pedagogic approach to the study of mortality, through 'learning on the move'.

Bridging research and teaching learning on the move has, I will demonstrate, a range of benefits for participants. These include the stimulation of the thanatological imagination, the cultivation of conviviality amongst walkers through a shared learning experience, and the schooling of participants to communicate effectively and ethically about death, dying and the dead. I will explore this through the highly successful York Death and Culture Walk, an open access self-guided fully podcasted walk through the centre of one of the UK's oldest cities. Designed to enable walkers to both know and understand mortality in historic and urban city spaces, since its launch the York Death and Culture Walk has become a powerful tool for understanding the city's rich history of death, dying and disposal of the dead in evocative ways across space, place and time. In making a case for learning on the move in both teaching and research, I will be encouraging all attendees to consider the potential of death walks in their own communities and how this can provide a complementary and alternative method to engaging with diverse audiences.

1a. Contemporary African Responses to the Aftermath of death: developments and decolonising challenges

Jane McCarthy

Death and bereavement studies have often claimed universality for the knowledge produced. Yet most empirical research has been undertaken by and with people in Europe or North America. In effect, 'Western' models of 'bereavement' have been exported to the rest of the world (Klass and Chow, 2011).

Yet different places have different histories associated with different social theories and ways of responding to death and its continuing aftermath. By focusing only on political and economically powerful regions, death and bereavement studies limit the questions asked and the conclusions drawn.

In this panel we explore what innovative insights can be gained about death and bereavement from contemporary research in Africa and / or informed by African social theories, at a period of national and African activism against epistemic injustices. These calls for epistemic justice are energised by colonial histories, as well as ongoing political and economic marginalisation. The

panel will offer empirical insights and opportunities to explore understandings of death and bereavement from different contexts, in forms not necessarily written or created in the academy. Innovative learning from beyond Europe and North America has much to contribute to the decolonising of death and bereavement studies.

Ref: Klass, D and Chow, A (2011) 'Culture and ethnicity in experiencing, policing and handling grief', in Neimeyer, RA et al. (eds) Grief and Bereavement in Contemporary Society: Bridging Research and Practice. Taylor & Francis.

1b. Innovation in body disposal from the producer and user perspective: what will drive change?

Kate Woodthorpe

In this panel we will examine and debate two emerging techniques to dispose of bodies, composting and resomation. We will reflect on the drivers for technological change, the role of legislation and regulation, and the mixed economy of provision in the UK via local authorities and commercial organisations. We will particularly consider the role of bereaved people as customers, a commercial perspective that is often overlooked in policy, practice and academia, and explore the evolving relationship(s) between deathcare service providers and consumers. Join us for a lively discussion and Q&A, with Julian Atkinson (Kindly), Mathew Crawley (ICCM and CDAS PhD student), Simon Cox (Funeral Solution Expert) Poppy Mardall (Poppy's Funerals), Howard Pickard (Resomation) and Kate Woodthorpe (CDAS).

2a. Evolving theory, concepts and practice

Non-Buddhist Butsudan and the evolving Kuyo Practices in Japan
Hui Lok Hang

Kuyo is an important Japanese mortuary practice that involves various ancestral rites and memorial services, often performed in front of a butsudan, the domestic Buddhist altar found in many Japanese homes. Based on extensive ethnographic research, this paper explores the new trend of using non-Buddhist butsudan and analyses their impacts on institutional Buddhism in Japan. In traditional butsudan, cremation remains of deceased relatives are placed on a lower shelf beneath the Buddhist icon, which is positioned at the centre of the butsudan. In some latest designs, the miniscule butsudan has only one single slot that accommodates either a small ash urn or a Buddhist statue. In contrast to their traditional counterparts, non-Buddhist butsudan features natural design which, as suggested by the makers, helps the altar act as 'a personal power spot'. This is aligned with the trending practice of temoto kuyo, in which the cremation ashes are kept at home indefinitely so that long-term affiliation with a temple is not required. This paper will illustrate the dilemma faced by Shin Buddhist monks whose doctrine diminishes the merit-making elements of kuyo practice and thus put them in a disadvantaged position in responding to the changing ritual mortuary care in modern Japan.

Rethinking the deaths of detained patients
Dr Carly Speed

Last year the CDAS conference afforded me the opportunity to present an overview of my research related to the deaths of patients detained under the Mental Health Act. This paper will focus on the importance of learning from the past in order to inform change concerning present issues. Such issues include the number of deaths of patients and the response to patients and

their families in both life and death. The areas drawn upon in the paper may appear innovative. However, and extremely frustratingly, in many cases these suggestions have been identified and campaigned for over a period of decades and, in some cases, centuries. With this in mind the paper will also explore issues of power, denial and the lack of accountability apparent.

Algorithmic Hauntings: pregnancy loss and grief in online social media
Paul Ord

Online technologies are central to pregnancy in 'advanced economies', where most prospective parents use social media to enhance their ante-natal experience. These media use artificial intelligence (AI) to analyse the historic activity of users, predicting which content will be most valuable to them. Such AI can be beneficial in pregnancy: a short-cut to maternity products and health services that meet individual needs.

However, when miscarriage occurs social media AI is slow to adapt. Adverts for baby clothes or notifications from 'pregnancy apps' can 'haunt' the bereaved online for months after their loss. These "hauntings" complicate grief, and are likely widespread: social media use is ubiquitous, while 1 in 4 UK women miscarry in the first trimester. Nonetheless, these "hauntings" remain entirely unexplored in sociological research.

This paper draws on the testimonies of parents "haunted" by online pregnancy content post-miscarriage, and considers what role these "hauntings" play in the construction of grief, or the remembrance of a lost child. It considers what protections for these parents exist in the new Online Safety Bill (UK Parliament, 2022), and lastly, examines the social media AI from which these "hauntings" arise; asking what such technologies reveal of the motives and priorities of their designers.

'Dinosaurs Are Only Alive in Erupting Volcanos Because They Are Already Dead': Young Children's Creative Accounts about Death
Zhaoxi Zheng

Children will say anything: they offer diverse accounts as experts of their childhood experiences, including subjects that are traditionally considered 'sensitive' and 'complex' by adults (e.g., death). These accounts, however, rarely receive meaningful adult attention under the common assumption of children being unknowledgeable and inarticulate. Children's perspectives about death, especially, are frequently dismissed as trivial, unrealistic, and silenced in conversations based on both a dominant biomedical discourse of life/death binary and a developmental discourse that reduces children's imaginations to merely magical thinking.

This ageist assumption is problematic; it downplays children's agency and expertise in everyday socio-material encounters with no appreciation to deaths' multiplicity. Uncritically prioritising linguistic competency and 'scientific' reasoning, it neglects the extensive socio-material participation of those in early childhood and risks diminishing children's creativity in conceptualising complex subjects.

In this work, I use artistic, play-based, and material-oriented approaches – using child-centred methodologies and video-reflexive ethnography – to gather children's (5-7 yo) engagements with death. Engaging with Braidotti's (2013) posthuman affirmative stance on death, I showcase children's socio-cultural-affective-bodily-material encounters with death to make (non-)sense of death as a messy yet philosophical subject. I argue that children's imaginative accounts about death matter: resisting death as merely a biomedical and humanist binary.

DEATH IMAGE TRANSFORMED BY TECHNOLOGY: THE THEME OF EVOLUTION, RISK AND IMMORTALITY
Adem Sağır

This study focuses on the relationship between death and technology, examining how technology has influenced our experience of death in three main categories. "Evolution" has been used to refer to the institutional transformationsbrought by the technology. The category carries the concern of expressing the change that the hospital and the health system have formed on death. This title is also considered to be directly related tothe fact that professional funeral service providers develop their service standards in a technology-oriented manner." The second category utilized in the study refers to the disruptive impacts created by advancements and technological alterations in societies, framed within the concept of "risk." The term "residues of science" encompasses discussions arising from the relationship between medical technology and ethics. Key areas of focus include organ transplantation, abortion, debates surrounding euthanasia, the vegetative state, brain death, and autopsies. The third category of the study delves into the reflection that science has reified death and reduced it to a mere biological phenomenon. This study aims to understand the relationship between death and technology by addressing the following fundamental questions within the aforementioned categories: What impact did institutional transformations have on attitudes towards death? How have medical technologies altered the definition of death? Was the collision of death with technological changes an opportunity to raise new ethical questions?

Digital necromancy: Users' perceptions of digital afterlife and posthumous communication technologies
Tal Morse

Technologies of digital afterlife and posthumous communication are more developed than ever, and the possibilities for communicating with digital representations of people who perished are coming to fruition. Studies about digital engagement with death reveals contradicting trends. Whereas technologies designed for interacting with the dead have thus far failed, users reappropriate means of online communication that were not intended to facilitate communication with the dead – to facilitate precisely this practice. This article searches for a fuller understanding of the changing attitudes toward death in light of emerging posthumous communication technologies (PCTs). Drawing on a national survey of Israeli Internet users, the study explores contemporary attitudes toward death and the digital afterlife and analyzes users' perceptions of emerging PCTs. Findings indicate that whereas the general public is still reluctant to adopt such technologies, digital literacy and willingness to access digital remains are significant predictors for considering the use of PCTs.

Necropolitics, Ageism and Naturalization of the Pandemic
Norichika Horie

This presentation will focus on Japan's response to COVID-19. Even before the pandemic, deaths from respiratory infections were increasing in Japanese society, which is the most aged in the world. This trend was also progressing in the world's high-income countries. However, death studies researchers were more interested in deaths from cancer and dementia than from infectious diseases, which were considered to have been conquered by modern medicine. Infectious diseases were seen as the "grim reaper's final blow" for the elderly, ending the lives of

those who had suffered from other diseases. It was seen as bringing a "natural death" to the long process of dying. This attitude was applied to the resolution of the COVID-19 pandemic. In Japan, in late 2022 to 2023, when the Omicron variant was pandemic, the number of deaths reached a record high, and for more than a month the death rate was the highest in the world, but the government decided to treat COVID-19 like the flu and tried to get people to take off their masks. Medicine as biopolitics was replaced by necropolitics: who to let die and how. However, it can be understood that this too was prepared before the pandemic.

The Online Immortality Industry and the contemporary mediation of mortality
Paula Kiel

Communication technologies play a key role in the social mediation of death. Rather than exploring bereavement or memorialisation, this paper investigates the role of media in mediating humans' awareness of their own future death. Distinguishing between the death of others and the future death of self and drawing on Lifton & Olson's work on symbolic immortality (1975) and Bauman's work on immortality (1992), the paper explores websites purposefully designed to offer services for dealing with mortality online as an entry point to understanding how contemporary media mediate mortality in Western societies. Combining a multimodal analysis of websites and interviews with founders of such websites, the paper shows how the Online Immortality Industry both constructs an illusion of control over one's future symbolic immortality and undermines it. The analysis also shows how rather than closure, the websites create a perpetually liminal practice. Finally, the analysis reveals the tensions between the perspectives of the future-dead and the future-bereaved. The paper argues that distinguishing between these two perspectives (future-dead and future-bereaved) is key for understanding the ethical consequences of the Online Immortality Industry and, more broadly, for exploring the role of digital media in the mediation of death.

2c. History and Culture I

The 2003 Burial Act and Innovations on Death and Disposal in Finland
Ilona Kemppainen

Laws about death and disposal are particularly strict in Finland, like in other Nordic countries. Church membership is on steep decline, but burial traditions follow this only slowly. Discussion about funerals and burial is rare and limited.

The Finnish Burial Act is from 2003, and it has not aged well considering the needs and possibilities of the present. The only possible means of disposal are burial and cremation, and even the ashes must be placed in a cemetery or a certain, legally defined place within a year. The framework of the Burial Act is seemingly secular, but the Lutheran church is a force behind it. All crematoria except one are owned by it, as are about 99 per cent of the 1000 cemeteries in Finland. The church is obliged by law to offer these services to all citizens, and the law also basically makes it impossible for example to open an independent crematorium: such institution must have a solid economic base, but it is not allowed to make profit.

The situation hinders any new innovations landing in Finland. It is the Lutheran church that would be necessary to convince about the need of for example aquamation or composting human bodies.

"When I'm dead I want to…": Cases in history of medics, dissection, agency of the corpse and informed consent.
Sue Jones

Historically medics and anatomists have been portrayed as heartless exploiters of the poor and disenfranchised to obtain dissection specimens. There is no doubt that they colluded with body snatchers and benefited from the unclaimed bodies of the poor and friendless. Despite current portrayals of ethics being a modern invention, there is a long history of medics and anatomists advocating for the "agency of the corpse"; for the living to bequeath their bodies for study voluntarily.

This talk will trace a number of cases to illustrate the struggles that anatomists have faced in their attempts to work ethically in a difficult world: Treating dissected bodies with respect, despite it being a proscribed punishment for criminals; dissecting colleagues who know first hand how hard obtaining bodies can be; signing up volunteers before the 1832 Anatomy Act; founding a museum and requesting to be displayed in it, only to be denied by your family; setting up a mutual brain club; and finally arguing for organ donation rights in the 1961 Human Tissue Act.

Building a system that works: Disaster victim identification after the 1949 Noronic Ship Fire
Vicki Daniel

In the early hours of 17 September 17 1949, the passenger ship S.S. Noronic caught fire in Toronto harbor. By the time firefighters extinguished the blaze, 119 passengers were dead, many burned beyond recognition. Fire had always been a significant barrier to disaster victim identification (DVI) in mass-fatality and, until the Noronic disaster, dental identification had been the best technique available to coroners. However, responders to the Noronic fire enacted a new system of identification that wove together existing technologies with a postwar bureaucratic systemization that ultimately led to 74 positive identifications. This remarkable number points to technological success; however, this paper argues that the Noronic is innovative not due to the development of new technologies. Rather, its tightly-run administration of staff, machines, and bodies made the Noronic case a precursor to modern DVI. Furthermore, responders published the knowledge they gained through the Noronic identification, thereby contributing to the growth of a defined community of experts concerned with the scientific legitimacy of identification science. As such, this paper will address the innovation at the ground level in Toronto, and within networks of knowledge production among coroners, disaster planners, and state governments.

3a. Place and time

The impact of Covid-19 pandemic on hospices: A cross-cutting thematic analysis of patient, carer, staff and senior manager experiences
John MacArtney

Background: Hospice specialist palliative care emphasises quality of life, timely interventions, holistic care. During the Covid-19 pandemic hospices had to adapt their approach and practices of caring and supporting people with terminal illnesses.

Aim: To provide a multi-perspective exploration of how Covid-19 and protections affected three key areas of hospice specialist palliative care.

Methods: Reflexive thematic analysis of interviews with patients, carers, staff and senior managers (n=70) at hospices across the West-Midlands.

Findings: The findings explore how the pandemic protections affected participant's quality of life and care; how timeliness of care was disrupted at different points in the palliative care journey; and, how holistic focus care was sometimes reduced to a focus on physical aspects of care. We also explore experiences of how hospices were able to re-instate and reengage their approach in pandemic context.

Discussion: Covid-19 brought significant – sometimes existential – challenges to hospice specialist palliative care, with each of core tenets challenged in ways that provided opportunities to reflect on what they mean not only to hospice palliative care, but also their significance in the context of wider ongoing covid and healthcare political landscape.

Biological life, social death and the spaces in between
Glenys Caswell

People die biologically when their bodies cease to function, and there is no chance of revival. Numerous studies have shown the ways in which people who are still alive biologically can be treated as if they are already dead, that is, as being socially dead. But what happens when a person dies biologically when they have not already undergone a social death? This paper explores the idea that each person has two deaths. It has been suggested that the final death occurs at the time of burial or on the last occasion when someone says the deceased person's name. Here the possibility is suggested that social death is a person's second death, and it can take place before, at the same time as, or after biological death. Using a strong definition of social death as the cessation of an individual acting on the world as an agent, it proposes that some people are accorded a limited level of social agency after their biological deaths. This will be demonstrated by drawing on data from a study of time in relation to death and the ways in which a bereaved mother worked to maintain her daughter's social impact on the world.

Implementation and evaluation of virtual grief cafés across two national Public Health organisations
Nicola Bowtell

Pandemic work at Public Health England and Test and Trace was unrelenting. Enforced home working enhanced isolation. Many colleagues experienced difficult bereavements due to COVID-19 restrictions and had little access to normal workplace support.

A grassroots group of bereaved staff and/or with bereavement expertise, established virtual bereavement cafes in May 2021, run by staff for staff. MS Teams (video teleconferencing, chat, signposting to resources) provided a safe, supportive meeting space. Facilitated Cafés are held fortnightly, with mental health first aiders present. Ground rules emphasised respect, confidentiality, the validity of all types of grief and all deaths (pre or during the pandemic). Chat and emojis offered support. Post café email and phone follow-up was offered. Additional themed cafés supported: Grief Awareness Week, the Queen's death, Pregnancy or Infant loss and bespoke sessions run for teams whose colleague had died (6). A rapid qualitative evaluation gives insight into experience of grief support provided by cafes.

All types of grief have been experienced: anticipatory, complicated, cumulative and disenfranchised grief - often in combination. There are significant levels of unresolved/complex

grief following the COVID-19 pandemic in working-age people. Virtual cafes provide critical emotional support in geographically dispersed organisations. We have enhanced compassionate workplace policies.

3b. End of life planning and care

Kashi Labh Mukti Bhawan: An Indigenous Hospice Providing End- of - Life Care for Salvation
Veenat Arora

While the western end of life care approaches focus on the caregiving and providing the best possible medical and humane assistance to comfort the deceased in the last days, Kashi Labh Mukti Bhawan is a unique model of end-of- life care, providing assistance to the deceased on the path of liberation. For a Hindu, present life is a temporary phase (one part) in the ongoing cycle of life and death. The moment of death is a transitional point whereby the atman (soul) separates from the physical body and wanders in its disembodied state for some time and is eventually reincarnated or transmigrated into a new physical form. The ultimate aim is freedom from this birth/death cycle through attainment of moksha (salvation). Dying in the city of Benaras (Kashi) is prescribed as a sure-shot way to attain moksha. Benaras is the abode of Lord Shiva, it is believed that at the moment of death, Lord Shiva himself appears to the deceased and whispers the name of Lord Rama/Krishna (incarnation of Lord Vishnu, the protector) in the deceased's ears ensuring moksha. Hence, Lord Shiva embraces every soul who dies in his abode with love. Therefore, in Kashi death is welcomed and celebrated instead of being shunned as a taboo. With this approach in view, since 1958, Kashi Labh Mukti Bhawan, a famous death hotel functions as an indigenous hospice in Kashi that provides end of life care to the patients in the last two weeks of their lives, providing assistance in their goal to achieve moksha. As detachment to the material comforts is the central theme of Hinduism, Kashi Labh Mukti Bhawan provides the inmates basic facilities for sustenance in the last days of life and offers a conducive environment for the attainment of moksha. Based on my qualitative study of this centre, my presentation shall focus on the religious importance of the city of Benaras, India in the context of death and moksha; functioning and popularity of this indigenous model of end of life care and I shall emphasise on how the caregiving for liberation of soul comforts the deceased in his/her end days of life.

Conducting virtual Advance Care Planning classrooms: Reflections from Thailand perspective
Thagoon Kanjanopas

Advance Care Planning (ACP) is an ongoing process to ensure that an individual can discuss their future needs and personal values toward end of life care in case of future incapacitation. In Thailand, discussing an ACP is challenging due to the lack of public awareness. Healthcare professionals (HCPs) also express the lack of skills to efficiently conduct an ACP with patients who have increasingly complex conditions. To mitigate these challenges, a series of ACP panel discussions were held virtually via Zoom to raise the public awareness and to discuss ACP within different contexts for HCPs.

Between August-November 2022, 14 ACP panel sessions were virtually hosted and livestreamed via Zoom, Facebook Live and YouTube; participants could ask questions and shared their experiences regarding ACP during the sessions. Topics covered were: an overview concept of ACP; ACP with specific populations e.g. children, adults with chronic conditions; ACP in LGBTQIA2+ populations; community ACP, ACP in the A&E. 15833 participants watched and participated with the sessions.

Feedback received from participants emphasised on the importance of the nuances around ACP within different context of care.

Virtual platforms proved to facilitate tacit knowledge exchange amongst ACP stakeholders due to wider accessibility and should be further utilised.

Surrey Child Death Review Team and the Cuddle Cot at Home Service
Nicola Eschbaecher

During the pandemic, Surrey Child Death Review Team became increasingly frustrated at the restrictions for wider families to meet and greet their new arrivals when a baby had died. In response to these barriers, the team designed the Cuddle Cot at Home Service. This innovative service continues to support bereaved families to take their baby or child home for up to 48 hours with the support of a nurse and a cold cot/blanket. This session proposes a 20 minute guided tour of the benefits, processes, equipment, challenges and triumphs of getting this unique, NHS community service 'up and running.'

<u>3c. Education</u>

"Can You Hear Me? I Can Hear You Now: Building a Blended Learning Interdisciplinary Module on Loss, Death and Grief for RUN EU Students"
Jennifer Moran Stritch

Since 2021, academic colleagues in nursing and social care from the Regional University Network of Europe (RUN-EU) have collaborated on the development of a short educational programme on loss, death and bereavement. Entitled "Supportive Care in Loss, Grief and Bereavement: An Interdisciplinary Approach" the goal of the module is for students, primarily in health and social care disciplines, to be more confident and competent in working with people who are experiencing a loss currently or are recently bereaved.

Using a wide variety of approaches, such as reflective journals, group work, and digital storytelling, the month-long blended learning programme aims to enhance both the death and grief literacy levels for participants. Unique aspects of the module include the interdisciplinary and multicultural approaches emphasised in the online workshops and the intensive residential week for university students from across Ireland, Finland, Austria, Hungary and Portugal. This paper explores the development of the module from the perspective of its creators and facilitators, focusing on our processes of engagement and the use of innovative teaching and learning interventions for death and grief literacy.

Using death literacy to identify the information needs of local communities: a population survey.
Alison Llewellyn

Death literacy refers to the knowledge and skills that support understanding and engagement with end of life (EOL) and death care options. Using commissioned market research, we aimed to assess levels of death literacy across populations served by Dorothy House Hospice (DH). Residents of Bath and North East Somerset and parts of Wiltshire and Somerset were invited to complete an online version of the Death Literacy Index (DLI) [1]. Invitations were primarily distributed via a commercial panel and DH's newsletters.

Responses were received from 796 residents across 10 neighbourhoods. Overall death literacy was higher than in previous studies [1,2] but broadly comparable when data from respondents to the DH newsletter (and whose awareness of EOL care might therefore be greater) were removed.

Whilst statistically significant differences in DLI scores across neighbourhoods were few, the data highlighted relatively high practical knowledge but low experiential and community knowledge in one neighbourhood, and low practical knowledge in another. Both had the lowest proportions of respondents with any prior formal EOL care role (e.g. caring for someone dying at home; working, volunteering, or receiving training in EOL care.)

Findings will inform initiatives to address inequalities of access to regional EOL and palliative care services.

1.   Leonard, R., Noonan, K., Horsfall, D., Psychogios, H., Kelly, M., Rosenberg, J.P., Rumbold, B., Grindrod, A., Read, N. and Rahn, A., 2020. Death literacy index: A report on its development and implementation. https://doi.org/10.26183/5eb8d3adb20b0
2.   Graham-Wisener, L., Toner, P., Leonard, R. and Groarke, J.M., 2022. Psychometric validation of the death literacy index and benchmarking of death literacy level in a representative UK population sample. BMC palliative care, 21(1), pp.1-15.

4a. Choosing Light: transforming grief through the practice of mindful photography and reflection on self made images
Jessica Thomas

This presentation is inspired by my research titled Mindful Photography and its Implications in End-of Life Caregiving: An Art-based Phenomenology (Thomas, 2016). The focus of the study was how making photos mindfully and reflecting on those images by those who are caregiving for a dying loved one might mediate the experience of anticipatory loss and assist in the meaning making process.

Practicing mindful photography and reflecting on self-made images is a process that allows caregivers and those anticipating the death of a loved one create the space that is needed to process and integrate thoughts and feelings, revealing a much deeper sense of awareness, acceptance, and meaning. As a clinician, I have integrated this method in therapy to assist clients in exploring and processing their grief related to caregiving, bereavement, including pet loss.

Photography can be practiced in such a way that is therapeutic and may increase awareness and opportunity for meaning making. The practice of mindful photography can be conceived through letting go of expectations, becoming attentive through seeing in moment-to-moment awareness, and accepting what is present. In the process of mindful photography, psychological components surface as one becomes receptive to feelings and sensations, thus allowing the eyes to open more fully to the present moment (Zakia, 2013).

As one begins to physically and mentally slow down, one can begin to confront the anticipated death and come to greater comprehension of their relationship with the dying person and create meaning from the experience while their loved one is still living. Perception, thinking, and feeling become interconnected within the act of making images. Meaning emerges as one reflects on the self-made images and connects with them their inner experiences as represented by the objects photographed.

This therapeutic method was inspired by Betensky's (1995) phenomenological art-based approach. The method consists of 4-steps. Each step building on the other to increase awareness and deep reflection, thereby positioning one to cultivate meaning through through ones grief and loss journey. As a therapeutic method, Within and Without is grounded in a process that brings light to the wholeness of ones experience through two modes of expression; visual imagery and reflective journaling (Thomas, 2021). In the fourth and final step, the therapist facilitates a phenomenological inquiry through reflective dialogue with clients about their photographs, thereby allowing deeper meaning and an expanded life narrative to emerge.

The conference presentation will include exemplars of images and journal entries from participants that have utilized this method through their experiences of anticipatory grief, bereavement, and pet loss.

4b. Redesigning future dead body disposal technologies
John Troyer, Heather Conway, Philip Olson, Kate Falconer and Georgina Robinson

The Redesigning Future Dead Body Disposal Technologies panel of experts will discuss contemporary concerns around ecologically sustainable dead body technologies. How ecologically sustainable is death? More importantly, why are some final disposition methods considered green and others natural? The panel will examine, for example, the alkaline-hydrolysis process, aerobic decomposition, and old-new systems such as organ donation and cryogenics.

4c. Help Texts, a new text based approach to delivering quality bereavement care to hospice families
Melissa Lunardini

Hospice providers have been calling for innovative approaches to meet the demands for bereavement services. This presentation will report on grievers' perceptions of the acceptability and helpfulness of Help Texts, an innovative, ongoing, expert, text-based grief support service aligned with a public health approach to bereavement care. The messages, grounded in contemporary models of grief and coping, provide support, information, and encourage engagement in adaptive coping behaviours. Participants in the evaluation were bereaved family members who received Help Texts as a hospice benefit. Based on program administrative data, the 13-month program retention rate was 86%. Among subscribers who met inclusion criteria for and completed a brief evaluation (N=100, response rate = 65%), 73% rated the program as "Very helpful" and 74% rated it as contributing "A great deal" or "Considerably" to their sense of being supported in their grief. Older grievers (age 65+ years old) and males tended to give the highest ratings. In their written feedback, most respondents expressed their appreciation for the program (e.g., "Thanks for being there") or listed something they liked or found helpful (e.g., "I don't feel as though I'm losing my mind anymore"). These preliminary data suggest that bereaved hospice family members find Help Texts to be acceptable and helpful as a bereavement support option.

5a. Community

The Death Positive Movement as Innovative Community
Anna Wilde

The Death Positive Movement is the latest iteration of death-related social movements, based on the concept that the discussion of death, silenced for many years, should be brought out from the shadows, into the light of open discussion and debate. Opinion varies as to whether this

perception of death being a forbidden subject is accurate, with many academics (Walter, 1991; Kellehear, 1984; Jacobsen, 2020) citing the ways in which death discussion seems to be universal. Death occupies column inches in the press, whilst community events such as death cafés, Death Over Dinner, Death Positive Libraries and other innovations flourish online and off. Drawing on interviews I undertook in the summer of 2022 with self-defined death positive workers such as death doulas, celebrants, funeral and mortuary staff, this paper examines how the events mentioned above serve communities and whether they help to alleviate fears and encourage open discussion. It will investigate the nuances of what being death positive means to the individuals who were interviewed and whether their opinions accord with the online communities of practice such as the Order of the Good Death and its leader, Caitlin Doughty, who coined the term death positive in a tweet sent in 2013.

Football, men and perinatal death: Uniting a community of loss
Dr Kerry Jones

This paper presents the findings conducted on men's experiences of grief and loss following miscarriage, stillbirth and neonatal death and how they sought to memorialise, commemorate and continue a bond with their baby as a member of a football team whose aim is specifically to support men across the UK.

Interviews conducted with 11 men suggests that these men seek unique ways to continue a bond with their baby and one which is visible on the football pitch. In so doing, the findings challenge the social norms to which grieving men have been traditionally bound according to dominant cultural and social expectations around 'being stoic and manly.'

The findings of this study demonstrate that men's expressivity and experience of grief can be given a space and a location within a football team that is founded by and for bereaved men. Within these spaces, men are able to make the invisible, tangible by declaring their identity as a father whether it is playing in a match dedicated to their child and which derive a source of belonging not found elsewhere.

Upholders of tradition? Innovation and novelty in the promotion of the 18th century undertaking trade
Dr Dan O'Brien

In eighteenth century England the very concept of an undertaker was innovative. During the period, many traders would adopt this new title and its associated responsibilities of funerary organisation and execution. This was innovation to secure commercial success and it was prompted by the competitive, saturated markets of contemporary towns where diversification offered advantage. Adding a new line of business in funerary products gave an individual an advantage over their rivals and using the title of 'undertaker' confirmed this to the public. In such a competitive climate, what role could innovation play? This paper considers how early undertakers used the innovative or novel quality of their businesses in their promotional materials. Analysis of trade ephemera reveals that many proponents of the early trade chose to foreground their funerary work over other lines of business. A close reading of the products depicted and described in this ephemera illustrates the importance of the items and services which would transform the funerary experience. Funerary goods did not simply reflect tradition but demonstrated a successful undertaker's ability to satisfy the changing expectations of their community. As a consequence we can argue that ambitious early undertakers wanted their businesses to be understood as innovative.

Choreographing Death: Negotiating Ambivalence Around Dying through Gift Giving and Narration
Miranda Tuckett

In October 2021, a woman I call Theresa died an assisted death in Switzerland. Those of us who had been present received an ornament a week later with a note that read: "The Stars are Bright Tonight, Love Theresa". This was one of many material gifts and artifacts that made up Theresa's death. Alongside gift giving, this paper will focus on a text that Theresa wrote she details a conversation between "mind and matter". Theresa articulates the tension as one between desire and fact. This text demonstrates the internal paradoxes of secular understandings of personhood, rationality, and decision making. There is an assumption that resistance to assisted dying concerns the biopolitical powers of the state. This analysis doesn't help to understand the ambivalence present among those who are planning to die. This ambivalence is often overlooked or repressed. Building on over 12 months of fieldwork in London and Switzerland, this paper attends to how Theresa choreographed her death. I contend that the term choreography can be opened up to consider doubt and ambivalence as it relates to self-reflexive personhood and decision making. I consider the notion of choreography as a novel form of narrating one's death which stays with uncertainty.

Replenishing Narratives, Crafting Grief: two innovations in reproductive bereavement support
Dr Tamarin Norwood

In the UK a baby dies near birth every two hours. One in five further pregnancies ends in miscarriage. Yet reproductive loss is typically unsupported by the culturally sanctioned rituals, life stories, and social acknowledgement we depend upon to make sense of death. This absence of shared cultural narrative leaves parents disenfranchised, isolated, and at higher risk of pathological bereavement trajectories. Meanwhile, the benefits of palliative narrative therapy—creative writing and auto/biographical reflection at the end of life—are well documented, and acknowledge the central role of storytelling in grief. This paper reflects upon the design, delivery and evaluation of two innovations in bereavement care for reproductive loss, each addressing the lack of relevant end-of-life narratives by supporting parents to craft and consolidate their own. These low-cost and impactful innovations, created in collaboration with Scottish baby loss charity Held In Our Hearts, comprise a writing group and training resources for peer supporters, and packs of keepsake writing prompts offered to parents including by NHS hospital midwives. The paper will outline new insights into specific narrative challenges of reproductive loss learned through the design of these innovations, and suggest pathways for future development.

The Harmony In Living And Dying Approach (HILDA) Project – A New Perspective On Death And Dying
Eleni Tsiompanou

The Harmony In Living and Dying Approach (HILDA) project wanted to address the difficult subject of death and dying using the universal concept of Harmony, which everyone can relate to. We felt that by linking Harmony to end of life care (EoLC) we could offer a gentle, compassionate and positive perspective that people could relate to, on a subject that many found difficult to approach. This way we could build communities of people who encourage each other to live fully while consciously preparing for our sacred time of dying.

During face-to-face and online events from 2019 to 2021, aspects of the natural dying process were explored alongside harmony principles: inter-connectedness, inter-dependence, cycles, diversity, adaptation, geometry, beauty, oneness and love. Theory and discussions were combined with practical components: geometry, drawing, meditation, natural movement, mindful walking in nature, cooking, music, singing, poetry and storytelling.

With the HILDA project we showed a proof of concept: harmony can be used to widen people's understanding of living, death and dying through a combination of theory with practical activities. Harmony can lift death and dying out of its medicalised box into our everyday lives, helping us to engage with each other.

6a. Writing for Work and/or writing for the self - the CDAS Writing Initiative
Kate Woodthorpe

Join us for our next CDAS Writing workshop, where we will reflect on what brought us to the topic of death and dying and to different and ways of thinking and writing about it. We will explore innovation with reference to how we write and what we write about.

Following a discussion between the panel members there will be 2-3 exercises for participants to work on, that consider how we might bring together our life experience, writing, and 'work' - be that for research, practice or teaching others.

If writing interests you, please look out for our activities, led by Visiting Professor Gayle Letherby, Visiting Fellows Bethan Michael-Fox, Tamarin Norwood and Renske Visser, and CDAS members Hannah Rumble and Kate Woodthorpe.

6b. Death - Exciting and New!
Caitlin Doughty and John Troyer

In this session for the 2023 CDAS conference, New York Times bestselling author, Order of the Good Death founder, and Ask a Mortician creator Caitlin Doughty will talk with CDAS's former director and Death Studies Scholar-at-Large, John Troyer, about innovation and change in 21st Century Death World. Doughty and Troyer have worked together on different innovative end of life projects for well over ten-years and their conversation will explore ideas and concepts they began discussing during the Australian Death Studies Society October 2022 conference on Redesigning Deathcare. The 2023 CDAS conference theme offers Doughty and Troyer an opportunity to expand their dialogue on the technologies supporting human composting and disposal tech in general, the politics of death and dead bodies, the historical waves informing end-of-life practices and where each of them thinks Death World is headed over the next ten-years. Doughty and Troyer are also good friends and have supported each other during multiple family deaths and they look forward to discussing those experiences for the CDAS conference during Dying Matters Awareness Week 2023.

1a. Relationships we live with

Planting the seeds: Facing COVID isolation, motherhood and grief with an online gardening community
Katy McHugh

What does death have to do with gardening? Gardening introduces us to the cycle of life and death as inescapable and comforting in its mundanity. The garden can be a legacy, or a safe space for difficult and upsetting discussions. The garden was where many of us turned during COVID for a sense of purpose, achievement, and temporality. A visual, physical reminder that time was indeed still passing during lockdown. The isolation of new motherhood, a newly started PhD program, and a niche topic which earned me the nickname "The Death Girl", also turned me towards the garden and to social media where I sought connection with fellow death studies scholars. Together we formed a group dedicated to discussing the intersection of death and gardening and created an ecosystem of support and speculation: a self-watering garden of women and mothers. Here I will discuss the connection of gardening, climate grief, death and bereavement studies, and the creation of an online support network as a metaphor for small urban forests – an idea from the mind of Japanese botanist Akira Miyawaki to combat climate change.

The Importance of the Multi-Species Death Doula
Racheal Harris

In considering innovation at end-of-life, it is essential to maintain a multi-species lens. Out of the shadow of the pandemic emerges a narrative of how animals came to fill the void created by endless lockdowns, and the general isolation which were unavoidable outcomes of pandemic protocols. This narrative, while sometimes heart-warming, is but an interlude. We must now begin paying attention to how we understand our relationship with these animals in the domestic space. Specifically, how we will mourn them.

It should be expected that as these animals, though they may now be considered newly adopted, inevitably die within the next decade not only will their departure bring forth the familiar grief that is a hallmark of pet death, but so too will it trigger emotional trauma of having lived through a global pandemic.

This paper highlights the importance of considering the role of the death doula as it pertains to the companion animal. It argues for the importance of being more open and transparent about the trauma of pet death (past and forthcoming) and acts as the fist step in a creating a serious dialogue about the role of the pet doula, for humans and animals, in the future.

Bereavement Support for In-home Dying Older Adults in Urban India
Sayendri Panchadhyayi

Notions and perceptions around death, dying and bereavement is culturally situated and historically contextualised. The propensity to homogenize and universalize experiences of dying and caring for "bodies in decline", and providing bereavement support to such families in congruence have led to an overarching view from 'Global North' that still remains the bastion of

knowledge production and theoretical edifice. Consequently, such gatekeeping has impeded the South Asian perspective on 'What death means for the dying patient?' 'The expressions and performance of bereavement attuned to the societal norms', and 'What does it mean to being there' in the face of despair. End-of-life care arrangements are contingent on interconnectedness of 'doing family', intergenerational exchange, state policies on death, circulation of labour, spatiality and temporality, and the emerging risks in late modernity. This paper aims to identify the missing link, fill up that gap, and prompt theorization on dying, caring and bereavement harnessing the experiences of untrained paid careworkers, locally known as ayahs in the Bengal area of India. I would term this as 'knowledge from below', alternatively an 'ayah-centred approach' to care, a departure from the top-down, 'knowledge from above', biomedical discourse. The paper adopts the methods of micro-ethnography, in-depth qualitative interviews and family case studies to abide to research rigour. Keeping this in mind, the objective is to stoke conversations around 'culture-sensitive approaches' to end-of-life care and advocate for theorizing from 'Global South'.

1b. Online II

Impact of the COVID-19 Pandemic on funerals: experiences of participants in the 2020 Dying2Learn MOOC
Deb Rawlings

A Massive-Open-Online-Course (MOOC) on death and dying (Dying2Learn) was offered in 2020. Designed to build conversations about death as a natural part of life, week 1 focused on how today's society engages with death through the language we use, humour, public mourning, and funerals. Given the concurrent impact of the pandemic, we used one activity to ask participants to reflect on funerals in general and then consider what changed during COVID-19 (n=549 responses received). This study investigated responses of those who attended a funeral during COVID-19 either virtually or in-person (n=204, 96% residing in Australia). Data were analysed qualitatively. Themes highlighted positive aspects such as (virtual participation when travel barriers existed, increased intimacy of a small funeral and challenges such as limited numbers, a sense of impersonal voyeurism, technology glitches, and inability to physically comfort bereaved due to physical distancing requirements. Other themes included conducting a funeral during COVID-19, new or adapted innovative mourning rituals and the need or wish to postpone funerals or memorials. Comments made as part of this MOOC activity provide a unique insight into the community's experience of funeral changes necessitated by COVID-19, with important implications for the grieving process.

Governing Ghostbots
Edina Harbinja, Lilian Edwards and Marisa McVey

This article discusses the legal implications of a novel phenomenon, namely, digital reincarnations of deceased persons, sometimes known as post-mortem avatars, deepfakes, replicas, holographs, or chatbots. To elide these multiple names, we use the term 'ghostbots'. The piece is an early attempt to discuss the potential social and individual harms, roughly grouped around notions of privacy (including post-mortem privacy), property, personal data and reputation, arising from ghostbots, how they are regulated and whether they need to be adequately regulated further.

We canvas two interesting legal developments with implications for ghostbots, namely, the proposed EU Artificial Intelligence (AI) Act and the 2021 New York law amending publicity rights to protect the rights of celebrities whose personality is used in post-mortem 'replicas'. The latter

especially evidences a remarkable shift from the norm we have chronicled in previous articles of no respect for post-mortem privacy to a growing recognition that personality rights do need protection post-mortem in a world where pop stars and actors are routinely re-created using AI. We propose an early solution to regulate the rise of ghostbots, namely an enforceable 'do not bot me' clause in analogue or digital wills.

Innovation, online learning and end-of-life care for people in Prolonged Disorders of Consciousness
Jenny Kitzinger

Innovation in medicine over the last few decades have resulted in more and more patients surviving catastrophic brain injury - some surviving long-term in prolonged disorders of consciousness [PDoC] (Vegetative and Minimally Conscious states). This created its own ethical dilemmas about end-of-life decision-making which have recently been addressed by changes in law and professional guidance: The Supreme Court judgment on PDoC (Re Y, 2018) and new BMA and RCP guidance (2018 and 2020) about clinically-assisted nutrition and hydration and patients lacking capacity to consent. Against this backdrop we will present how technological innovation (medical simulations, and interactive online learning platforms and design) can be used to roll out changes in understanding and practice to keep pace with the rapidly changing context for decisions about life-sustaining interventions and the provision of end-of-life care. We will examine how this innovation is ensuring hospice and neuro-rehabilitation centres take on board the innovations in practice (and sometimes complete changes in 'culture') needed to provide optimal support for PDoC patients, their families, and the staff caring for them around the end-of-life.

1c. Planet and people

The media framing of long-distance grief of migrants during the COVID-19 pandemic
Tram Nguyen

The COVID-19 pandemic has profoundly disrupted the important acts of grieving, including 'saying goodbye' and organising funerals. For migrant populations, these interrupted grieving experiences were exacerbated by their existing migratory experiences (e.g., years of separation, migratory grief). This made migrants' grief more complex during the pandemic with layers of individual, cultural and political changes. These challenges of grieving at a distance also gained considerable media attention internationally. This paper examines how the media framed "grief at a distance" during COVID-19 using qualitative media framing analysis. Twelve international online newspaper articles reporting on migrants' grief from afar published between 1st of February 2020 and 31st of July 2022 were analysed. Long-distance grief was represented as a result of a series of individual choices (e.g., how to handle the deceased's body, decisions about staying/attending the funeral). In spite of the regulatory context of these experiences during COVID-19, the media framed stories of grief as personal accounts of intimate relationships. As a result, the media created an image of migrants' grief during pandemic that emphasised the personal nature of these experiences and overlooked the social and policy context that shapes these experiences. The paper provides insights into the impact these representations may have on public perception and actions regarding migrant experiences.

Dead Bodies' Agency and Western Politics: The Women, Life, Freedom Movement in Iran and its International Political Impacts
Hajar Ghorbani

Relationships between dead bodies and power have preoccupied scholarly debates, as a pronounced propensity of specific political systems to govern and colonize the dead to legitimize themselves. While this view ignores the dead body's agency, a new perspective gives the dead power and voice and highlights their ungovernability. Focusing on the case of contemporary Iranian society, Mahsa Amini's death, this research bridges the gap by emphasizing dead bodies as exercising a specific, strong form of agency and authority. In Mahsa's death and burial rituals, several women activists cut their hair which caused the "woman, life, freedom" movement. Furthermore, the funeral rituals revealed the power of the dead for the Islamic Republic's authorities to the extent that they have been trying to steal the dead bodies of protestors and burying them secretly overnight without allowing anyone to participate in the burial rituals. These events rapidly circulated worldwide, socially and politically, affecting many Western societies and politicians. In this work, I will show the dead's role in the transition of power from the living to the dead, helping us to understand, for example, how the dead's agency pushes Western politicians to perform socio-political acts.

2a. Mourning Italy: rites and spaces for a sustainable experience of death
Giovanni Corbelli

Italy is facing a long and complex 'death crisis', with fully exhausted cemeteries, no space available to expand them, and a general lack of cremation infrastructures that, in other countries, have taken care of the management of the 'disposal' of bodies, while offering suitable settings for the last goodbye, regardless of any religious affiliation.

Actually, Italian society, increasingly secular and multicultural, hardly provides appropriate contexts to celebrate this important moment, and the lack of meaningful spaces deeply influences the awkward and improvised ceremonies too often experienced by those who have lost someone. On the other hand, such delay offers an opportunity – and a testing ground – to consider advanced approaches, beyond the energy-intensive and polluting burning of bodies. Now that the baby-boom generation is ageing and a wave of death looms on the horizon, rethinking spaces, thresholds and rituals for dealing with bodies, mourning the beloved and keeping their memory alive represents a more urgent task here than elsewhere.

The panel, which includes different disciplinary approaches – from architectural design to philosophy – will collect and critically elaborate on some examples that can offer a viable, significant perspective on the contemporary Italian death landscape.

2b. Decolonising the aftermath of death in UK contexts: theoretical approaches, institutional 'constraints' and everyday experiences
Jane McCarthy

Innovative decolonising work, over a wide range of areas and with variable remit, always entails going beyond diversity. Decolonisation has only recently been raised in relation to 'bereavement' (Hamilton et al, 2022), while the language of 'bereavement' and 'grief' itself arguably constitutes a major constraint (Ribbens McCarthy et al, in press). In the UK context, evidence of inequalities and discrimination has been recognised as arising from institutional racism across many areas of life. In the bereavement sector specifically, the paucity of support for minoritized ethnic populations was raised as a central issue in the 2022 UK Bereavement Commission Report, while services are poorly placed to respond (Selman at al, 2022). While such work is often framed as EDI – Equality/equity, Diversity and Inclusion – this risks constituting Endless Distraction and Inaction (Ahsan, 2022). In responding to these potential developments and innovations, what are the challenges for decolonising work in the UK bereavement sector, in

terms of theoretical paradigms, epistemological in/justice, and institutional power constraints? What will enable decolonising work to fulfil its potential to respond to lived experience and institutionalised colonial histories, to both develop social justice and enhance the resources potentially available to all in responding to the aftermath of death.

Refs:
Ahsan 2022 https://www.bps.org.uk/psychologist/edi-endless-distraction-and-inaction
UK Commission on Bereavement 2022 https://bereavementcommission.org.uk/ukcb-findings/
Hamilton et al 2022 'Do we need to decolonise bereavement studies?
https://doi.org/10.54210/bj.2022.20
Ribbens McCarthy et al. (2021, in press) 'The aftermath of death in the continuing lives of the living: extending 'bereavement' paradigms through family and relational perspectives.' Sociology

2c. From voluntary to commissioned: learning innovative end of life doula provision in Leeds
Erica Borgstrom

End of Life Doulas provide practical and emotional support to people who have a terminal diagnosis and those around them. Their role is non-medical; they focus on wellbeing, sense of identity and self-worth, advance planning and funeral arrangements, and bereavement. Most people in the UK are not supported by a doula at the end of life; there are only approximately 250 doulas who are practicing or currently receiving training. Moreover, doula services are typically privately paid for or provided voluntarily by the individual doula. In a one-of-a kind innovation, clinical commissioners in Leeds have contracted End of Life Doula UK to provide doula support in the locality, making doula support more accessible and to complement existing palliative care services. Since 2021, End of Life Doula UK have been working with researchers at The Open University to understand how this arrangement, including the ways in which it is shaping what doula support looks like. This presentation share insights covering: generating referrals to the doula service, what support is provided in an evolving context, measuring doula impact on end of life experiences, and doulas' perspectives on their role in this context.

3a. Creativity II

End-of-Life Narratives. Innovative Ways of Creating Legacies
Zoë Ghyselinck

In recent years, the creation of end-of-life (EOL) narratives, often supported by biographers (e.g., Amfora, Belgium), attests to an innovative trend of storytelling practices in Western-European palliative care that prompt us to rethink the ways in which the dying anticipate death. Research has emphasized the therapeutic benefits of narrative life-review for the dying, relatives, and caregivers in EOL stages. Little is known about its implications for the bereaved. I draw on a literary-sociological approach to address this challenge from the perspective of literary studies. By comparing non-fictional with fictional EOL narratives, I argue that literary techniques, such as imaginative narration, structure the ways in which the dying want to be remembered and how they anticipate a future of which they will no longer be part. I hypothesize that the dying and the bereaved not only attribute meaning to EOL narratives in terms of a continuation of intimate roles in absentia. EOL narratives likewise elicit disrupting experiences and intergenerational incomprehension. Insights into how literary techniques modify the communicational character of EOL narratives will enhance our understanding of how these texts help the bereaved imagine the

deceased, and will lead to evidence-based guidance for those involved in innovative practices in EOL care.

#RIPBozo: memes as ritual practice of contested memory
Anu A. Harju & Johanna Sumiala

Death-related rituals are an important part of the social life of death. New and innovative practices of participating in the death event are emerging (Sumiala 2021): in the context of public death, memes have become a popular form of vernacular remembering with multiple social and cultural functions (Shifman, 2013).

This paper approaches memes as ritual practice. We argue memes have the potential to disrupt and challenge the hegemonic and official memory and bring to public ritualisation aspects otherwise avoided in public commemoration. As cultural performance, memes can be perceived as structured, ordinary forms of symbolic communication that bring together different publics. To participants of this ritual activity, memes are easily recognisable, yet their complexity also excludes. The empirical focus is the death of Queen Elizabeth II. An iconic and historic figure, she became a rich source of memes from benevolent expressions of grief to the more malevolent ones that speak to the troubled history and legacy of the Queen and the British monarchy. Playing with popular culture, memetic performances draw on historic authority, but also challenge it (Silvestri, 2018) with competing symbolisations and narratives about the dead, thus contributing to contested memory of the longest ruling monarch in British history.

New Ways of Writing Loss: A Peculiar Case of COVID-19 Obituaries
Pia Bakshi

In March 2020, The New York Times launched an obituary column dedicated to the victims of COVID-19, "Those We Have Lost to Coronavirus," modeled on the erstwhile "Portraits of Grief" column following the 9/11 terror attacks. The peculiarity of the column lies in its attempt to memorialize a global phenomenon that continues to be a part of the present. I suggest that the column provides us with new ways to engage with death-writing and its temporality. By close-reading the digitized section of the newspaper and its interactive sections (comments, responses, calls etc.), I contest that this process of memorialisation goes beyond the realms of individual memory and enters the networks of preventive discourses (where it also serves as a warning against indiscriminate pandemic behavior) and public dismay at the administration. In doing so, the obituary becomes a narrative made of what Jonathan Gil Harris has called untimely matter, an exoskeleton, that inhabits death and also survives it. I will be drawing from Judith Butler's works on grievability, Pierre Nora's lieux de memoire, Arjun Appadurai's work on archive and aspiration, Derrida's thoughts on mourning, and Paul Bijl's postulation of emerging memory to situate my arguments.

Compassionate Acts: Implementing Forum Theatre as a tool to create a compassionate peer structure for bereaved students
Alex Cahill

Child Bereavement Network estimates 127 children are bereaved of a parent every day. Compassion Arts, in partnership with St Luke's Hospice, aims to change the taboo nature around death and dying by 1) training young people to understand bereavement, dying, and anticipatory grief and 2) talking about death and bereavement in an open and honest forum through the method of forum theatre workshops. Between 2018-19 and 2021-22, Compassion Arts trained approximately 450 students in the Southwest through the Compassionate Buddies pilot program.

The aim of this program was to create compassionate peer structures around bereaved students in an educational setting. Initial feedback states that the forum theatre training provided to secondary school students has increased students' awareness about bereavement by 86% with a further 65% saying they now feel confident talking to a bereaved peer (Cahill 2023). Approximately 90% of the teachers from these schools indicated the need for this education to be included in public policy (Cahill 2023) – an area we hope to address in the project's next phase. This conference paper aims to disseminate the initial findings of that pilot project and analyse the efficacy of using forum theatre as a tool for creating a Compassionate School.

3b. Support

Unpacking Grief for Children - How could "Therapeutic Toolkit" resources provide support for bereaved children and increase confidence for adults in their interactions with them?
Callie Harrop

A presentation of a mixed methods study exploring parents, carers' and professionals' experience of supporting and having conversations with bereaved children and an introduction to the resources developed in line with this research. Using ANOVA testing on the quantitative data, which explored comparisons between parents/carer and professionals and those who had supported a bereaved child and those who haven't, results highlighted differing levels of confidence. Thematic Analysis (Braun and Clark, 2021) allowed exploration of perceived challenges and successes in the conversations and interactions the participates had or imagined they would have with bereaved children and provided direction for the development of the contents of the toolkits. The study explored four key areas of initial conversations, emotions, narrative and memories and considered how they would be encapsulated in a therapeutic resource for bereaved children. This paper explores the findings of this study and the presentation of the subsequent toolkit created to support bereaved children, whilst discussing further implications for the development of bereavement services and resources.

Maximising impact through a knowledge to action approach: The Palliative and End of Life Integrated Care System Care Data Packs
Nicola Bowtell

There are wide reaching reforms within the Health and Care Act 202. Clause 21 states that Integrated Care Systems (ICSs) have a legal responsibility to commission PEoLC services that meet population needs. In 2022 NHSE/I published statutory guidance to address health inequalities for PEoLC: emphasizing improving equity of access to services and reducing inequity of outcomes and experience. The first step is a needs assessment utilising population- based health intelligence.

Responding to the Statutory Guidance the National End of Life Care Intelligence Network worked with NHSE/I developing data packs for ICSs showing how to use the NEoLCIN resources and interpret comparative local data. Sections include: undertaking a PEoLC needs assessment, early identification in general practice, care homes and hospital use at EoL. The packs were disseminated to ICSs in July 2022 using Knowledge to Action (K2A) methodology including: a national webinar and regional interactive presentations. This enabled local evidence-based decision making, facilitated refinement of the packs, and maximised impact.

Developing intelligence to inform commissioning is critical. A K2A process makes products accessible and tailored to different product users, product users have the skills to use the products, have input into the design, make better use of the intelligence, and increases impact.

Evaluating the Implementation of the Dorothy House Hospice Service Transformation
Natasha Bradley

Background: Dorothy House Hospice has embarked on a comprehensive redesign of its services. The overall aim is for more people to receive excellent palliative care, by increasing the number of people cared for, and providing care closer to their homes. The experiences of people involved in, or affected by, the service redesign will shape how successful it can be in reaching these aims. However, there is limited evidence available to guide the implementation of change in hospices.

Aim: This research will study the implementation for its first year from April 2022. We aim to develop evidence-based explanations for how and why the implementation influenced adoption of the new model.

Research question: What worked well, and less well, during the implementation of the Dorothy House hospice service redesign, for whom, in what circumstances, to what extent, and why?

Methods: This is qualitative research informed by realist evaluation, which is a theory-led approach to complex and changing interventions. Data collection will involve qualitative interviews (n=60), followed by focus groups. Normalisation Process Theory is used as a theoretical framework.

Conclusion: The presentation explains how realist evaluation and implementation science can be used to research the transformation of hospice services. Knowledge gained can inform ongoing and future change projects.

Saying 'Hello Again', rather than a Long Goodbye
Elizabeth Gilmour (MPsych Hons Candidate) and Dr Edith Steffen (Supervisor)

The 'Hello Again' letter-writing technique in grief counselling facilitates continuing bonds with the deceased (Neimeyer, 2012). Family member caregivers of those living with dementia often experience a 'long goodbye', a form of grief. There are limited interventions to support them with grief and developing continuing bonds.

This project applies the 'Hello Again' letter-writing intervention to family caregivers of those in later stages of dementia to explore the helpfulness of this intervention with this population and to understand the meanings of the relationship as expressed through letter writing. This involves three half-hour meetings with the researcher and two take-home letter-writing tasks. The first task is writing a letter to their loved one. The second task asks participants to take on their loved one's perspective and write a response to their letter. Dialogical narrative analysis (Riessman, 2008) is conducted on the letters and interviews.

The project is in progress, to be completed by April 2023. Preliminary interviews and analysis suggest positive perceptions. It is hoped that the findings of this study will enable researchers and therapists to create interventions and better understand the needs of close family caregivers in the later stages of caregiving and dealing with the grief associated with dementia.

3c. Post-death

Developing a holistic approach to bereavement care across Europe through collaboration across disciplines and country borders
Eva Zsak

Scientists, scholars, practitioners, educators, and policymakers who work to advance the field of bereavement care, and bereaved people themselves often do not read the same journals or sources, interact or attend the same conferences. This is a shame, because important information, including research- and practice-based findings, and learnings are not shared with all who might benefit. As a result, both advancement of the field and bereaved people pay the price. We call for a more holistic approach to bereavement care, one that promotes sharing of scientific, experience and practice-based information across professions and facilitates collaboration across Europe.

This presentation will discuss the inaugural European Grief Conference 2022 (held in Denmark), as an example of an innovative attempt to encourage dissemination, interaction and collaboration across professional fields and European borders. The conference was structured around a four-tiered model of bereavement care (inspired by the public health model). Great care was taken to insure broad representation across disciplines and European countries on the conference planning and scientific review committees, among presenters, and participants, including bereaved people's perspectives. 250 people from 27 countries participated.

Post conference evaluations confirmed our belief that such diverse and inclusive conference would be timely and well-received.

Rethinking 'disposal': making meaning from our processes, rituals and bodies after death
Poppy Mardall
In this individual paper I will explore how the current framing of what happens to the body after death as 'disposal' in the UK has created a death care culture that isn't working for people or for the planet. I will look into current technologies, processes and rituals around death using the lens of disposal to clarify what isn't working and why. I will posit a new lens through which we could reimagine our thinking about, relating to and working with the dead body, based on innovative technologies and approach and also on past traditions and practices, to better serve our physical, mental and emotional needs as individuals and communities, as well as our planet, when someone dies.

Theoretical innovations in the aftermath of death: extending 'bereavement' paradigms through family and relational perspectives
Jane McCarthy

While there is a significant interdisciplinary and international literature available on death, dying and bereavement, literature addressing responses to death is dominated by assumptions about individuality, framing 'bereavement' and 'grief' in terms of the 'inner' psychic life of the individual. Furthermore, existing models and approaches are driven by an interventionist orientation, towards the reduction of 'risks' regarding undesirable 'outcomes'. Consequently, scholarly literature tells us little about how the continuing aftermath of death is experienced in the everyday relational lives of the living. Inspired by research from Majority Worlds where death may be understood as a communal event, we consider opportunities for an innovative 'relational' sociological approach, and explore what that might involve. We outline the potential for family

sociology to provide an intrinsically (if variable) relational lens on the aftermath of death, along with two approaches of relational theorising more generally, drawing on the work of Karen Barad on intra-action and relational materialism, and the African philopraxis of social personhood understood as ubuntu. We argue for a reframing and broadening of the dominant 'bereavement studies' of Minority Worlds towards a much-needed paradigm shift in understanding the continuing aftermath of death in the lives of the living.

Saying 'no' goes against the grain – UK funeral directors' experiences and the complexities of 'choice' during and beyond the COVID-19 pandemic
Jennifer Riley

'[We're] not used to having to say, "No" to our families. Where it is legally possible, we will always give them what they want.'

The idea of funeral 'personalisation' receives significant emphasis in the UK, especially for secular funerals. Funeral directors often seek to facilitate what clients 'want' or 'choose,' and may see this as an important aspect of providing 'care.'

In the first years of the COVID-19 pandemic, funeral options were constrained in various respects by legal restrictions and other measures put in place to reduce the spread of the coronavirus. Interviews with funeral directors about their experiences of these times revealed the discomfort many felt at having to 'say no' and to - sometimes reluctantly - enforce unfamiliar boundaries. These interviews – together with those conducted with bereaved individuals – also highlighted complexities relating to the notion of funeral 'choice' and signalled creative and sometimes innovative ways in which funeral directors could serve people well and offer 'good' funerals when options were constrained. The pandemic situation challenged the priority often awarded to 'choice' and re-emphasised the different forms care can take.. This paper reflects critically on questions about choice and care in UK funerals beyond the pandemic context.

<u>Keynote</u> - Sociopolitical Grief

Darcy Harris, King's University College at Western University London, Canada

While most of us think of grief as an individual response to loss, there are losses that originate at the level of social and political institutions, with many creating a unique type of grief that is hard to describe. Sociopolitical grief includes the direct losses that are experienced by individuals and groups as a result of political policies, ideologies, and oppression enacted and/or empowered at the sociopolitical levels. We see the suffering that political policies and laws have caused those who are need care, are vulnerable, or who have been moved to the margins of society. We also grieve the losses created by inaction, such as the loss of our precious environmental balance and resources.

In this keynote, the concept of sociopolitical grief will be explored from many different perspectives, along with approaches to better understand the impact of losses that originate at the structural level and their impact upon those who work in various settings, such as health and social care settings.

4a. The Death Studies Podcast with Tony Walter
Bethan Michael Fox and Renske Visser

In this live podcast recording, we will interview Professor Tony Walter about research, innovation, climate crises and ecological emergencies. The audience will have the opportunity to ask questions, and we will explore how Professor Walter has innovated, contributed to and supported innovation across his career. We can also offer a 'in case you missed it' and 'recap' episode, which will include discussion of the conference and its key themes summarising what took place, audio captured during the event, a brief interview with the organisers and clips from willing attendees.

5a. Structural inequality

Dying at home: Integrating findings from a large-scale Canadian mixed methods study
Laura Funk

Background: In this paper, we offer an integrated analysis of a large scale Canadian mixed-methods study on preferences for dying at home. Data include two national surveys of public preferences for location of dying, community stakeholder and policy representative interviews, and discursive analysis of public policy texts.

Findings: When public narratives idealize dying at home as an uncomplicated best choice between options, or as signifying hope for mutual aid and community empowerment, this tends to obscure impacts on family caregivers as well as inequities and structural barriers shaping choice. A tendency among policymakers to naturalize dying at home as 'commonsense' serves multiple aims, while simultaneously contributing to idealization. Countering this normativity, people with more professional and life experience with death and dying commonly reference financial costs and structural barriers, with implications for their personal preferences. Although public preferences for dying at home might be relatively idealized, vignette methodology illuminates these preferences as fluid and shifting in response to contextual circumstances, as well as the broader socio-historical context of the pandemic.

Conclusion: Collective knowledge across these findings, alongside a critical theoretical orientation, help to nuance and problematize issues of advance care planning, informed choice and death literacy related to location of dying.

Authors: Funk, L., Cherba, M., Cohen, S.R., Krawczyk, M., Mackenzie, C., Rounce, A., & Scott, E., Chan, W.S., & Stajduhar, K.

"Bottom Line Blackness": Revising Death Awareness Discourse in light of Black American Activism
Ara Francis

The interdisciplinary field of death studies is premised narrowly on the experiences of white, middle-class people living in North America, Australia, Western Europe, and Scandinavia. The sociology of death, dying, and bereavement has done little to challenge this premise, and recent scholarship in our discipline calls for a decolonization of the subfield (Puri 2021). This paper responds to that call by bringing scholarship on Black American's experiences of state-sanctioned violence into dialogue with sociological debates about the denial and sequestration of death in the modern West. American public discourse treats the violent deaths of Black

Americans as an aberration, even though such deaths are a longstanding, institutionalized feature of American society. I argue that sociologists adopt a similar framework when they make sweeping claims about modernity and mortality without accounting for deaths caused by routine interpersonal, structural, and state-sanctioned violence. Taking the history of Black American activism and collective identity vis-à-vis death as a case-in-point, I consider in this paper how "bottom line blackness" (Alexander 1994) might lead us to revise our theorizing.

5b. Death Tech
Doing User Experience Research in Death Tech: Pain Points and Positives
Kathrina Mazurik

Death tech is quickly becoming part of the contemporary conversation about death and dying. Alongside this trend, we have seen growth of User Experience Research (UXR) - a form of applied research aimed at gathering knowledge to best inform the design of technology products, services, and experiences for users. Over the past year, a research partnership between Cadence and the University of Saskatchewan permitted a team of psychology, anthropology, and health researchers to conduct several research projects to better understand end-of-life administrative processes and their intersections with family conflicts, the fear of death, and grieving processes. In this presentation, we first share some of the challenges of this UXR program, focusing on 1) ethical considerations, 2) the need for agile research within a start-up environment, and 3) the learning curve in moving from academic research to research within the tech world. We complement this discussion by recognizing four major benefits of our research program, notably for 1) developing a company-wide understanding of families' and professionals' challenges with end-of-life administration, 2) re-inventing our tone and messaging, 3) building our inter-professional network, and 3) creating innovative, accessible, and useful products that help families during some of the most challenging times of their lives.

Cultivating Innovative Death Technology
Victoria J. Haneman

The U.S. consumer must, ineluctably, contend with a menu of death care options shaped and limited by the current regulatory environment of the industry. Death care services are regulated almost entirely at the state level, by an industry that arguably has an oversized voice and influence. Current operators have an incentive to entrench status quo. The concept of regulatory capture is difficult to conclusively prove with empirical data because excessive influence against public interest is generally not an issue that lurks in the light. This presentation considers the way in which innovative death technology may be fostered through regulatory design that acknowledges incentives to resist change.

In Their Presence: Technologically Mediated Departures
Emily B. Campbell

This paper is a critical auto-ethnography that narrates the experience of two "FaceTime farewells"—experiences of witnessing the death of kin over video call. I narrative the experience of two FaceTime farewells occurring during the height of lockdowns related to the covid-19 pandemic. These two events, firstly, were marked milestones in my own personal biography as I experienced the deaths of two beloved mothering figures in my life. To say little of the profundity of the losses, the nature of the farewells was deeply disorienting as they collapsed time and space. Each call pulled me outside of my body and into the presence of a dying, beloved family member. With the ever-growing ubiquity of video cellphones, the possibility of "FaceTime

farewells" is a new frontier in the ethics, culture, and experience of dying. What solace and community do these new forms invite? What ethical challenges?

5c. Hear here: where real and fictional death meet
Mel Keiser

Mel Keiser (b.1985, 2003, 2007, 2007, 2011, 2014, 2018, 2020) is a multidisciplinary artist exploring the social and psychological impact of treating herself as a linear progression of distinct selves rather than a single person in fluid development. With the birth and death of each discrete self, the-person-who-is-Mel changes. Keiser's work builds evidence that these selves exist: she makes a body for each self to bury it in a cemetery. Entangling the borders of reality and fiction, this project is a journey to understand self-death. Keiser collaborates with experts to prepare a funeral for her first self. Modeled from 3D scans of her body, they hand-carve disarticulated bones as a surrogate body for burial. Concurrently, a gravestone is hewn by a stone carver trained to be a priest; a casket is hand-built from a tree that clones itself; and mourning clothes are tailored from the clothes of the living and deceased selves. With these objects, Keiser will hold a public funeral, burying the bodies of these past selves, incorporating a small plot of land in Illinois as a family cemetery, creating a public art site. In this performance lecture, "Hear, Here: Where Real and Fictional Death Meet," Keiser introduces the audience to her artistic practice and this fiction-based project on death, and how through the surprising influences of the pandemic and birth of her daughter, became a real scholarly interest in death studies, which led to the founding of Northwestern's Death Studies Research Group, but also inadvertently prepared her to witness actual death, the death of her grandmother. Through the presentation, it will become clear that Keiser's pursuit of death studies, while originating as complementary research to creating a funeral for self-death, was ultimately an act of resistance to our deeply held fear of death, heightened as it was for Keiser by the coterminous experience of mass death and early motherhood. Her lecture shows that the most radical form of resistance we can use to fight death is to gaze at it unblinkingly.