# Good Grief: Co-creating a public engagement festival

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@GoodGriefFest
@capcbristol



#GoodGriefFest #CAPCwebinar



### Social attitudes

- Although grief is universal, our society struggles to handle it well
- YouGov, January 2022 (n=2264 adults, nationally representative):
  - 43% are worried about saying the wrong thing to someone bereaved
  - 32% don't know how to start a conversation after a bereavement
  - 12% have actively gone out of their way to avoid someone who is grieving because they don't know what to say to them
  - 49% who have not experienced a bereavement say they are unprepared in knowing how to help a bereaved friend or relative
  - ✓29% are interested in learning how to better support the bereaved



### Bereavement experiences

- Of people bereaved in the last 5 years (YouGov 2022):
  - 29% said they did not have access to the right bereavement support
  - 60% said their community had not helped them deal with their grief
  - 30% had experienced people not referencing their loss at all
- Younger people and ethnic minority groups less likely to access professional support (Sue Ryder, 2019; Murray, 2020)
- Key barrier is feeling uncomfortable asking for help (Sue Ryder, 2019)

### Aims of Good Grief Festival



- Provide ways to talk, think, learn about and share experiences of grief
- Widen access to research (social science, arts, humanities)
- Widen access to bereavement services
- Focus on disadvantaged young people and BME community groups

Support a shift in social attitudes and the development of compassionate communities

# Choosing collaborating partners



- Leaders in the field, diverse sectors, expertise and skills
  - Bereavement and end-of-life care charities, young people's organisations, major cultural organisations, festival producer
- How do you attract collaborators?
  - Identify shared values and aims
  - How can you help them achieve goals they already have? Link with their existing work, initiatives and timelines
  - Establish trust and rapport
  - Be authentic, show humility
  - Offer an inspiring vision



### An inspiring vision

- Clear and simple
- Motivating, uniting
- Clear about your motivations and what you bring
- Clear about what you are not doing

## What we planned...

• Originally: **Good Grief, Bristol** – A city-wide festival integrating arts and sciences, refined through community consultation – planned for Dying Matters Week, May 2020



### Collaboration with Creative Youth Network – spring term 2020





#### 9 courses: animation, textiles, film, theatre, music, dance, fashion, printmaking, puppetmaking

- 90 sessions 180 hours
- 76 young people

#### **Good Grief - Creative Showcase 2020**

Our Creative Courses bring together over 80 young people aged 10-18 from diverse backgrounds every term. Delivered in community settings across Bristol and South Gloucestershire, often in youth clubs, we explore difficult topics with young people who use creativity to express themselves, build resilience and develop relationships based on trust with experienced Creative Youth Workers.

This spring term, we have worked in partnership with Good Grief Festival. Using nine different artforms, we enabled young people to think, talk and learn about grief whilst learning new creative skills.

The ten week long courses are led by professional artists trained in youth work and assisted by young emerging artists, for whom this is a crucial step into their creative careers.



THEATRE

The five stages of grief enacted.

FILM MAKING

d. You're at the gates of heaven and hell, who goes through and who gets transferred?



PUPPET MAKING

ANIMATION

MUSIC

Jam with us.

What characters are in your after life? These are ours.



? Climate grief, inner thoughts and secrets brought to life.



**CRAFT & TEXTILES** 

Celebrating nature, and its interconnected, ever moving cycle of living and dying.



STREET DANCE

Day of the Dead dance routine.



ART & PRINTMAKING Exploring different cultural traditions of death

through diverse imagery and techniques.



FASHION

What would you wear to welcome back souls during Dia de Muertos?

https://www.creativeyouthnetwork.org.uk/good-grief-showcase

### Good Grief Film Workshops



Has someone important in your life died? Would you like to share your experience of grief?

Work with film-makers to produce a short film about grief to be screened at Good Grief Bristol, a new festival to help people talk, think and learn about grief.

Tue 18th – Thu 20th February 10am – 4pm The Station, Silver Street, BS1 2AG

This workshop is for 14-19 year olds who have experienced bereavement. Workshops are supported by youth workers from Creative Youth Network and bereavement specialists from Winston's Wish.

Sign up now: www.creativeyouthnetwork.org.uk/good-grief 0117 947 7948



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#### **Five Stages of Whatever**

Using lived experience, this short film plays on and explores the framework of the Five Stages of Grief - denial, anger, bargaining, depression, acceptance.

The film was produced by a group of 14-19 year olds who have experienced bereavement and used film making as a way to tell their story. They wrote the script and gained skills in camera work, lighting and editing as well as featuring in the film themselves.

The group had support from youth workers and bereavement specialists.



This film was made by Creative Youth Network in collaboration with the Good Grief Festival, University of Bristol and Winston's Wish.

- 5 young women from more disadvantaged backgrounds who had experienced grief
- Youth workers, uni film students, social scientist, bereavement counsellor
- Film available at:

https://www.creativeyouthnet work.org.uk/five-stages-ofwhatever

### COVID-19



Clear by March 2020 the festival couldn't go ahead as planned

 COVID-19 a mass bereavement event in the most difficult circumstances

>Even more need for the festival

## What were we building on?

- Brilliant team of collaborators
- Network of supporters and public contributors
- Strong social media following of 3000+
- Great interest and ticket sales prior to lockdown
- Website, links to speakers and facilitators, the original programme

What did we change?

Free

3 days, not 7 days

Shorter sessions, interactive where possible, some events pre-recorded

Online, but with a pop-up studio in Bristol: live facilitators, linking to remote presenters

Constant contingency planning!

2 'stages' – main stage plus workshops & webinars





#### TALKS + INTERVIEWS

On the Main Stage, we have an incredible lineup of panel talks and interviews with speakers including Robert Webb, Cariad Lloyd, Valentine Warner, Julia Samuel, Professor Alice Roberts, Dr Rachel Clarke, Dr Kathryn Mannix and many, many more.

10:00 on Friday, October 30th to 19:00 on Sunday, November 1st.

#### WORKSHOPS + WEBINARS

Our programme includes interactive workshops, and talks by academics across disciplines working on the topic of grief. Learn how to write a memoir with bestselling author Nikesh Shukla, design a meaningful memorial service with award-winning funeral celebrant Rosalie Kuyvenhoven or listen in to a lecture on Grief in Film with Dr Jimmy Hay. 09:30 on Friday, October 30th to 18:00 on Sunday, November 1st. The Studio.

### **GRIEF SCHOOL**

Our Grief School will cover 14 different types of bereavement and loss including grief as a result of suicide, stillbirth, the death of a child, infertility, dementia, life-threatening illness diagnosis, pet loss, substance misuse, childhood bereavement and grieving during Covid-19.

Each Grief School event will repeat on a loop during the festival.

### **GRIEF CHATS**

Our Grief Chats are intimate conversations between two guests who have both experienced the same type of bereavement or loss. They are hosted by writer and broadcaster Mark Lemon, who's behind the acclaimed podcast, Grief is my Superpower.

Each Grief Chat will repeat on a loop during the festival.

### Structure



# What happened next?

- 8500+ people attended the first festival
- Set up the Grief Channel
- Collaborated with Marie Curie on National Day of Reflection, 23 March 2021
- Second and third festivals in March and October 2021, plus ongoing events

www.goodgrieffest.com www.grief-channel.com



# Key ingredient: Consultation, collaboration

- Bringing partners on board while developing the application
- Market research when developing application; when adapting due to COVID-19
- 8 listening meetings with stakeholders in 8 months (Dec 2019- July 2020)
  - Bristol Bereavement Network 10 December, 10 March, 23 June (online)
  - Academics, clinicians and counsellors 22 January, 22 July
  - Young people (age 11-18) (PPI) 3 January
  - Diverse group of adults (PPI) 23 January, 8 July (online)
- Plus planning meetings with collaborators every 3 months

# Key ingredient: Integrating the arts

• My background – early modern literature, medical humanities, history of emotion; Arts and Culture Lead for the Good Grief Festival.

How does integrating the arts benefit public engagement?

How do they open up new perspectives?

Examples of collaborative projects that sprang from or fed into the Good Grief Festival.

# How do the arts benefit public engagement & open up new perspectives?

• The arts provide a way into challenging topics - Music, poetry, film, art, etc.











# The arts give insight into the lived experience of grief

- Artistic expressions of mourning highlight the individual nature of grief.
  They allow us to think about grief in a manner that is particular and culturally specific.
- The arts can capture something of the lived experience of grief and provide examples of how we express our continued relationship with loved ones who have died.

# Historical Perspectives

- Exploring grief across a broad historical framework helps us understand our own cultural moment.
- 20<sup>th</sup> and 21<sup>st</sup> century notions of death and grief vs older paradigms.
  - Are we an outlier?
  - Continuing bonds and older models?

## Creative Grieving

- Brigstow-funded project which explores the therapeutic potential of creativity & the way art can help us to express and process loss.
- Examines the dual role that the imagination plays in grief.
  - Both as a source of suffering & an important tool in integrating loss.
- What happens to emotions and memories when we engage with them creativity?
- Why do some activities console whereas others intensify the pain of loss?
- Includes interviews, book & creative components.



### Hay, Dawson, and Rosling, Lost Property-

A short collaborative fiction film which investigated whether storying loss and representing it through narrative, images, and embodied movement could be therapeutic. (Dawson et al., *Therapeutic creativity and the lived experience of grief in the collaborative fiction film Lost Property.* Research for All, 2021. 5(2))

<u>'Children, Grief and Creativity'</u>, a short animation created in collaboration with psychotherapist and bestselling author Julia Samuel MBE, and animator and widower Gary Andrews (and his children, Lily and Ben)







**<u>'Children, Grief and Art Therapy'</u>**, a short film produced with Art Therapist Victoria Tolchard featuring children's artwork.





FOR GOOD GRIEF FESTIVAL



# 'Gathering' by Jayde Perkin

**Baby Loss and Grief** – a project funded by the Elizabeth Blackwell Institute for Health Research, University of Bristol and the Wellcome Trust Institutional Strategic Support Fund.



## Engagement since October 2020



- •c.24,500 unique viewers of festival content and webinars
- •8000 people subscribed to the Grief Channel [24 CPD points for doctors]
- •16,000 social media followers; 22,500 email subscribers
- •Brilliant engagement with online chat alongside the events

•Community blackboard

#### **Good Grief Festival Community Blackboard**



A space to share your experiences of the festival and connect with everyone attending. Photos, videos, messages, questions, drawings all welcome! Please note that all posts are moderated so there might be a slight delay until your post appears. Feel free to share email addresses, but remember this is a public forum. Please don't use this Blackboard for advertising. By contributing to the Blackboard you agree that your responses may be used (anonymously) in future reports about the festival. For general enquiries, email hello@goodgrieffest.com. Many thanks.

#### Anonymous 7d

#### **October Grief Festival**

Hello there, thank you for providing this wonderful resource and information on grief. It is truly helpful and needed. I live in the States and missed a large part of the festival since the events were overnight here. Will there be a replay? When will the replays be available? Thank you,

#### Natalie

Good Grief Festival 1m Hi Natalie, all the festival sessions will be uploaded to the Grief Channel this week: grief-channel.com.

 $\Omega^2$ 

Good Grief Festival 1m So glad you are getting

#### Anonymous 7d

Grief is a long journey best punctuated by festivals.

I am a funeral celebrant and studying for a PhD examining the role of other celebrants. I have experienced being both an observer of the grief of others through my work and of my own personal experiences of losing loved ones over lockdown including a suicide and an accidental drowning. The onset of close grief is like the loss of innocence, one can no longer deny the ever present face of death. But at times death can be a welcome face when watching or experiencing great suffering. However, it is always the finality that

#### Anonymous 7d

Thank you so much for this. I lost my dad two weeks ago suddenly, no chance for goodbye, and can't attend the funeral, I live far away. Having access to all this wisdom and authentic vulnerability means everything right now. It really is a lifeline. If you do more in the future I would love to see a panel discussion around complex grief, losing a parent you weren't able to be close to due to abuse/trauma. Sending love and solidarity to all here.

#### Add comment

Anonymous 8d
A couple of series I have enjoyed

#### Anonymous 8d

#### Thank you

Thanks for the two inspirational speakers I heard (Raynor Winn and Ruby Wax) and also for the interviewers Colin Midson and Julia Samuels. Also for the Death Cafe, my first but hopefully not my last.

🌕 Add comment

#### 🚯 Kate V 8d

The Good Grief Fests have been deeply inspiring, informative, and nourishing, especially in helping me navigate the sudden loss of my brother Michael during this past year,



#### Good Grief Festival coverage report

Number of articles by source location



Social behavior is making betravement harder to tops with a study by Delated University and Dard III these states is a formal

Reopie who are grinving have told measurchars is a darupting their support structures and they have linear people should around to help them

The research project is still, looking for people to share their stories on how they have deals with applaity

Articles Reach

...

error Coronavirus UK World Business Politica Liech Science Health Family & Education

72 1,216,316,000

### -theguardian

#### 'Not ordinary grief': bereavement festival attracts thousands

UK virtual event over three days will explore how Covid-19 has shaped the way people mourn Coronavirus - latest updates

See all our coronavirus coverage



A Drie of the specifies of the event, psychotherapist Kathryn de Posthoe, whose father. Tony Eley, died in Apri after contraction (four) that aged ((), such one have at home in ) and, with the fluctuant Mr. one, both and her within, Joyna Class, Photography Chendodrian Disproved The Geardian

> hat could be more 2020 than a festival of bereavement? Ove 6,000 people have signed up to Good Grief, a three day even billed as "a virtual festival of love and loss" that will explore the unique shape of grief during the Covid-19 pandemic.

With a line-up resembling a lively literary festival rather than an undertake convention, speakers will include comic actor and writer Robert Webb, psychotherapist Julia Samuel, a friend of Princess Diana, and palliative care expert Dr Rachel Clarke. It was planned pre-pandemic to help open up British attitudes towards grief. But the event has taken on fresh urgency after nearly 60,000 more deaths in England and Wales since the start of the crisis than on average - a 23% increase in mortality,

It means that when all deaths are considered, at least a million people have been bereaved at a time when normal rituals, visits and contact have been upended by lockdowns.

A study is underway at the universities of Cardiff and Bristol seeking evidence from people who have had to go through socially distanced

UK TO HOST THE WORLD'S FIRST VIRTUAL GRIEF FESTIVAL



### Evaluation

- Pre- and post-festival surveys; post-festival questions:
  - Tell us your suggestions for how the festival could have been improved. n=689
  - Is there anything else you would like to say about the festival? n=543
- Independent researcher conducted 4 online focus groups:
  - older people (65 or older)
  - younger people (32 or younger)
  - attendees from Black, Asian and minority ethnic communities
  - men

>Used data from first festival to inform second festival (and third)

### Audience

#### Gender, ethnicity, age

More popular with women! c.90% of those completing the evaluation survey

•c.10% of the audience are from Black and minority ethnic communities

- Increased by 2% from first to second festival
- Significant attention to content and speakers
- c. 15% younger people <34 years
- Proportion of people aged 65+ increased from 20% to 25%

•Over half the people attending were members of the public

- 77% attend to learn about grief and bereavement
- 52% to be inspired
- 49% to feel part of a like-minded community
- 94% had experienced a bereavement, 33%
- within the past year
- 10% of attendees live outside UK

## Rating of festival experience

- •89% rated the festival excellent or very good (median rating 5/5 [excellent])
  - 2<sup>nd</sup> festival: 92% rated excellent or very good
- •76% agreed or strongly agreed with the statement "Through attending the festival I feel more confident talking about grief."
  - 2<sup>nd</sup> festival: 80% agreed or strongly agreed
- •Attending a greater number of festival events associated with higher rating of experience and confidence

# Integration with research & policy engagement

National study of bereavement during the COVID-19 pandemic and the impact on bereavement services (Co-PIs: Selman, Harrop), funded by UKRI/ESRC – see: <u>Covidbereavement.com</u>



### Integration

#### Public engagement supporting research

- Disseminated research survey at Good Grief Festival 2020 – chance to be heard
- Media attention for 2020 Festival used to publicise survey
- Festival as platform for dissemination of research findings and a resource for research participants

#### Public engagement & research supporting policy

- Good Grief delivered launch of Commission's Call for Evidence
- Research evidence used as a media hook for Call for Evidence
- October 2021 Festival raised awareness of Call for Evidence

#### Research supporting public engagement

- Research and scholarship within the festival
- 'Creative Grieving' arts research formed part of March 2021 festival
- Media attention for research study used to publicise festivals and policy initiatives

### Reflections and challenges

- Hugely rewarding
- Time pressure, time management
- Being over-ambitious vs. perseverance, dedication
- 'Scrappy start-up' mentality agile
- Grief and trauma in the team; boundaries, self-care
- Safeguarding and support

## Take-away messages

- Foundation of integrated public engagement, research and policy: collaboration, networks, relationships
  - Collaborate with those you'd like to benefit/support/influence from project inception
- Academic freedom allegiance to a cause, not an organisation
- Bring who you are personal experience is a strength [but see: boundaries]
- Build in inclusivity
- Embrace the messiness, seize opportunities

# Next steps: Good Grief Connects

- Two-year project, starting April 2022, funded by the National Lottery Foundation (c.£300k)
- Aim: to help shift the public conversation around death and grief and create a more inclusive, compassionate and open society by:
  - 1. Developing, delivering and evaluating **three pilot community development projects**, working with partner organisations
  - 2. Sharing learning and disseminating best practice from across the UK in community engagement and development around grief, death and dying creating and supporting a strong, supportive network
  - 3. Developing an online **Grief Hub** which provides resources and events, signposts to stakeholders and provides people with the knowledge and confidence to support themselves and each other







All the people who have attended and contributed to Good Grief and all our coapplicants, collaborators and supporters

The Good Grief Team – especially Event Director Aisling Mustan

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