



The All-Party Parliamentary Group on Bereavement Support

Secretariat The Good Grief Trust Agenda

Date: 19th May 2022, 10am to 11am

Venue: Meeting Room T at Portcullis House and Zoom

In attendance:

Baroness Ilora Finlay of Llandaff	House of Lords
Afzal Khan	Labour MP - Manchester Gorton
Wera Hobhouse	Liberal Democrat MP - Bath
Emma Lewell-Buck	Labour MP – South Shields
Linda Magstris	The Good Grief Trust Founder & CEO
Paula Sandiford	The Good Grief Trust Admin Manager & PA
Charley Davey	The Good Grief Trust PR Manager
Lydia Baker	The Good Grief Trust Ambassador – Bereavement Midwife - Epsom and St Helier NHS Trust
Emma Foster	Campaigner for the LCWRA Benefit for Bereaved Parents
Fiona Murphy MBE	Honorary Doctorate – Health Care Director of Nursing Corporate Services Liverpool Royal Foundation Trust
Millie Beaver	Office of Tobias Ellwood MP - Bournemouth East
Eve Henderson	Murdered Abroad
Christine Martin	King's College Hospital
Janet Robson	Contact
Revd Karl Carpani	Deputy Head of Chaplaincy Kings College Hospital NHS Foundation Trust
Alison Penny	Childhood Bereavement Network
Mohamed Omer MBE	Board Member- External Affairs, Gardens of

	Peace Muslim Cemetery
Julia Stirling	SUDEP Action
Julie Love	Ambassador
Millie Beaver	Tobias Ellwood's Office
Holly Koegh-Davies	Co-op
Richard Boyd	Tamba Bereavement Support Group
Kim Bird	Before You Go
Carolyn Brice	The Companionate Friends
Nikki Speed	SUDC UK
Alison Summers	St Christopher's Hospice
Morgen Evens	Cruse
Joanne Early	SAMM
Julia Stirling	SUDEP Action
Laura Ellis	Office of Wern Hobhouse MP - Bath

Apologies:

Tobias Ellwood	Conservative MP – Bournemouth East
Patricia Gibson MP	SNP MP - North Ayrshire & Arran
Jan Soulsby	The Good Grief Trust Trustee
Sian Duddy	The Good Grief Trust Trustee
Mark Baxter	The Good Grief Trust Trustee
Helen Churchill	The Good Grief Trust Trustee
Finella Craig	Great Ormond Street Hospital
Beverley Radcliffe	Director, The Coroners' Courts Support Service
Jane Harris	The Good Grief Project

Agenda:

1. Introductions & Welcomes
2. **Emma Lewell-Buck MP** - to present an update on her work to support a change in legislation around registering a death for bereaved parents, going through an inquest
3. **Emma Foster, constituent of Wera Hobhouse MP** - to discuss the need to secure greater awareness and improvements around bereavement support for grieving parents of terminally ill/disabled children
4. LM - Update on **DHSC/Good Grief Trust Condolence/Signposting Cards** - need for ongoing funding
5. LM - Planning - call to action - **National Grief Awareness Week 2022**.
6. LM - **Good Grief Cafes** - bereavement support for MPs/staff
7. **Refugees** - how can we support the bereaved
8. AOB

Minutes:

1. LM introduced and welcomed everyone to the meeting.

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2. Emma Lewell-Buck apologised for not attending in person

- Summarised the work with the Manchester Attack parents to change legislation around registering the death for bereaved parents going through an inquest

Fiona Murphy

- Thanked Emma for her support and tireless verbalisation on this subject
- Supported the Manchester Bombing families
- Asked for everyone's support to give the parents the choice to register their child's death if that's what they want to do

Mohamed Omer

- Offered the full support from the Muslim community as this is vital
- Raised the point that during Covid, the registration of deaths was done virtually and now gone back to in person, why can't this continue to make it easier for bereaved families?
- Mentioned any legislation was passed in a matter of minutes during COVID.

Baroness Finlay

- Parents should have the option to register a death,
- Should be able to work with the State's investigation and be part of the registration to help mental health problems.
- Strengthen the argument by framing it decrease long-term morbidity with the bereaved but no cohesion on those who don't want to register.

Eve Henderson

- Death is registered in the foreign country; body is repatriated so there is an inquest.
- These families do not have the ability to register the death in the UK

Baroness Finlay

- Ballot for the private members bill has just been released.
- Would be worth going high up in the ballot now to take this forward as a private members bill

Christine Martin

- For families registering deaths, recommends a robust communication between registrars, crematoriums, and families when an inquest is held and completed so that everyone knows when an inquest is concluded and to advise families when they can register.

Alice Penny

- Agrees with MO's point and BF's suggesting a preference around registration
- Aware of a mother who is unable to name her partner on the birth certificate of the child because he died while she was pregnant.
- Suggested registrars collected data on how many children are bereaved – happy to discuss once the current change has been succeeded

Mohamed Omer

- At a recent Medical Examiner conference, they discussed upgrading the registration system to include capturing ethnicity and to digitise it so would be the opportunity to raise this with the private members bill to include collecting additional data to identify bereaved children.

Emma Lewell-Buck

- Thanked everyone for their support and asked everyone to use your connections to put pressure on Government for change

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3. Wera Hobhouse

- Raised the issue of parents who are full time carers to children with life-limiting illnesses who immediately lose financial support when their children die.
- All proposals have been rejected to date (see attached 'Neriah's Law Proposals')
- Would like to see a benefit like the Bereavement Support benefit as well as after 6 months, parents are contacted and provided with ongoing bereavement support and assistance to return to work to bring their skill set up to date.

Emma Foster's Story

- Summarised the new proposal where bereaved parents to be automatically allocated limited work- and work-related activities without going through assessments, which Emma has achieved but it was a fight!
- Doesn't think parents should have to go through the fit to get access to these.
- Left in financial hardship when her daughter died; Emma was a full-time carer to their daughter and her partner worked but on minimum wage
- Hardship was made worse by not being in the head space to cope with the fight and to find work

- Emma wasn't aware everything stopped immediately once her daughter died. Previously received lots of benefits, equipment, and a mobility car; all were taken away immediately after her daughter's death. Their family struggled financially, emotionally and finding a job was hard as her skill set was not up to date.
- Also seen as a risky candidate requiring extra support in the workplace.
- First contacted Wera in December 2019 and wants to prevent others from going through a similar hardship.

- Action: Increase awareness and needs to be bigger than one person and bereaved parents have a voice and support. Requested the APPG to support

Lydia Baker

- Need to look at the whole picture and the compounding grief in the most horrific way and there is no acknowledgement what they're doing is brutal
- Look at process of removing support and resources, and let the parent decide when things are taken away and give control back to the parents
- Put in MH support and other resources

Afzal Khan

- Pledged to support all of these issues

Alison Penny

- Thanked Emma again for sharing her story.
- Recommended getting in touch with Together for Short Lives or Disabled Children's Partnership, as potential vehicles to move these proposals?

Wera Hobhouse

- We're in contact with TFSL who joined our last meeting; if there are other organisations, we should approach please let us know.

Emma Foster

- Has been working with TFSL's head of policy

Baroness Finlay

- Thanked Emma for sharing her story and highlighting the difficulty of the uncertainty of when your child is going to die.
- Flagged there is a difficulty with benefits, that parents are not told they are time limited and attached to the child.
- Legalisation coming out next week and plans to pick up about how families are prepared for when the benefit stops and how it's measured.
- Some bereaved parents are upset if equipment is left too long and not taken away immediately. Suggested a partnership approach to provide tailored support, person centred approach.

Emma Foster

- Regarding equipment, it depends on the relationship with the community nurse and the area.
- Regarding benefits and suggesting a backup resource is a hard conversation to have with parents because they will never know when that day is going to come.

Wera Hobhouse

- Support must come after a child dies and give everybody time to mourn and adopt a central approach around the bereaved parent and the family.

Baroness Finlay

- Immediate loss of benefits needs to be flagged/open/honest from the offset, so it is clear the benefits are linked to the child and advise to have a backup resource; cruel to expect bereaved to carry the burden of grief plus loss of income and support when a child dies.

Nikki Speed

- Suggested the key worker role should be crucial for parents with terminally illnesses.

LM thanked Emma for sharing her story and Wera for attending in person to summarise the proposals gone through to date

Action: APPG members must continue discussions to help to see what we can do moving forward

4. Good Grief Condolence/Signposting Cards

- **LM** outlined the project to date. DHSC funded 150,000 in 2021. Good Grief have supplied to all NHS Trusts UK and over 2,500 GP Practices.
- Now working with other health professionals and front-line services including the Met Police and Family Liaison Officers to supply the card.
- 1,500 independent pharmacies across Scotland, including Boots/Lloyds have received 60,000 cards, plan to roll this out across the other three nations
- Request submitted for additional funding to achieve this and to supply NHS Wales, Scotland, and Ireland
- Need to replenish stock levels to get the cards out to all frontline staff

Action: APPG support needed to secure more funding

Lydia Baker

- Always mentions the Good Grief Trust in her work with bereaved families – Epsom & St. Helier Trust.
- Recently worked with Trust in Devon who have received the cards in the post and although being aware of the Good Grief Trust, they were sure what to do with the Good Grief Trust cards.
- Suggested volunteers continue to raise awareness of the cards so that health care professionals

LM: Reiterated the importance of early signposting to tailored support and the card is a great resource to deliver that message and ran through some of the many testimonials from NHS healthcare workers received praising the cards

Fiona Murphy

- Spoke at ME national conf and introduced the Good Grief Trust cards and Charity
- Rolled out across Manchester hospitals
- Working successfully in Liverpool where we have the cards and staff are handwriting in them so making use of the condolence card element
- Hospitals need guidance on how to use them and has received lots of family feedback who like the cards especially when the cards have been personalised.

- Get them to GPs and bereavement nurses in the coroner service. Suggested mentoring from Lydia would be great for their new nurses
- Suggested the best way to use the cards, do we make them more personal or give them out as they are

Nikki Speed

- Loves the idea of handwriting in the card!
- Bereaved tend to keep the cards from clinicians as mementos

Fiona Murphy

- The cards are giving staff nurses control and that they are part of the grief journey of the family, which mirrors SWAN model (See attached 'REA-SWAN Final report 16thFeb2022FINAL' document)
- Helps to make our staff kinder and made them focus on the grief journey due to the harsh conditions brought on by the impact of COVID, which is remarkable

Lydia Baker

- In bereavement midwifery, nurses are trained to provide families with ever lasting memories, personalising the cards is a brilliant idea to help make those memories

Mohamed Khan

- Agreed space to personalise is very important to add a personal message and agrees it is important to understand what to say for different cultures and faiths.
- Offered to help with translations for the Muslim community.

Actions

- Look at changing the design to add space to add personal messages
- Secure ongoing funding to distribute cards nationwide
- Continue to roll out the cards to everyone involved in bereavement
- Continue to raise awareness of the cards as a vital resource for everyone involved with bereavement

5. NGAW – National Grief Awareness Week – 2- 8th December

- LM Summarised previous campaigns and the plans for this year's campaign has just started.
- This year we are working hard to get our messaging right and we will share an update with you soon
- Requested support from APPG members

6. AOB

- Good Grief Pop Up Cafes – rolling out the Good Grief Trust cafes and working with health care professionals and the Met Police putting out well-being cafes.
- The Good Grief Trust are keen to launch a Café at Westminster to support MPs and staff.

- To help raise awareness of services available for bereavement support & issues around funding for the sector.

Ukraine

Thank you everyone for joining us today and for your support.

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