All-Party Parliamentary Group on Hospice and End of Life Care oral evidence session on people’s experiences of providing end of life care during the pandemic: Minutes

1 November 2021

Attendees:

Parliamentarians:
- Baroness Finlay of Llandaff - Lord Sentamu
- Jack Dromey MP - Rosie Cooper MP
- Baroness Hodgson of Abinger - Sally-Ann Hart MP
- Baroness Hollins - Baroness Masham of Ilton
- Dr Brendan McCarthy on behalf of the Lord Bishop Of Carlisle

Stakeholders:
- Katie Reade (Hospice UK) - Olivia Warnes (Hospice UK)
- Dominic Carter (Hospice UK) - Catrin Edwards (Hospice UK)
- Rachel Cripps (Cicely Saunders Institute) - Rebecca Hammond (Marie Curie)
- Karolina Gerlich (the Care Workers Charity) - Verena Hewat (Compassion in Dying)
- Joanna Gough (British Geriatrics Society) - Patrick McGrath (North London Hospice)
- Sharon Brennan (Alzheimer's Society) - Pippa Dean (Camden and Islington NHS)
- Amanda Young (Queen’s Nursing Institute) - Jan Bolton (Northampton General Hospital)
- Rebecca Barrow (St Mary’s Hospice, Cumbria)
- Gail Precious (National Bereavement Alliance)
- Glynis Berry (Greenwich & Bexley Community Hospice)
- Safiya Jones and Adrienne Betteley (Macmillan Cancer Support)
- Daisy Cooney and Joe Dunne (NHS England and Improvement)
- Anne Cullen, Association of Palliative Care Social Workers
- Lesley Goodburn (patient representative and campaigner)
- Richard Walsh, Rachel Gould and Eleanor Parry (DHSC)
- Clara Collingwood (COVID-19 Bereaved Families for Justice UK)
- Robert Maltby and Steve Statham (St Luke’s Hospice Plymouth)
- Amy Ramsay and Lana Ghafoor (Motor Neurone Disease Association)
- Catherine Millington-Sanders (Marie Curie National End of Life Care Clinical Champion)

Apologies:
- Sir Roger Gale MP - Caroline Ansell MP
- Wendy Chamberlain MP - Emma Lewell-Buck MP
- Chris Green MP - Clive Lewis MP
- Sarah Champion MP - Hilary Benn MP
- The Lord Bishop Of Carlisle - Peter Gibson MP
- Bambos Charalambous MP - The Lord Bishop of Coventry
- Baroness Smith of Newnham - Esther McVey MP
- Baroness Ritchie of Downpatrick - Dr Liam Fox MP
- Baroness Lister of Burtersett - Lord Wigley,
- Drew Hendry MP - Mark Menzies MP
- Baroness Walmsley - Lord Browne
- Baroness Sheehan - Baroneess Watkins of Tavistock
- Lord Gold - Lord McNally
- Baroness Grey-Thompson - Baroneess Greenross
- Baroness Hamwee - Sir Bernard Jenkin MP
- Ann Smith (Princess Alice Hospice)
The APPG on Hospice and End of Life Care

Individuals providing evidence:
- Debbie Martin, NHS General Manager for North Warwickshire Community Services, attending in her capacity as a former informal carer of her husband Rich, who died of Motor Neurone Disease in 2020.
- Clare Godden, Director of Client Services, and Tony Collins, Chief Executive, at North Yorkshire Hospice Care, providing evidence on the Just B support service for frontline staff.

Summary:

Introduction by Jack Dromey MP and Baroness Finlay of Llandaff:
- Jack Dromey MP began the session by sharing his own personal association with the hospice movement before welcoming and thanking the speakers.
- Jack Dromey MP also emphasised the purpose of these evidence sessions, being to;
  - Uncover people’s experiences of death, dying and bereavement
  - Understand the impact of the pandemic on how palliative care will need to be delivered now and moving forward
  - Make recommendations to government.
- Attendees were encouraged to respond to the open call for evidence, available here.
- Baroness Finlay then spoke about the impacts of the pandemic on the hospice and end of life care sector, highlighting the significant increase in unpaid carers during this time.

Oral evidence from Debbie Martin:
- As she worked as a nurse, Debbie felt that she would be prepared for caring duties and as a result she underestimated how hard it would be to care for Rich.
- During her husband’s diagnosis process, no single consultant took responsibility for the tests taken at A&E. Debbie had to contact the hospital to ask for the test results – and to be told that Rich had Motor Neurone Disease.
- Due to working in the NHS, Debbie feels she benefitted from her knowledge of how the system worked.
- A ‘fantastic’ palliative care nurse supported Debbie and her husband – however lockdown meant they could no longer access face-to-face help.
- She felt very lonely when coping with this huge diagnosis.
- Debbie’s husband’s disease rapidly progressed and within 2 months he was needing care to perform day to day tasks. By the third month, Rich was unable to use the stairs, at which point they had a Hospital bed delivered to the house.
- Getting the funding for additional care was ‘effortless’, however, getting the right care agency was ‘a battle’.
- Some carers that came into the home would ignore Rich. They would simply wash or dress him, ‘fill in a book’ and then leave and were not providing for his specific requirements as an end of life patient.
- A big concern for Debbie was ensuring the carers were trained in end of life care and cared for Rich as a dying person. As a loved one, it was important to Debbie that the carers cared for Rich as she would.
- Debbie had to ‘battle’ for 4 weeks in order to secure consistent carers that met their needs. Securing this care was a ‘relief’ for both Rich and Debbie.
Trying to get pads (incontinence) for Rich to give him dignity was difficult due to paperwork and barriers, therefore she resulted to ordering them privately.

6 months after diagnosis, Debbie was informed that Rich was in his last two weeks of life. All of her husband’s medication changes were communicated between the palliative care nurse and the GP – Debbie never got a single call from the GP and this was a particular point of pain. The GP only contacted Debbie, 6 days after Rich had died, to ask if she was happy with the wording on the death certificate.

Debbie worked throughout the period in which she was caring for her husband but in the last two weeks of her husband’s life she contacted the GP to ask for a sick note from work. However, she was told she would need to do a mood assessment.

In the end, Rich had a peaceful death, which reflected what he wanted his death to look like.

Debbie only had care support for one hour a day, the other 23 hours a day caring for Rich was down to her. This made her feel very lonely, and was particularly isolating due to the pandemic. Despite this, Debbie was very conscious of not ‘burdening’ her children.

Debbie expressed concern that people 20/30 years older than herself, with no prior knowledge of the system, have to deal with similar experiences.

Debbie also wished to reflect on what went right. Debbie felt that the specialist palliative care team were her rock. She was particularly thankful that she could always get a response when she contacted the them. She felt supported by this team and found this support important for those who choose to die at home. Finally, she reflected on the bravery of her children during this time.

Oral evidence from Selina Rogers:

Katie Reade of Hospice UK interviewed Selina on her experiences:

- Selina was asked how she felt when the pandemic hit and what the immediate impact was on her work? Selina responded:
  - There was a feeling of ‘utter fear’ during the beginning of the pandemic especially not knowing what to expect.
  - An additional difficulty was that they could not rely on having appropriate hand washing facilities and other protections when in others homes.
  - There were significant fears over PPE – Selina and her colleagues had to count whether they had enough to last the weekend and she feels fortunate that PPE was eventually supplied and they were able to protect themselves and their patients.
  - It was quite quiet at the beginning of the pandemic when the Hospice and her team were not getting many referrals, however, when lockdown lifted there was a sudden influx, as people returned to appointments.
  - A major fear was of taking the virus into vulnerable people’s homes or taking it home to their own families.

- Selina was asked what the biggest challenges throughout the pandemic were. Selina shared that:
  - She had to care for people at home who were dying from Covid-19 and at times they had to put PPE on in the back of a car to prepare to enter someone’s home.
  - Going into someone’s home dressed completely in PPE made it difficult to connect with patients and reassure them, especially when she could not see their face and physical contact was limited.
  - The hospice began to see a lot more complex patients coming through than usual and thus they needed to adapt quickly to new needs.
  - More people were choosing to die at home due to restrictions on who can visit in a hospital.
o Previously, patients would be under the hospice’s care for 19-20 days before death, however now it has become more like 5 days – and they can lose 2 or 3 patients in a single day. This is because people are coming to them later in their illness.

o Having to comfort so many and have difficult conversations at such a high volume has had a massive impact on her mental health.

o She is thankful for the level of staff wellbeing support from the hospice.

o Staff members are also getting the virus and having to pick up extra shifts to make sure the hospice can deliver care is having an impact on staff wellbeing.

o The feeling shared amongst herself and her colleges is that they are simply very tired.

To conclude, Selina was asked if there was anything else she wanted to share regarding the challenges she is experiencing at the moment. Selina explained that;

o The predominate challenge is the volume of people – ‘it’s just not normal’ to have to go into people’s homes and by the next shift the patients you see have completely changed due to the numbers dying.

o This is the ‘new normal’ for hospice care.

o It is important to keep this service going with Hospices, as the services they provide are needed more than ever.

Oral evidence from Tony Collins and Clare Godden:

- First, Tony gave an overview of the Just B helpline;
  - ‘Just B’ is a reactive and pro-active trauma support helpline for NHS and care frontline workers. Since it was established in Spring 2020, it has supported over 1000 individuals.
  - 35% of those who have called the Helpline were suffering from bereavement, another 20% called about stress, and the majority of other calls concerned anxiety and trauma.
  - Just B is also undertaking work to start to provide pro-active support. Working with East Midlands Ambulance Service, Just B ran a pilot to call staff to offer support and signpost to local resources, rather than wait for individuals to decide to call. They have run a successful pilot of approx. 500 calls and have a plan to conduct a further 2000 calls.
  - From these calls they have gathered that many feel that things on the ground are getting more challenging, feelings of panic and/or low mood are common, resilience levels are being challenged and a general theme has been ‘sheer exhaustion’. This all highlights a need for additional support.
  - Those at Just B are committed to finding new and innovative ways to meet this need.
  - Just B have run a project on a regional basis, in partnership with Integrated Care Systems, to support any member of the public across the local community experiencing grief. So far, 800 people have accessed the service.
  - The first Helpline they set up was ‘Hear to Help’ for children, young people and adults to call when experiencing loneliness, anxiety and isolation. This has received 800 calls.

- Following this, Clare spoke about the dedicated Just B staff and volunteers and those they support;
  - People who reach out do so because they are experiencing emotional pain which they feel unable to cope with alone. Just B’s role is to support them to find a way to manage those emotions and help them to continue their work.

- Clare then shared the story of one individual who has used the service, named ‘John’ –
  - John has called Just B many times over the last 18 months – at times he felt completely overwhelmed due to the volume of work and witnessing his colleagues in distress. At the time, John was also a carer for his elderly mother. John shared that he was emotionally and physically exhausted. In previous years, he would have been able to access respite care but this was not available during the pandemic. John called Just B every evening, and would often break down, saying that he was not sure how to continue.
John described the helpline as a ‘life line’. When his mum died this devastated him. He felt additional guilt as there were times he had wished that she would die in her sleep because he was unable to cope any longer. John continues to call the helpline to manage his grief and process his pain.

Q&A:
- Baroness Finlay asked Debbie whether getting medication for her husband was particularly difficult, and asked her thoughts on how well the hospice care team functioned:
  - Debbie said that the specialist palliative care team softened the blow. However, there was one occasion when Rich needed a syringe driver for a medication increase and it took hours of travelling and waiting and showing her ID to retrieve this. Arranging for someone to sit with him while she got the syringe driver was also difficult.
  - Debbie shared that the integrated care team worked well and were helpful. She found that generally, if she needed equipment, it was brought to her and that the blended team was effective at providing what she needed.
- Baroness Finlay asked Selina’s thoughts on this blended team approach:
  - Selina shared that, within her hospice, they also have a blended approach that includes Physiotherapists for example, and allows them access to equipment.
  - Despite this, Selina says at times getting medication can be difficult due to shortages which needs to be looked into, and that a lot of time is wasted trying to fix things that should have been done well in the first place.
- Following this, Karolina Gerlich (Care Workers’ Charity) raised the importance of the skills of the workforce and highlighted the current staffing shortage, which many in the industry feel is the worst recruitment crisis they have ever seen.
- Lord Sentamu asked about the shortfall of funding for the hospice sector and the pressure that this has placed on services, encouraging Tony and Clare to look into this.
  - Tony said he shares Lord Sentamu’s concerns over hospice funding going forward and deficit budgets.
- Sally-Ann Hart MP asked Debbie whether accessing palliative care leave would have made things easier
  - Debbie said her line manager was great and she felt she could have stepped back from work at any time but that work kept her grounded. In the last two weeks, she did not want to worry about what leave she was taking and therefore wanted the sick note. In general, however, she did feel like the NHS and her team were good at supporting her to take time off.

Closing remarks from Baroness Finlay of Llandaff and Jack Dromey MP:
- Both spoke of the funding needs of Hospices and the end of life care sector and that this needs to be addressed going forward including the role of public support and government support.
- Jack Dromey MP emphasised the need for the APPG to continue to investigate the impact of the pandemic on end of life care and to think about how it can influence government policy. He referenced the upcoming independent public inquiry on Covid-19 and the importance of feeding what is highlighted in these sessions into that.