

All-Party Parliamentary Group on Hospice and End of Life Care oral evidence session on the rise in deaths at home during the pandemic: Minutes

13 December 2021

Attendees:

**Individuals providing evidence:**

- Maureen Anderson, former carer of her Mum and Dad, who died at home in summer 2020
- Dr Matt Sweeting, Director of Care at Farleigh Hospice in Essex
- Dr Sarah Scobie, Deputy Director of Research at the Nuffield Trust

**Parliamentarians:**

- Baroness Finlay of Llandaff
- Jack Dromey MP
- Caroline Ansell MP
- Esther McVey MP
- Silas Ojo on behalf of Kate Hollern MP
- Revd Dr Brendan McCarthy on behalf of the Bishop of Carlisle
- Helen Walker on behalf of the Bishop of Coventry
- Sophie J Clarke on behalf of Danny Kruger MP
- Iona Casley on behalf of Barbara Keeley MP
- Baroness Masham of Ilton
- Lord Sentamu
- Fleur Anderson MP
- Baroness Grey-Thompson

**Stakeholders:**

- Alison Gray (Farleigh Hospice)
- Alison Stevens (Farleigh Hospice)
- Ann Lee (St Margaret's Hospice)
- Carolyn Doyle (Royal College of Nursing)
- Charlie King (Hospice UK)
- Chrissie Dawson (Mountbatten Hampshire)
- Christine Ezediuno (Sanone Physiotherapy)
- David Brooks (Royal College of Physicians)
- Donald McGeachy (Provide)
- Erika Lipscombe (Rowan's Hospice)
- Gail Precious (NBA and CBN)
- Helen Bulbeck (Brainstrust)
- Isobel Roberts (Independent Age)
- Joe Dunne (NHS England and Improvement)
- Julia Verne (Public Health England)
- Kate Woodthorpe (University of Bath)
- Keith Spiller (Farleigh Hospice)
- Liz Arnold
- Mel Hargreaves (Hospice UK)
- Nicola Bowtel (OHID)
- Olivia Warnes (Hospice UK)
- Rachel Hutchings (Nuffield Trust)
- Rebecca Hammond (Marie Curie)
- Sally Davis (Farleigh Hospice)
- Sarah Malik (Compassion in Dying)
- Sommia Chand
- Sue Bottomley (NHSEI)
- William Lee (British Healthcare Trades Association)
- Alison Moorey (St Wilfrid's Hospice)
- Amanda Young (QNI)
- Cammille Webb (Farleigh Hospice)
- Cat Sullivan (Hospice UK)
- Charmaine Hood (Farleigh Hospice)
- Christine Craven (CQC)
- Daisy Cooney (NHS)
- Dominic Carter (Hospice UK)
- E Burns
- Funmi Bisi-Adewole (NHS)
- George Holley-Moore (Macmillan)
- Dr Iain Lawrie (Royal College of Physicians)
- Dr Jamilla Hussain (NIHR Clinical Lecturer)
- Jonathan Ellis (Hospice UK)
- Kate Flemming (University of York)
- Katie Reade (Hospice UK)
- Kerry Jackson (St Gemma's Hospice)
- Lynne Smith (Castle Point & Rochford CCG)
- Melanie Hodson (Hospice UK)
- Nikki Tuff (Farleigh Hospice)
- Rachel Gould (DHSC)
- Rebecca Barrow (St Mary's Hospice)
- Safiya Jones (Macmillan)
- Sally Greenbrook (British Geriatrics Society)
- Sheona Evangeli (Farleigh Hospice)
- Sophie Meagher (LGBT Foundation)

**Apologies:**

- Andy Langford
- Baroness Afshar
- Baroness Deech
- Baroness D'Souza

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| - Baroness Lister              | - Baroness Mallalieu                     |
| - Baroness Sheehan             | - Baroness Walmsley                      |
| - Baroness Young               | - Professor Bee Wee                      |
| - Beth Winter MP               | - Beverley Pickett                       |
| - Brendan Clarke-Smith MP      | - Chi Onwurah MP                         |
| - Chris Thomas (IPPR)          | - Crispin Blunt MP                       |
| - Crystal Oldman (QNI)         | - Diane Woodhouse                        |
| - Emma Rushton (MSA Trust)     | - Fabian Hamilton MP                     |
| - Fiona Ross (Kingston)        | - Henry Smith MP                         |
| - Hywel Williams MP            | - James Cleverly MP                      |
| - Jeremy Hunt MP               | - Jim Shannon MP                         |
| - Julie Challenger             | - Karen Wesson (Mid Essex CCG)           |
| - Kathryn Collins              | - Layla Moran MP                         |
| - Leanne Creighton (Sue Ryder) | - Lord Alton                             |
| - Lord Best                    | - Lord Bragg                             |
| - Lord Crisp                   | - Lord Davidson                          |
| - Lord Elis-Thomas             | - Lord Gold                              |
| - Lord Grade                   | - Lord Hodgson                           |
| - Lord Hylton                  | - Lord Jopling                           |
| - Lord Kamall                  | - Lord Lipsey                            |
| - Lord Patel                   | - Lord Rooker                            |
| - Lord Selkirk                 | - Lord Swifen                            |
| - Lord Wills                   | - Lucy Carlisle (CNS in Palliative Care) |
| - Marion Fellows MP            | - Mark Menzies MP                        |
| - Michael Naseby               | - Peter Gibson MP                        |
| - Richard Shail                | - Sarah Champion MP                      |
| - Siobhan Baillie MP           | - Stephen Timms MP                       |
| - Wendy Chamberlain MP         | - Wendy Shelvey                          |

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, and John Taylor Hospice, before welcoming and thanking the speakers.
- Jack Dromey MP also outlined the review and the importance we collectively learn lessons from the ongoing Covid-19 pandemic, and use this to influence public policy agenda.
- Jack Dromey MP stressed that we continue to live through the pandemic, the worst public health crisis since WWII.
- Baroness Finlay spoke about the increase in deaths at home during the pandemic, the concern that people have not had access to the care they need and the importance of services moving forward in line with what people need/want.

**Summary of the evidence provided by Maureen Anderson:**

- When Maureen’s parents were discharged home from hospital, two days apart, she cared for the both of them in the living room of their home. Maureen moved in order to take care of them.
- Maureen’s dad was in a ‘poor state’ when discharged – he had food matted into his beard and did not look washed – with her encouragement he was able to wash and shave himself.
- When Maureen’s mum was discharged, Maureen felt that she did not ‘look like [her] mother’. Her right leg was contracted at a right angle, she looked frightened and could not talk and hadn’t been speaking to staff for weeks.
- Maureen looked into the paper work her parents had been sent home with and discovered that her mother was considered end of life and had up to 1 week to live.

- Maureen had spoken to someone at the hospital everyday while her mother was in their care but had not been told that her mother was end of life – there were opportunities to share this information prior to her coming home.
- Her mother was sent home without end of life medication, incontinence pads or specialised food.
- Maureen and her family had not been told details of the dying process - Something was coming out of her mum’s mouth, which they tried to wipe away – they were unaware that this was part of the process of dying.
- They were helped by carers – two of which were very good, while others were young and inexperienced.
- Maureen felt that there had been an assumption that they knew what it looked like when people are dying therefore they were not given details, didn’t know what would happen at various stages, and weren’t asked if they needed more information.
- When Maureen’s mother was discharged from hospital, she had a bed sore on her leg that had not addressed and had gone black.
- No incontinence pads came to their home until the day after her mother died.
- Maureen shared how her and her family *‘tried to give [her parents] the best end of life care that we could’*.
- They did have help from nurses and carers but Maureen and her sisters had to be there all the time to give her parents the best possible care.
- Maureen feels that health care staff need to ask the families of end of life patients what they need to know – there should, for example, be a tick list of things that could happen as someone dies to go through with the family in order to prepare them.
- Maureen wanted to know what had happened at the residential care home in which her mother had stopped speaking and eating (e.g. who had been engaging with her mum). There is no record of conversation/verbal exchanges so they cannot categorically say when she stopped speaking. It would be valuable to have some record of questions asked and answers given between staff and her mum to get a better idea of when she actually stopped speaking/engaging with them.
- Comments in records of her parents activities in the residential home included *‘watching tv comfortably’* or *‘listening to the radio comfortably in his room’* – this seemed to ignore that her father was deaf and partially sighted and so leaves more questions.

#### **Summary of the evidence provided by Dr Matt Sweeting:**

- Farleigh Hospice serves around 400,000 people. The hospice provides palliative and end of life services to the community, ranging from basic personal care to specialist intervention and advice
- Farleigh Hospice has around 250 staff. Last year they cared for around 1100 patients and supported 650 people dying in their own homes.
- Before the pandemic, they followed a traditional hospice model with 10 inpatient beds, as well as community teams, including a day therapy team and a high functioning bereavement service.
- During the pandemic, up to 50 of staff had to shield and therefore could not be patient facing. They had to think about how to be most effective with their resources and workforce during the pandemic.
- During this time, most institutions increased their bed space. However, Farleigh Hospice closed all in-patient beds and deployed all staff as community facing.
- The hospice retrained some fundraising and retail staff to be patient facing carers and healthcare support workers.
- They also created a telephone advice line managed by shielding staff and an overnight clinical advice line run by specialist nurses.
- Farleigh started an education program to train new care staff in the community across mid-Essex.
- In the second wave of the pandemic, Farleigh Hospice created a virtual ward to support people dying at home, especially overnight.
- All the changes were achieved by a quick reorganisation of clinical services into 3 locality based care teams. These were multidisciplinary teams including nurses, therapists and social workers.

- There were challenges involved in such a large scale reorganisation such as ensuring regulators were onboard.
- Farleigh had to manage reputational damage as hospices are still seen as beds in a physical location, despite the fact that most care is provided in the community – Increasing care in the community resulted in some raised eyebrows and difficult conversations.
- The organisational culture of Farleigh also changed as people were changing roles and responsibilities.
- The hospice had to care for people with more complex conditions at home in the community to ensure they didn't go into hospital beds.
- There was an increase in mortality with the majority of people dying in community settings, part of a massive shift towards people dying in their own homes.
- At points there were also concerns over PPE.
- Another challenge was funding. 55% of Farleigh Hospice's funding is normally from charitable giving - cancellation of events was a problem but income generation team were great with new fundraising ideas.
- Matt feels the Hospice were supporting more people to die at home which allowed them to see loved ones, which hadn't been possible at the beginning of the pandemic.
- Farleigh managed to support 90% of people in their preferred place of care. The virtual ward has cared for over 90 people.
- The pandemic fast tracked the reshaping of clinical services to respond to the increase in people dying at home.
- Inpatient beds have re-opened but the way they are used has changed and is now more specialist. The virtual ward is still running.
- Matt emphasised that hospices are far more than a building with beds in and that this model of care will help meet the challenge of people dying at home and allow people to live and die well.

## **Summary of the evidence provided by Sarah Scobie:**

- Nuffield Trust undertake research and analysis in order to further evidence based policy and increase the quality of healthcare.
- Trends in place of death have shifted over the course of the pandemic.
- There were 57,000 more home deaths from January 2020 to September 2021 in comparison with those expected based on the 2015-2019 average. There were also almost 8000 fewer hospice in-patient deaths for the same period.
- Even outside of the peaks of the Covid waves, there were still around 30% more people dying at home compared to the 2015-2019 average.
- Sarah also showed home death rates by local authority comparing 2021 to 2015-19. This highlighted there had been more home deaths, particularly in rural areas.
- There is still a lot we do not know about what is driving this shift e.g. whether it is patient choice, the pressure on health services.
- This shift is happening in the context of a lot of longstanding challenges in end of life care.
- There is wide variation across the country in terms of hospice services and the level of charitable giving these hospices are receiving.
- There is an opportunity for ICS's to take a more strategic approach to end of life care.
- A related issue is that there is unequal access to specialist end of life care – e.g. access of ethnic groups and geographic differences.
- It is important to think about workforce. We know there are challenges across the health and care sector and there is a pressing issue here and need to improve care with providers who have the skills and expertise to deliver this care.
- Considerations need to include home carers as well as NHS and Hospice staff.
- There is currently a challenge with good quality data on the hospice sector as well as in community and social care services more generally. There is a huge amount that needs to be done in terms of data.

### Summary of Q+A and discussion:

- Carolyn Doyle asked Maureen if she was supported to visit her parents in the hospital and supported as someone who would be taking on care duties as an equal partner in delivering that care. She raised that it could have been helpful if Maureen and her siblings had truly been seen as equals in the caring role.
  - Maureen explained that they have complained to the nursing home over her parents care but have not yet complained to the hospital.
  - Maureen and her family were not supported by the hospital. Her Mum had worked at the hospital for 40+ years which made it even more infuriating.
  - Maureen shared that perhaps issues in care arose as people are, and were, busy, and as she, and her family, are articulate and professional there may have been an assumption that they knew what they were doing. In reality they were simply being daughters and sons of loved ones and were not supported as such.
  - It would have helped if someone from the palliative care team had told them Maureen to look out for and what to expect (when her parents were dying) and asked whether they were prepared for this.
- Dr Jamilla Hussain stressed the importance of something coming out of this evidence and that to understand how to stop experiences like Maureen's happening we need to know about these experiences. She said that these disparities are not acceptable and we cannot just accept that they are happening.
- Matt agreed that disparities are well documented, and their systems and model of care likely differ from neighboring hospices. He added that there needs to be a detailed health needs analysis.
- Regarding of evaluation of their work, Matt explained that they had looked at data collection and staff feedback. They found that people wanted the model to continue and that dignity, choice and especially choice on where to die were important to them.
- Sarah added in the chat *'at the Nuffield Trust we are starting a project to understand service provision for people who died at home during the pandemic, compared with pre-Covid. We are working with NHS England, the Office of National Statistics and the OpenSAFELY programme.'*
- Baroness Masham raised concerns over Maureen's mother being sent home with a pressure sore:
  - Maureen shared that nursing staff that attended at home did begin to care for and treat the sore and that the home carers were shocked by it.
  - The sore had occurred at the hospital and Maureen was shocked that this was not noticed or treated by the hospital.
- Lord Sentamu emphasised the importance of putting in a complaint and the unacceptable quality of the care Maureen's family received. He asked Sarah who will be finding the information on dying at home and what is driving this:
  - Sarah explained that work is starting to try to understand this better, this will result in more questions but it is a start. She said it is difficult to unpick what went on as there were big shifts in how people used services during the lockdown.
- Baroness Finlay shared that she feels we should give families more credit for the care they offer and involve them in conversations.
- Julia Verne shared her experiences and her apologies to Maureen for the care she experienced.
  - She highlighted, in response to earlier questions over the rise in deaths at home, that her team has seen an increase in the proportion of people dying from cancer at home from 31% in 2019 to 41% in 2020.
  - She also highlighted the need for fast-tracked funding to enable end of life patients to achieve rapid impact from the health care sector and from social care. She also emphasised how people who provide social care are vulnerable in terms of pay and conditions and need support.
- Matt shared his experiences of Farleigh doing fast-tracked referrals.
- Maureen added in the chat - *'I'll also add that in hospital my parents were identified as a 'bed number' and not given their names. We had to insist that nursing staff called them by name.'*

- David Brooks said he had heard first hand that restrictions of visits to hospital were a key driver to increased deaths at home. He asked whether the Furlough scheme and the ability to work from home may have allowed people to be more present to care for loved ones at home:
  - Maureen explained that her and her sister were fortunate in that they were able to drop what they were doing to care for their parents. She emphasised that the key issues for her were around the information they needed to have in order to know that they were caring for their parents correctly.
  - Matt added that managing symptoms, emotional support and supporting family members to manage symptoms needs to be framed around 24/7 access – help doesn't always have to be a visit but access to help needs to be there at all times.
  - Baroness Finlay emphasised the importance of 24/7 access to support.
- Cat Sullivan said that while it is hard to hear Maureen's story, it is important. She asked Maureen *'Where are you now as a family? Do you feel you are getting support for the bereavement?'*
  - Maureen explained that her some of her siblings have had bereavement counselling; she herself has set up [The Kitchen Table](#) to support people who have experienced multiple loss.
  - A key thing for Maureen is ensuring she speaks her parents' names aloud. She has also found that supporting others is key.
  - Maureen and her siblings are at different stages in their healing journey but are determined that their experiences will help others.
  - Maureen stressed the importance of honest conversations and avoiding assumptions.
- Sue Bottomley:
  - Sue shared that she nursed her husband at home and was thankful for supportive 24/7 care.
  - She shared that NHSEI is committed to improving and enhancing end of life care. There is now a much better system of working across ICS's and a focus on access, equality and sustainability.
  - NHSEI is working at bringing together the sector and their contribution to end of life care.

## **Closing remarks from Baroness Finlay of Llandaff and Jack Dromey MP:**

- Baroness Finlay encouraged attendees to stay enthusiastic because we can change the system.
- Jack Dromey MP addressed each of the speakers, thanked everyone for their participation and alerted attendees to the next session on the fragility of the current funding model of end of life care. This session will be held from 10-11am on 19 January 2022 and parliamentarians and stakeholders can RSVP by emailing [o.warnes@hospiceuk.org](mailto:o.warnes@hospiceuk.org).