

Witness Name: Adrienne Betteley

Statement No.: 1

Exhibits: AB/1 – AB/6

Dated: 17 July 2023

## **UK COVID-19 INQUIRY**

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### **WITNESS STATEMENT OF ADRIENNE BETTELEY**

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I, Adrienne Betteley, will say as follows: -

#### **Introduction**

1. I have held the role of Strategic Advisor for End-of-Life Care at Macmillan Cancer Support ("Macmillan") since 13 January 2020 and have worked in similar roles at Macmillan since 17 January 2011. During the period of the Covid-19 pandemic (between 1 March 2020 and 28 June 2022) I played a significant role in Macmillan's work on palliative and end-of-life care.
2. Macmillan is the UK's leading cancer care charity. We work with partners to provide services for people living with cancer at every stage of their cancer experience, including those living with treatable but not curable cancer and those approaching the end-of-life. Our work in end-of-life care service developments is not cancer specific as services are for anyone with a life limiting illness.
3. Macmillan is widely known for its cancer professionals. In 2020, we reached an estimated 1,061,158 people living with and affected by cancer through our Macmillan nurses, of which the majority (976,265) were people living with cancer. During the same period Macmillan's allied health professionals, including therapeutic radiographers, physiotherapists and dieticians reached an estimated 144,599 people living with and affected by cancer, of which the majority (133,031) were people living with cancer. In 2020 Macmillan doctors reached an estimated 9,568 people living with cancer.

4. Macmillan professionals, including nurses, doctors, and allied health professionals, are employed by NHS Trusts, Health Boards, Health and Social Care Organisations and independent sector organisations (such as hospices) across the United Kingdom. Macmillan usually provides grant funding for posts for a set number of years and thereafter the partner organisation sustains the post through their own funding. Nurses who have been funded by Macmillan remain badged as 'Macmillan nurses' for the duration of their time in post, but they are at no stage directly employed by Macmillan. Macmillan remains an important strategic partner, there to support with training and professional development as well as emotional wellbeing, whilst maintaining its status as an independent charity. In some circumstances Macmillan does not fund posts at all and 'adopts' a post. This means that the postholder can use Macmillan's name in their job title and access a wide offer of professional development support from Macmillan.
5. An internal analysis from 2022 suggests that 1,771 full time equivalent Macmillan professional posts in 2022 were focused on end-of-life and palliative care. Macmillan are not currently able to specify the number of people supported by our professionals who are specifically receiving palliative or end-of-life care, as we do not hold this data.
6. In addition to our professionals, Macmillan offers information and support services for people living with cancer, including those with treatable but not curable cancer and those approaching the end-of-life. This includes providing up to date cancer information written by specialists, as well as emotional support and practical advice and solutions for the everyday problems that can arise from living with cancer.
7. In 2020 we supported a total of 102,167 people through our support line for people affected by cancer, responding to 221,828 calls and web enquiries. We also distributed 1,658,491 leaflets, posters, and cards. In 2021 102,713 people were supported by the Macmillan support line responding to 274,135 calls, emails, and web enquiries.
8. While conversations about death and dying represent a relatively small proportion of calls to our support line, there was a noticeable increase in mentions of palliative care as part of calls during the pandemic period. Internal data suggests there were month-on-month increases between March and September 2020, then mentions of palliative care remained at a higher level until June 2022.

9. Prior to the pandemic Macmillan invested in NHS palliative and end-of-life care services through the Care and Wellbeing Fund (the "Fund"). The Fund was jointly funded by Macmillan and Big Society Capital and managed by Social Finance. The Fund entered into outcomes-based contracts with NHS Trusts and/ or NHS Commissioners with the aim of reducing bed-days and non-elective care use for those in the last 12 months of life. Investments totalled more than £3.5 million over the course of the Fund.
10. The pandemic had a major impact on the operation of the Fund, significantly slowing the pipeline of investments, as staff within the NHS had limited capacity to engage with new contracts. This resulted in the Fund extending its investment period into 2021, after originally planning to close to new investments in 2020. It also necessitated a change from the original outcomes-based payment framework, as the baseline measures were not appropriate during the pandemic.

#### **The impact of the pandemic on palliative care**

11. The pandemic had a profound impact on people living with treatable but not curable cancer and those approaching the end-of-life. Gathering insight on people's experiences at the end-of-life is inherently challenging, but we were able to collect some learning through our clinical networks. For those facing end-of-life, the sense of being abandoned or forgotten during the pandemic was seen as particularly profound. We heard that decreased access to clinical trials had left some feeling their 'last hope' was gone as there was no longer the possibility of accessing innovative treatments.
12. A lack of access to support and face-to-face contact was particularly challenging for those receiving palliative and end-of-life care. National guidelines and local policies affected the level of support people could receive both from health and care services and informal sources like friends, families, and other support networks. The impact of not being able to be with family members until the final days of life, if at all, caused significant distress.
13. During the pandemic we also heard through the media about examples of situations where Do Not Attempt Resuscitation ("DNACPR") decisions were poorly handled in England and Wales. In response to this we endorsed a joint UK-wide statement from the British Medical Association, Care Quality Commission, Royal College of General Practitioners and Care Provider Alliance (AB/1,

**INQ000235489**) on the need for advance care plans and DNACPRs to be made on an individual basis according to need, and never to be applied generally and routinely to a particular category of patients.

14. Macmillan conducted a snapshot survey of healthcare professionals in July 2020 to capture their experiences in the early stages of the pandemic. Most respondents identified an increase in demand for support at end-of-life. The respondents identified that it had been difficult to increase capacity to meet the demand, although pockets of good practice had emerged. Much of this demand was in the community, with people at end-of-life wanting to avoid hospital admission at almost all cost and not wanting hospice care due to restrictions on visitors. Primary care and palliative care were working differently with people receiving palliative care and healthcare professionals reported some areas of concern that remote or new ways of working could be resulting in poorer care. When asked where most people were choosing to die, since the Covid-19 outbreak, most respondents who answered the question identified the patient's home as the place of choice. Highlighting challenges faced at a local level, a significant minority said that people did not have an opportunity to express where they wanted to die or did not die where they wanted.

#### **The impact of the pandemic on Macmillan**

15. Macmillan as an organisation was also significantly impacted by the pandemic. We faced a significant loss of income due to Covid-19 and this meant that some grants to fund posts in the NHS had to be paused and a proposed programme of work on end-of-life care could not be progressed.
16. During the pandemic there were various changes to the services we were able to provide for people living with cancer, including for those receiving palliative care. As a result of the pandemic, we were no longer able to offer face-to-face advice and support services but continued to provide support through our telephone support line and online services. We do not have data to show whether this change had a disproportionate impact on any particular group.
17. We were also no longer able to offer face-to-face volunteering services, leading to the launch of our Macmillan Telephone Buddies service during lockdown in 2020. This service aimed to provide emotional support and combat loneliness. 2,455 people were supported by our Telephone Buddies service in 2020 and 3,128 in

2021. During 2020, 27% of people supported were already at the end-of-life care stage of their journey at the point of referral.

18. Macmillan also offered an emotional support counselling service in partnership with Bupa, for those identified through the support line as having high levels of emotional need. While this service was not specifically designed for those approaching the end-of-life, we know it was utilised by people in this situation.
19. Macmillan provided expert information to people living with cancer and professionals through our Coronavirus Hub. By nature, this content evolved rapidly and there were many different iterations of the information published as understanding and guidance changed. The information for healthcare professionals on palliative care and Covid-19, as it currently stands, can be accessed on the Macmillan website (AB/2, INQ000216437). We no longer publish specific information aimed at people living with cancer on palliative and end-of-life care in a Covid-19 context. If it would be of value to the Inquiry, we can attempt to source content from the Coronavirus Hub that was available on specified dates.
20. Macmillan also provided training for healthcare professionals during this period, including a webinar on advance care planning and an adapted version of our 'difficult conversations' training, which has a focus on end-of-life care. This training includes content on communicating while using protective personal equipment and using technology to communicate.

#### **Macmillan's advisory, influencing and campaigning activity**

21. Macmillan took on an advisory role with National governments and health services during the pandemic, offering expertise and insight from our professionals and people living with cancer to inform conversations around their support needs.
22. We used several different routes to share this expertise. Macmillan was represented at weekly meetings of the Covid-19 End-of-Life Care National Voluntary Community Organisations Task Group in March, April and May of 2020. The Task Group met with Health Minister Helen Whately on three occasions during the pandemic to discuss issues related to palliative care. Macmillan was also represented at a weekly cancer charities meeting with the NHS England cancer programme, during April and May of 2020.
23. Macmillan worked to influence national governments and health services in relation to key issues for people living with cancer. Of most relevance to palliative

and end-of-life care is our influencing in relation to guidance on visiting people at the end-of-life in a home setting. We raised this issue across all four nations, as an example we have provided our letter to First Minister of Wales, Mark Drakeford (AB/3, INQ000216438). New guidance was subsequently published in England, with verbal confirmation in other nations, clarifying that visits to loved ones receiving end-of-life care were essential and allowed under lockdown rules.

24. In May 2020, we submitted evidence to the Health and Social Care Select Committee on delivering core NHS and care services during the pandemic and beyond. We raised concerns about interpretation of guidance on visiting care homes and hospices for those at the end-of-life and capacity in community services to address the anticipated increase in demand for palliative care in the community (AB/4, INQ000216439).
25. Macmillan submitted written evidence to the All-Party Parliamentary Group on Hospice and End-of-Life Care on the lasting impact of COVID-19 on death, dying and bereavement in November 2021 (AB/5, INQ000216440).
26. Macmillan also publicly campaigned during the relevant period. We used our Forgotten C campaign to draw attention to the impact of the pandemic on people living with cancer. This was primarily focused on delays to treatment, which is relevant to many people with treatable but not curable cancer who may be receiving palliative care (AB/6, INQ000216441).

#### **Macmillan's key learnings from the pandemic on palliative care**

27. Macmillan identified a number of key themes for learning around end-of-life care from the pandemic as part of an internal insight report in July 2021.
28. Palliative care professionals' roles were extended during the pandemic, with palliative care specialists moved to working remotely to support larger numbers of people. Specialists saw their roles extended to support the wider healthcare system, including in decision-making.
29. Non-specialty community and primary care professionals also took a more active role in end-of-life care during the pandemic, with community nursing teams acquiring extended roles in palliative and end-of-life care. They were increasingly able to make medical care decisions with remote GP support and verify expected deaths. District nurses also trained carers in delivery of medication where appropriate.

30. Third sector and non-specialised roles also supported new ways of working. Students and volunteers received verification of death training and advance care planning training and delivered positive outcomes in initiating conversations with families. Volunteers provided emotional support by working to create memories, being a point of contact for the family and listening to wants and feelings.
31. Teams learnt to work together in a different way during the pandemic and many of the changes implemented were seen as likely to be sustained beyond the acute pandemic, including use of virtual technology for meetings, better integration of clinical and academic working, and promotion of mind and body wellbeing within the team.
32. Macmillan convened a roundtable with healthcare professionals in August 2020, where those professionals expressed that the pandemic had catalysed new ways of working, with greater collaboration across services to meet rising demand.
33. Attendees indicated that greater involvement from primary care in end-of-life and palliative care during the pandemic was positive and there was a desire to maintain better joint working between primary care, secondary care, ambulance services and care homes in future. Attendees discussed training needs and the need to build on increased appetite for training and education due to increased availability of virtual offers. They discussed the role of Macmillan in ensuring that higher education and training for nurses, allied health professionals and medical students covers having difficult conversations. They discussed support needs for staff, including the deployment of clinical psychologists and the need for this support to be appropriately directed to support mental health and wellbeing.
34. Macmillan are aware that there are long-standing issues of inequality in relation to access to and experience of palliative and end-of-life care. Unfortunately, our insight from this period does not provide specific information on how these inequalities were impacted by the Covid-19 pandemic.

#### **Statement of Truth**

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

**Signed:**

**Personal Data**

**Dated:**

17 July 2023