Subject: Call for written evidence into experiences of end of life care at home and in care homes during the pandemic

Dear Senedd Cross Party Group on Hospices and Palliative Care,

Before the Covid-19 pandemic it was estimated that there were 487,000 unpaid carers in Wales providing care to family members or friends who required support due to age, illness, disability or because of a mental health condition. At the height of the pandemic in summer 2020, the number of unpaid carers in Wales was estimated to have increased to 683,000. 80% of carers have told us that they are having to provide more care compared to before the pandemic, often due to service reductions and disruption. Caring through the pandemic has had a clear negative impact on carers, with Carers Wales research finding 71% of carers say their mental health has deteriorated over the course of the pandemic, and 60% saying their physical health has worsened. Many carers will have experienced bereavement during the pandemic, and the reduced nature of the support they could access will have made the experience even more difficult.

As Carers Wales has not previously conducted research into the experiences of carers in relation to palliative or end of life care, we created a short survey to gather testimony from carers to inform our response to this call for evidence. 3 carers shared their experiences which we have summarised below.

How did changes to health and care services as a result of the pandemic affect the delivery of palliative and end of life care?

Carers told us that changes to health and care services negatively impacted on communication. A carer told us that there was a “Lack of communication between professionals involved” while another said “The inability to have face to face visits impacted harshly on everybody” which “made it far more stressful for both the person and their family”.

What affect did changes to services have on the person receiving palliative and end of life care?

A carer told us that service changes meant “Pain management was not controlled correctly”. Another spoke of the confusion and hurt caused to a loved one with dementia when rules meant that people were involved in their care who they had not seen regularly in person for some time. Service changes “made it far more difficult for them”.

What affect did changes to services have on you as an unpaid carer supporting someone receiving palliative and end of life care?

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2 ibid
3 Carers UK (2020): Caring Behind Closed Doors: Six Months On
4 Carers Wales (2021): State of Caring 2021 Wales Briefing
5 ibid
A carer said that professionals were “not seeing the hands-on demands and underestimating our need for more help”, while another said professionals missed opportunities to teach them how to deliver end of life care at home.

A carer commented on lacking control in the situation, saying “I wasn’t able to care for my loved one as I would have wanted to. I wasn’t allowed to visit, touch or sit by my loved one until 3 days before they passed.”.

Did the person who was nearing end of life face any barriers in accessing palliative and end of life care?

Carers who said the person nearing end of life faced barriers in accessing care said it was due to understaffed services unable to provide the required care and in another case the barrier was due to the fact that they couldn’t receive end of life care at home as they would have wished.

Another carer said they didn’t feel barriers had been faced but noted that “all decisions were made via a computer screen” and they felt a lack of involvement of the GP and family in decision making had left them with doubts about whether the right decisions were made at the right time.

Have you experienced or heard of any positive changes or innovations to the delivery of palliative and end of life care that have been developed during the pandemic?

A respondent said they had heard of positive work undertaken by Hospice of the Valleys.

How could unpaid carers be better supported in future to support individuals receiving palliative or end of life care?

Carers should “be listened to” and professionals should “recognise the expertise of unpaid carers”. A carer also called for carers to be involved in co-producing all national plans and strategies around bereavement and end of life care. Another carer felt all decisions should be “made face to face with proper consultation between GP or hospital doctor and family.”

Yours faithfully,

Carers Wales.