Appendix C:

Survey Feedback Summary 2024-25 (including End of Life Care)

South West London

Bereavement Services and Support:

Gaps workshops report 2025

healthwatch
Kingston upon Thames

Appendix C: Survey Feedback Summary 2024-25 (including End of Life Care)

South West London Bereavement Services and Support: Gaps Workshops Report (June 2025)

To support the South West London Bereavement Services and Support: Gaps Workshops initiative, Healthwatch Kingston conducted an online survey to offer a further opportunity to people across SWL to share their experiences of bereavement services and support, and End of Life Care (EoLC). 48 people part completed the survey with 33 people responding to the questions on EoLC.

Participant responses from our 2024-25 south west London (SWL) survey, show similar experiences to those provided during our SWL pilot in Kingston focus groups, that we reported in our Bereavement Services and Support in Kingston - Community Engagement Report (published in 2022).

In total, 48 people responded to the question asking, '**Has someone close to you died?**', 42% shared with us that one person they knew had died, and 35% responded that more than one person they knew had died.

When we asked the survey participants about their '**relationship to the person who had died**', 48 people responded, with 33% sharing that they had lost a parent, 16% told us that they were the partner/husband/wife of the person who died, and 8% said they were the grandchild. Other responses included, being the parent, the grandchild, sibling, other family members, friend, member of the community, professional carer. Some people shared that they had lost many people, and one respondent told us:

- "I have experienced the loss of 9 people I loved and cared about over the last year. Many of them were unexpected and sudden. I have also witnessed the loss of many others in my circle of family and friends who are grieving many losses."

Most people who responded to the survey spoke '**English as a first language, and English was the first language of the person who died'**, however, out of the 48 people who responded to this question, 19.5% (8) told us that English was not the first language of the person who had died. Only one person shared that there was a cultural need for a rapid burial.

We asked respondents to share with us where the person had died, as this may have a bearing on the level of bereavement support, they received. 33 people responded to this question. 33% of whom shared that the person had died at home, 30% shared that they had died in Hospital, 21% people told us that the death had occurred in a hospice. We also heard that people had died abroad, or in care and nursing homes.

When asked, '**Did anyone talk to you / the person you cared for about end-of-life care and what mattered most to you / them?**', 32 people responded to this question with 38% informing us that they had conversation, and 34% confirmed that they had not.

11 people told us about what had been discussed during EoLC and what mattered most. 30% said that discussions about '**Managing any symptoms**' and '**What could be offered to keep you, or the person you cared for comfortable?**' had taken place. Others shared that '**Where you/the person you cared for would prefer to be/die for end-of-life care**', had been discussed and others shared that '**Specific spiritual/religious/cultural needs**' and '**Emotional/psychological needs**' were all things discussed, and whether people should go to hospital for some treatments.

43% (10) people told us that **EoLC was not discussed** with them, or the person they cared for and felt this was something that they would have liked to discuss:

- "I was told my dad was at end-of-life care by a doctor at the hospital who assumed I'd been told. I was told this whilst being taken in to a sluice room as there was nowhere else to have a conversation."
- "The nurses in the hospital told me that he was being put on palliative care, but I didn't really understand what this meant."

56% (13) told us that they did not want to have EoLC discussions:

- “I wouldn’t have wanted to know my mum was at end of life.”

And some shared that these conversations were not possible due to the death being sudden.

Only 6 people told us that they had an advanced care plan, with two of these suggesting it could have been improved, however, out of the 32 people who responded to the question, ‘**Were you/the person you cared for involved in decisions about care and treatment, as much as you/they would have wanted in the last two to three days of life?**’, 19% said, ‘They were involved as much as they wanted to be’, 22% said ‘They would have liked to be more involved’ and 12% said they were unable to be involved. One respondent also shared that they would have liked to be less involved.

When we asked in the survey, ‘**Did you / the person you cared for feel the last days and weeks of life were well planned?**’ 31 people responded. 16% said, yes, 39% said, no and 45% answered, not applicable. Additional comments included:

- “The process of end-of-life care was never explained to my family, and we were not made aware of how soon my dad might pass away.”
- “Didn’t initially understand the diagnosis. Person was in coma in Intensive Care, hoped he didn’t feel any pain.”
- “To have a peaceful pain free death which was not my parents’ or families’ experience in the hospice unfortunately.”
- “I hadn’t realised the end was so close when he was sent home from hospital, and I think the NHS workers were also surprised how soon it happened. When we were in the hospice the treatment was very good. The problem was the time at home between leaving hospital and going into the hospice and the care from the district nurses.”
- “My sister and brother died in the Netherlands, and I am living in UK, the effect of their passing was therefore a very sad occasion, as I could not be with them and my family at the time of their passing.”

- "It's hard to plan when the death is unpredictable and somewhat unexpected."

In the survey we asked '**Bereavement and grieving is a very personal experience and a sensitive topic for many. The support people need differs between faiths, beliefs, life philosophies, cultures, social circumstances and across generations. When grieving, what matters most to you?**', respondents shared the following:

- "More support needed much faster, I waited six months, which when you are grieving is far too long."
- "Support and understanding" and "Having companionship and not being left alone."
- "For someone to listen, be patient and in confidence face to face. Some advice to coping with multiple deaths within one year is hard when living in another country."
- "Someone who understands the different stages of grief."
- "Knowing my loved one died where he wanted. Sharing support with friends and family. Some elements of routine."
- "Empathy, compassion and understanding. Time to process the loss and grief. Having the support of family/friends. Knowing where to get support if I need it. Practical help. Support with advice/paperwork/processes."
- "Faith."

52% (13) of respondents told us, '**Bereavement had had an impact on their mental health**', with a further 8% saying they were unsure.

- "I have had to change. After being married for 50 years I was very lonely and frightened of being alone at night, hearing noises. I am not a very confident person but have muddled through and now enjoy my own company as well as friends."

- "Grief is immense. I believe it is the price we pay for love. Bereavement is not just about the loss it is the domino effect that it causes in people's lives. Grief effects everyone differently and people should show empathy, compassion and understanding at this time. They should allow people the time and space and support that they need. It effects your life in so many ways, physically, emotionally, spiritually. Your relationships with others, your daily routines, finances, work. Bereavement is not recognised enough within workplaces and society. There has been a huge increase in sudden deaths over the last few years, and I have seen the impact of this in my life and the lives of family members and friends. This year alone, I have buried nine people who were close to me and important in my life. This does not include all the others whom my family and friends have lost. It has been immense, so you are not only witnessing your own grief but the grief of those you love and care about, the people that you support, and within your community and the collective."

Healthwatch Kingston is an independent statutory service (not part of the NHS nor Kingston Council). You can find out more about us on the Healthwatch Kingston website.

Healthwatch Kingston was set up by the Health and Social Care Act of 2012 to be the independent champion for local NHS and social care.

We seek the views of patients, service users, carers and the public to help services work better for the people who use them. We play an important role bringing communities and services together. Everything we say and do is informed by what local people tell us.

As well as encouraging those who run local services to act on what matters to people, we also share local views and experiences with Healthwatch England and the Care Quality Commission who make sure that the government put people at the heart of care nationally.

Tell us what you think about your NHS and social care

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Kingston Voluntary Action is an infrastructure organisation that provides a wide range of support to the voluntary sector. We support local charities and community groups at all stages of their development.

Our Vision: Communities and people that KVA works with are empowered to drive social change towards a fairer, more inclusive, healthier and happier society.

Our Mission: Meeting the needs of community organisations and individuals by equipping them with relevant tools, skills, knowledge, confidence and voice to drive positive change.

Our Values: We are Collaborative, Resilient and Creative.

Our Strategy: 2025-2028: Stronger Organisations, Healthier Communities

Our Role: KVA is part of a national network of over 250 local infrastructure bodies, known as Councils for Voluntary Service (CVS).

We believe that infrastructure has a crucial role in helping to build strong, connected communities.

We see infrastructure as based on three complementary and intertwined strands: capacity building, connecting and representation.

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Please visit the KVA team page to contact individual staff members.

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