The Commission on Palliative and End-of-Life Care – call for evidence

March 2025

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Background

The World Health Organisation (WHO) defines palliative care as an approach that improves the quality of life of individuals and their families facing problems associated with life-threatening illness.

The Palliative and End of Life Care Commission aims to 'identify the current strengths and significant shortfalls in provision and the barriers that exist in the current systems of such care'. It will look at the relationship between specialist palliative care services and generalist services and present findings to ministers, MPs and the public.

In March 2025 the commission called for evidence from patients, relatives and carers. Healthwatch Surrey champions the voice of local people to shape, improve and get the best from NHS, health and social care services. As such, we were keen to submit evidence to the commission demonstrating the experience of palliative care of Surrey residents.

This report

No targeted engagement or questioning around experiences of palliative and end of life care has taken place; this report is therefore a snapshot of what we've heard between as part of wider discussions with residents of Surrey around health and social care between September 2024 and March 2025.

PLEASE NOTE: Any urgent or concerning experiences within this report have been escalated to the appropriate teams. All appropriate information and signposting has already been given.

What have we heard?

Poor communication to relatives and carers

Poor communication to relatives and carers from health and social care staff is the theme which we hear most about in relation to palliative and end of life care.

> "My husband is on end of life care and they [care home staff] have not been communicating issues as they arise. There have also been some issues with management recently, over the use of [pain medication] for my husband. He was showing obvious discomfort so the GP and hospice nurse prescribed him [pain medication] to manage his pain. However, the management were reluctant to give it to him and didn't on several occasions. During a meeting with them, they told me their reasoning was because "of the risk of toxic shock". The hospice nurse said that there is a risk of toxic shock with every medication and wrote to them to say that he needs to have it administered daily from now on. My daughter also wrote in to the managers via email in August, to raise her concerns. However, she has still not received a response from them, not even an acknowledgement. I am finding it all very draining now. I just feel like I have to be so on top of them and its tiring."
> **221602, Epsom and Ewell resident**

This can lead to concerns amongst relatives and carers about the intentions and professional conduct of staff.

> "Bumbling staff, the story kept changing. The took the decision my father should die. The Palliative team murdered my father. They will lie when I make a complaint."
> **227663, Epsom and Ewell resident**

It can also impact decisions around end of life care, potentially leading to patient wishes not being adhered to.

> "Nothing went well. Despite repeated questions from the family, the teams caring for my aunt failed to acknowledge where we are at. This meant that she died in the place she least wanted to be."
> **226879, Surrey resident**

In the case below, a patients' individual circumstances – the need for translation – weren't considered.

> "I had to be with my mum to translate for her as she didn't speak English but I was only allowed in during visiting times but when the doctors did their rounds, my mum didn't know what they were talking about and they couldn't understand her either. I was allowed in once when it wasn't visiting and a nurse said to me 'what are you doing here?' The doctors seem to want me there but the nurses didn't. I knew all about her medications and could have helped with all this information but I wasn't asked/included. I wish that I had know about the advanced directive letter and the 'This is me' care passport. It would have made things much easier for mum and me."
> **222441, Guildford resident**

Clarity and compassion

In some cases poor communication is related to a lack of clarity around end of life care, and / or these processes being communicated in a way which lacks the compassion required for such a difficult time.

> "They also talked to me about signing a DNR (Do Not Resuscitate). I was not in the right place mentally to have this conversation, it wasn't done very sensitively. They talked about what resuscitation entails and she could have broken ribs etc. This wasn't nice to hear. I didn't sign and then mum died and we got to see her notes, I saw that the doctor had gone against what I said and our DNR. I didn't know what my rights were."
> **222441, Guildford resident**

> "One night she was breathless in the night. The night carers called an ambulance, who asked to speak to mum. They then said they wouldn't send an ambulance. The carers called the care home manager, she called Frimley Park Hospital and demanded that an ambulance came for her. Mum had had a heart attack. She was in hospital for 19 days, and she had another 2 heart attacks while she was in hospital. She rallied. I tried to speak to the consultant to find out what was happening, I spoke to junior doctors - none of them told me that she'd had another heart attack. It's disappointing that no one told me. The consultant said, if the care home are happy to take her back, she could go home tomorrow. The care home said they'd take her. I went to see her, and had a lovely time with her. Then sadly she died before she could go back to the care home."
> **226540, Epsom and Ewell resident**

Positive experiences – care in the community

People do share positive experiences with us, in the case below this was related to experiences with the community nursing team.

> "Did not really know how/when to get them involved with my very elderly, slowly deteriorating mother but once I suspected that she was developing a pressure sore and called them in to look at that they were brilliant and organised a hospital bed, end of life meds and came out to administer her meds any time I called, day or night. Also came promptly to certify her death."
> **226826, Woking resident**

About Healthwatch Surrey

Healthwatch Surrey champions the voice of local people to shape, improve and get the best from NHS, health and social care services. As an independent statutory body, we have the power to make sure decision makers listen to the experiences of local people.

We passionately believe that listening and responding to local people's experiences is vital to create health and social care services that meet the needs of people in Surrey. We seek out people's experiences of health and care services, particularly from people whose voices are seldom heard, who might be at risk of health inequalities and whose needs are not met by current services. We share our findings publicly and with service providers and commissioners to influence and challenge current provision and future plans.

We also provide reliable and trustworthy information and signposting about local health and social care services to help people get the support they need.

Contact us

Website: www.healthwatchsurrey.co.uk

Phone: 0303 303 0023

Text/SMS: 07592 787533

WhatsApp: 07592 787533

Email: enquiries@healthwatchsurrey.co.uk

Address: Freepost RSYX-ETRE-CXBY, Healthwatch Surrey, Astolat, Coniers Way, Burpham, Guildford, Surrey, GU4 7HL.

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We are proud to be commended in the National Healthwatch Impact Awards, recognising our work helping to improve local NHS and social care. You can view our video highlighting how feedback has enabled us to make positive changes to health and social care services.

Committed to quality

We are committed to the quality of our information.
Every three years we perform an audit so that we can be certain of this.

The Healthwatch Surrey service is run by Luminus Insight CIC, known as Luminus.
Registered office: GF21, Astolat, Coniers Way, Burpham, Surrey, GU4 7HL.