Conversations about end-of-life care in South Gloucestershire

What matters most?

May 2025

Contents

Executive summary

This project arose from work priorities identified by Healthwatch BNSSG's Prioritisation Panel in 2023. This identified the need to look at people's experiences of palliative and end of life care in South Gloucestershire to find out more about:

- Improvements that individuals and loved ones would make to palliative and end of life care.
- How individuals and loved ones can share their feedback about palliative and end of life care.
- How care can be personalised to meet the needs of every person.

We asked adults aged 18 years and over living in South Gloucestershire about their experience of end-of-life care and that of their families and carers. We asked about experience and awareness of end-of-life services, what information and support they were given, where people feel that the gaps in support are, knowledge of Advanced Care Planning, and about what matters most to people about end-of-life care now and in the future. This was a qualitative project during which we interviewed people in depth about their experience of end-of-life care of family members.

What matters most to people about end-of-life care?

We asked people what matters most to them about end-of-life care. This is what they told us – these are the overall themes from our interviews with family carers of people at the end-of-life.

- **Dignity and respect** for those at the end-of-life, their families and carers

Communication

- **Better communication** between health professionals and families, and carers
- **Clear communication** between different hospital departments
- **Timely communication about end-of-life** by medical staff to families and carers whilst people are in hospital
- **Privacy** whilst family members are dying in hospital wards, particularly during family visits

End-of-life care planning

- **Ensuring that end-of-life care plans are in place**, that final wishes of families and carers are communicated to hospital or care home staff

Carers

- **Acknowledgement** of carers' roles
- **Involvement of carers in end-of-life care planning** for those living at home, in residential care homes or in hospital
- **Respite support for carers** looking after their families and relatives at end-of-life
- **Need for support for self-care** for carers and families of the dying

Choice at end-of-life

- **Choice of care** – at home, in residential care or in hospital
- **Choice of where to die** (home, care home or hospital)

About Healthwatch

Healthwatch BNSSG's statutory duty and remit is to provide a voice for people who use health and social care services. We give people an opportunity to have a say about their local health and social care services and we report these experiences to influence service providers and improve outcomes. We have a representative on the Health and Wellbeing Boards, Health Overview and Scrutiny Committees, and at the Integrated Care Partnership and Board. We feed issues back to local care providers and nationally via Healthwatch England and the Care Quality Commission.

Equalities statement

Healthwatch BNSSG is committed to promoting equality and diversity and tackling social exclusion. We aim to ensure equitable access to our projects for all.

We include peoples lived experiences in our work and identify and mitigate against barriers to enable people to become involved in our research. We address the participation needs of those who share one or more protected characteristic, or those that experience hidden discrimination, or are part of an ‘invisible minority.’ We provide access to communication support to adjust for people’s needs and proactively assist people in attending events and meetings we hold.

Healthwatch BNSSG will connect with existing patient, service user and voluntary sector organisations to develop relationships with diverse communities, and especially with people whose voices can be harder to hear.

Background

This project arose from work priorities identified by Healthwatch BNSSG’s Prioritisation Panel in 2023. This identified the need to look at people's experiences of palliative and end-of-life care in South Gloucestershire.

Definition of palliative care and end-of-life care

End-of-life care is defined by NHS England as care that is provided in the last year of life. “Personalised care in the last year(s) and months of life will result in a better experience, tailored around what really matters to the person, and more sustainable health and care services.” (NHS England: www.england.nhs.uk/eolc/).

Palliative care is defined by the World Health Organisation as “an approach that improves the quality of life of patients and their families who are facing problems linked with life-limiting illness, usually progressive. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems whether physical, psychosocial or spiritual. Palliative care is a crucial part of integrated, people-centred health services. Thus, whether the cause of suffering is cardiovascular disease, cancer, major organ failure, drug-resistant tuberculosis, severe burns, end-stage chronic illness, acute trauma, extreme birth prematurity or extreme frailty of old age, palliative care may be needed and has to be available at all levels of care….It is estimated that globally only 14% of patients who need palliative care receive it”. (www.who.int/health-topics/palliative-care).

A recent article by Healthwatch England states that: “A report recently commissioned by Marie Curie highlights that 90% of people who die each year could benefit from end-of-life care. However, access and quality of this care varies, with people experiencing long waits for referral, understaffed teams and a lack of advanced care planning.” The article identifies four key themes that matter most to dying people and their families and carers:

- Timely access to end-of-life care
- Good co-ordination between different services
- Rapid and round-the-clock access to pain and symptom control
- The importance of staff attitudes

What was also highlighted was that people talked about healthcare professionals not being willing to discuss with the dying person or their families the fact that they were dying. “In relation to the importance of co-ordination of services at end-of-life, where this breaks down, the impact of doing this co-ordination falls on family members who are already struggling to come to terms with their loved one dying”. (Healthwatch England, March 2024)

A report from the Kings Fund (2023) reviewed literature and engaged with stakeholders about dying at home in England. The Kings Fund then asked recently bereaved families and carers to identify issues that they should focus on. “Families and carers told us that good quality end-of-life care includes: consistently caring, as well as clinically competent staff; good communication and involvement, for example, in care planning; information about what to expect, what services are available and how to access them, and seamless, co-ordinated care that adapts as people’s needs change”.

End-of-life care provision in South Gloucestershire

Provision of end-of-life care and palliative care services for people living in South Gloucestershire include hospital care provided by North Bristol Trust and UBHW Trust, St Peter’s Hospice, hospice at home services provided by Macmillan and Marie Cure, and care provided in residential nursing homes. GP surgeries can refer people to end-of-life care services including those previously mentioned.

Sirona provides the end-of-life care service across South Gloucestershire. Referrals to this service are made via a healthcare professional, including a GP or hospice nurse, through a single point of access system.

The End-of-Life Specialist Service supports clinicians with non-urgent advice, guidance, training and competencies. End-of-Life Specialist Nurses work regularly with community teams and undertake joint visits to enhance clinical skills, give peer support or to help manage the care of people with more complex health problems. The specialist service has links with local hospices, hospitals, care homes and other organisations across the area.

Data on location of death across BNSSG

Hospital is the most common location where people die followed by those who die at home, and those in residential care homes, and those in hospices. This is revealed by the following data.

Locations of deaths across BNSSG 2023/2024	
Hospital	3298
Home	2300
Residential care home	2204
Hospice	363
Other	223

(Data Sources: The activity datasets have been accessed via NCDR: Mortality, SUS+ Emergency Care Dataset, Admitted Patient Care, Critical Care & Outpatient Datasets. In addition, the Palliative Care Register is derived from GP Quality Outcomes Framework (QOF)).

Palliative and end-of-life care (PEoLC)

In Bristol, North Somerset and South Gloucestershire 968 of the people receiving PEoLC in care homes were temporary care home residents, 39.7% of all those who received PEoLC in a care home. This compares to 36.0% in England. (https://fingertips.phe.org.uk/static-reports/end-of-life-care-home-factsheet/).

Purpose

This project asked people living in South Gloucestershire about their experience of end-of-life care provided for their families, friends, and relatives. This was a small-scale project that took place between December 2024 – April 2025. Its aim was to collect qualitative data in the form of in-depth semi-structured interviews with people, their family, friends and carers, who have experienced end-of-life care during the last two years (2023-2025).

We undertook this project to identify good practice that could be replicated but also to provide those delivering care with information about what people felt could be done better, and to provide lived experience views to improve services going forward. We wanted to look at people's care experience, knowledge of services and support available during end-of-life, identify what people feel is most important in terms of support in their community and identify gaps in support.

Engagement methodology

We worked with St Peter's Hospice and Sirona End-of-Life Care services in identifying what the information needs are within end-of-life care. The Engagement Officer regularly attended the South West Palliative and End-of-Life Care Collaborative meetings from October 2024 – May 2025. Participants were recruited via local carers' support groups, Sirona end-of-life care services, and care home support organisations.

Twenty-five organisations and individuals working in health and social care and the community were contacted to promote participant recruitment to this project. This included memory cafes for people with dementia, bereavement support groups, and voluntary organisations supporting people with long-term conditions, and local hospital chaplaincy services. Information about this project was posted across multiple community social media sites via Facebook, including long-term and terminal illness support groups, bereavement groups, and across Healthwatch BNSSG social media to recruit participants.

Methodology

All participants were given a participant information sheet to read and asked to sign a consent form prior to being interviewed.

Semi-structured qualitative interviews were held with participants and were conducted on Zoom or by telephone. All qualitative interviews were recorded for transcription purposes. Transcripts were written up and analysed, from which key themes were drawn.

Project participants

We spoke with ten people with end-of-life care experience, six of whom came forward to be interviewed, all of whom lived in South Gloucestershire. This included one man, and five women aged between 65 - 87 years, bar one who was 31 years. Interviewees were all carers for their family members who died between 2022 – 25, and three were carers of their partner with advanced dementia. Five participants had looked after family members for several years with dementia or other long-term conditions for example, Huntington's disease, dementia with Lewy bodies and Parkinson's disease. Five participants talked retrospectively about their experience of their relative's end-of-life care, and one was currently caring for their family member. Three of the participants experienced death of their family member in hospital, and two experienced this within their family member's home.

Outcomes

The outcomes of this project will be shared with local health commissioners, Healthwatch England, the CQC, the Sirona End-of-Life Care service, St Peter's Hospice and the South West Palliative and End-of-Life Care Collaborative.

Findings

What matters most to people about end-of-life care?

We asked people what matters most to them about end-of-life care. This is what they told us – these are the overall themes from our interviews with carers of people at the end-of-life living in South Gloucestershire.

- Dignity and respect for those at the end-of-life, their families and carers
- Better communication between health professionals and families, and carers
- Clear communication between different hospital departments
- Timely communication about end-of-life by medical staff to families and carers whilst people are in hospital.
- Privacy whilst family members are dying in hospital wards, particularly during family visits
- Ensuring that End-of-Life Care Plans are in place, that final wishes are communicated to hospital or care home staff
- Acknowledgement of carers' roles
- Involvement of carers in end-of-life care planning for those living at home, in residential care homes or in hospital
- Respite support for carers looking after their families and relatives at end-of-life
- Need for support for self-care for carers and families of the dying
- Choice of care – at home, in residential care or in hospital
- Choice of where to die (home, care home or hospital)

What did they tell Healthwatch?

Three participants said that their relatives died in hospital. Several of these deaths were unexpected and their relatives were in hospital for up to a week. This includes one person whose relative was in Southmead ICU for 4 days prior to death. Several project participants (3) had not been informed by hospital staff that their relative was at end-of-life stage; this included people who were days from their actual death.

Support for end-of-life

Of those that received support for their relatives at the end of life, this included for example, voluntary organisations and charities offering support for long-term conditions such as 'Parkinsons Face-to-Face', the Alzheimer's Society, South Gloucestershire Age UK, council care workers, privately employed carers, Sirona end-of-life support team, hospital social workers, and their local GP. Participants stated that they received information on support for end-of-life for their family members from their GP. One participant commented on support they had received.

> "The lead on dementia health at Sirona - she's been outstanding, support from the Alzheimer's Society, get a call every 6-8 weeks. A lot of that is because I know where to go having worked in the system. A lot of people wouldn't know where to start (to look for support). The other organisation that has been outstanding is our GP practice – our GP has on occasion phoned us up and asked us to come and see her. She's regularly reviewing our health both of me and my wife, physical and mentally as the strain of looking after my wife has impacted on me. She made an appointment with a mental health nurse through the surgery."
>
> (Man, aged 65 +years, carer of wife with Alzheimer's disease)

Where support worked well, participants highlighted how GPs had been helpful in signposting to end-of-life care support and information for example, the Sirona End-of-life Care service, South Gloucestershire Council adult social care services and the Alzheimer's Society. The importance of the role of Care Co-ordinators was highlighted in supporting carers to access for example, timely GP and physiotherapy appointments for their family members.

Peer support

Those who regularly participated in carers' groups found this type of facilitated support around carer issues, end-of-life issues, and informal bereavement support particularly helpful. They emphasised the need for ongoing funding for these type of facilitated support groups (currently run by Carers Support).

We asked participants about what type of support they would need to feel empowered. These were the comments from participants on this:

> "For me to be empowered, I needed information. I was there as my partner's carer and needed to be acknowledged as that (which I wasn't). If I was there now, would I be acknowledged as a carer, as well as his wife, I'd been caring for him for a year." (Woman, aged 65+, carer for partner)

> “You should go out with your dignity intact.”
> (Woman, 75 years, relative died in hospital)

Gaps in support

Gaps in support that participants identified included support for carers during their relatives’ end-of-life period, and hospital staff not being fully aware of the person and their families’ wishes of preferred choice of place to die. This is revealed by the following comments:

> “That hospitals are aware of the wishes of the person and the family where someone wants to die and is timely with that process. I’m still convinced that if my dad had come home sooner, he would’ve lived longer.”
> (Woman, 31, full-time carer for family member)

> “I really needed someone to guide me and support me, that it’s not my fault that he’s dying, or how his breathing is, none of that is my fault and also `How do you feel that your Dad’s dying?’ as I was so busy with practical support. I wish I’d had more opportunities to be with my Dad, to play music and sing to him, and say everything I wanted to say to him rather than ‘Has he had his medication?’”
> (Woman, 31, full-time carer for family member)

Information needs

For those whose relatives died at home, which was their choice, they felt they needed information and support about this process:

> “The only thing I didn’t have information about was what to do when someone dies at home - who to call? All the other family members had died in hospital. Ringing funeral directors to collect the body, the time this takes and talking to the family about this. It would’ve been helpful to have those conversations a bit earlier particularly with Parkinsons. It would’ve been good to choose the best option for him as a family. As a family we didn’t want to keep his body in the house. It would’ve been good to know

that information earlier, the process of death, how do you choose a funeral director?" (Woman, 31, carer, for relative with Parkinsons' disease)

Communication about end of life

Several participants felt that hospital staff had not communicated or not communicated early enough with them that family members were at end-of-life stage. This is illustrated by the following comments:

"Nobody ever told me about end-of-life care, I knew about his heart failure, they (hospital staff) told me about his kidney failure, and they told me about protein in the last stages it was kidney failure, and liver failure. I think Covid had an impact on poor communication between different hospital departments." (Woman, aged 60+ years, carer for husband who died in hospital).

"End-of-life care wasn't mentioned. I knew what to look for, and I'd look it up on the computer. If I hadn't known what to look for, of what was end-of-life, and then I could say to my children that 'We need to go in to say goodbye to Dad'."
(Woman, aged 65+ years, carer for husband who died in hospital with a long-term condition)

"It was mentioned in the last few hours in terms of putting a purple butterfly on the door. I think the gap was when they brought him on to the ward and they moved him to another ward/room and he deteriorated, had a proper doctor seen him at that point, then conversations could've happened earlier. I feel that we hadn't had the opportunity what we needed to be expressed. When we realised that he wouldn't make it, I wanted him to be at home not in the hospital and that didn't happen. I hadn't wanted him to be in the hospital.... partly because it wasn't where he wanted to be."
(Woman, aged 60+ years, carer for husband who died in hospital).

Others revealed on the other hand that timely information about end-of-life stage given by their GP and the Palliative Care End-of-Life team had been helpful:

> "I think at that point when the GP came, we had the best information they could provide. She said that he had 72 hours, and he lasted a lot longer than that. They obviously were quite cautious what information they gave me at what point. It was only in the last 48 hours they (palliative care team) told us what to look for and how someone's breathing pattern changes. I had no idea that there's a similar pattern of how someone's breathing pattern changes near to death." (Woman, 31, full-time carer for family member)

Communication around hospital discharge

One participant felt that communication about hospital discharge at the end of life had been poor and had taken longer than necessary:

> "Also, hospital discharge, particularly when they know he's end of life, if they knew that he was end of life, they should listen to the carer and the family. We did not want him to die in hospital. To the point that I took the breaks off his hospital bed and pushed it towards the door, I didn't want him to die in hospital. They (the staff) didn't listen. Those things, organising a hospital bed, ensuring the home carers are booked in seem so simple…" (Woman, 31, full-time carer for family member)

What matters most to you about end-of-life care?

People told us that what matters most to them about end-of-life care is communication between healthcare staff and families and carers, involvement of family carers in planning care, understanding people's preference of where they want to die and the quality of death, and support for carers during this often-challenging process.

> "I think just being kept informed. If you know what's going on, you can prepare yourself and deal with it. His diet was changed in the hospital, they started giving him mashed up food, easily absorbed food. Nobody

had said why this was happening. Protein-losing enteropathy. I knew that this was one of the end-of-life symptoms. If that information was shared about why they were doing things, but it wasn't."
(Woman, aged 65+ years, carer for her husband with a long-term condition)

"I think one of the things is that I need to be involved. If my wife was living away from home, that I was supporting her, not just being the husband, that anyone involved in her care, I'd be the secondary person there and being a participant in the care, I think that's important – to be part of the care team, not feeling left out or about conceding care to somebody else."
(Man, aged 65 +years, carer of wife with Alzheimer's disease)

"Not dying alone, and being pain free, making sure nursing staff 'let me go' and don't keep me hanging on, so I wouldn't be kept alive for the benefit of others." (Woman aged 75 years, carer for a relative who died in hospital)

What came across in this project was that what is important to people, their families and carers at end of life is being enabled to have earlier conversations about end of life and being given choice around preferences for location of death and communicating these wishes with health and social care professionals.

"At the time what was most important was that dad wanted to be at home; glad we were there the moment he died. What's important to me: how the carer and family members are supported at that time. I would really like someone to have said to me, 'Go for a walk, go and do the things you really need, go and have something to eat, have a shower, go back to your own home and bed. To be able to offer the care he deserved you need to go and have that 10 minute (break)'."
(Carer, 31, of family member with Parkinsons disease).

Awareness of the hospice service

Participants interviewed knew of the hospice service however, several were not aware that the hospice service supports people with non-malignant conditions in the community during their last year of life. A few participants thought hospices predominantly support people with cancer and no other terminal conditions. This was commented on:

> "I always assume that hospices are for people dying of cancer, but they're not. Nobody ever said about my husband going to a hospice, which wasn't mentioned."
> (Woman, 65+ years, carer of partner with a long-term condition)

> "I have had contact with St Peter's and Winsley, outside of Bath. What I'm not sure about is whether they support people with dementia."
> (Man, 65 + years, carer of wife with Alzheimer's disease)

Another participant expressed a retrospective need for respite support as a primary carer, and questioned whether the hospice service could have provided this:

> "We weren't ever asked about hospice care. It may be because we wanted him to die at home that we weren't asked about it. I developed Chronic Fatigue symptoms after caring for my dad during that period of end-of-life and previously. I'd been sleeping on a 2-seat sofa. It would've helped to have respite support during this period." (Woman, 31, full-time carer for a family member).

Knowledge of Advanced Care Planning

On being asked whether people had knowledge of Advanced Care Planning, a couple of people had discussed plans for what type of care and location of care with their families if they had been looking after family with long-term conditions or had experience of this with wider family or friends.

One person commented,

"I've talked about this with my cousin, about my wife, and with our GP, it's recorded on our medical notes (both of us). That kind of information is lodged with the GP and my cousin. We've got a Lasting Power of Attorney and included what our wishes are for our funerals. In terms of care that's the sort of preparation I've been doing, bringing carers into the home here. With dementia it's very difficult to put a timescale to it, with the other conditions my wife has got, it's very difficult to know. It could be in 3 years' time or tomorrow morning." (Man, aged 65+ years, carer for his wife with dementia)

Others said that they would have liked to have information and support around Advanced Care Planning:

"I've not heard the term before, but I can guess by the wording. I think that would've been a brilliant conversation with my dad at the beginning. With something like Parkinsons you know the prognosis is around 12 years. It would've been good to have someone support us to do that, or like a guidebook or something. Afterwards then it would be a lot easier for the family to make decisions in your best interests." (Woman, 31, full-time carer for family member)

Recommendations

This project has enabled in-depth conversations with people about experience of end-of-life care of friends and family members they have cared for or are caring for. This qualitative patient experience data suggests the need for:

- Community health and social care professionals to signpost families and carers to available end-of-life care support in their communities, including hospices and relevant charities.
- Hospital trusts to ensure health care professionals involve family carers in end-of-life planning.
- Hospital trusts and healthcare professionals to improve information on the eligibility criteria and the support provided by hospice services.
- Hospital trusts to ensure improved communication between healthcare professionals and people and their families about when someone is at the end-of-life stage
- Hospital trusts and healthcare professionals to improve communication with patients, families and carers on personal wishes about location of end-of-life.
- Hospital trusts to improve communication about hospital discharge at end-of-life stage and involvement of families and carers in this process.

Provider responses

Andy Newton, Head of Integrated Care, NHS Bristol, North Somerset and South Gloucestershire ICB

End of Life Care in Bristol North Somerset and South Gloucestershire is delivered by a range of provider organisations, including hospice care, community services, acute trust and the voluntary sector. All the providers are represented at the End of Life Collaborative group – a joint forum to support the development and improvement of services across organisations, and advocate for End of Life Care. The ICB will circulate this report to the End of Life Collaborative to agree any subsequent actions together and incorporate in plans to develop end of life care services.

Resources

Qualitative data was coded by common and recurring themes. All project participants who took part in a telephone or online interview were remunerated with a high street shopping voucher.

Collaboration

All participants were provided with participant information sheets and completed consent forms prior to being interviewed.

Quality assurance

This project was designed and completed by Anna King, Engagement Officer, Healthwatch BNSSG using Healthwatch BNSSG methods for research and engagement. Graphics and pictures: Healthwatch England.

Conflicts of interest

No conflicts of interest were identified.

Audience

This report is aimed at service commissioners in health and social care.

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