



Leeds Palliative
Care Network

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Leeds



Bereaved Carers Survey about End-of-Life Care in Leeds

People's experience of end-of-life care and support
for their friend/relative in hospices, hospitals, in their
own homes and care homes

2022-2023

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Summary

Introduction

Healthwatch Leeds worked with the Leeds Palliative Care Network to gather peoples experiences of end-of-life care in various healthcare environments. These included hospitals, community settings (such as GP surgeries, services delivered by Leeds Community Healthcare, private care agencies, and care homes), and hospices.

Healthwatch Leeds collaborates as a partner in this project, contributing to the development of surveys and producing the report. The clinical partners within Leeds Palliative Care Network have played a vital role in informing the process and leveraging their service level expertise to assist in interpreting the findings within this report.

Over 5 months, we received feedback from 109 individuals spanning across all the mentioned settings. It should also be noted that not every respondent provided responses to all questions.

The survey findings have been analysed and recommendations have been provided in real-time to each service area. A collective summary of recommendations made is presented at the end of the report. These suggestions will guide our future efforts in improving services.

The action plan for the 2021-22 Bereaved Carers Report is available here:

<https://www.leedspalliativecare.org.uk/seecmsfile/?id=340>

Background

Since 2015, through a partnership approach, Leeds has been running an annual survey of bereaved relatives' experiences of care in their loved ones' last days of life across different healthcare settings in Leeds (this includes hospitals, hospices, care homes and people's own homes). Over the years, the survey has been redesigned, making it shorter, accessible and with more focused questions to understand the perspectives of bereaved relatives/carers.

Why we did it

We wanted to help Leeds Palliative Care Network measure the quality of the care delivered to patients who have died within Leeds. This was done through a city-wide survey listening to bereaved carers of adults who died between 1st February 2023 and 30th April 2023. The focus of the survey is the care of patients in the last days of their lives.

What we did

The survey was conducted from February to the end of June 2023, offering respondents the flexibility to submit their responses online, by post and telephone. Interim feedback to individual providers was sent in real-time throughout the process of receiving survey feedback. **For a more detailed understanding of what we did and how we did it, including where the survey was distributed, please see Appendix 2.**

The report will now outline the findings of the survey responses; a copy of the survey can be found in Appendix 3.

Equality Monitoring and Accessibility

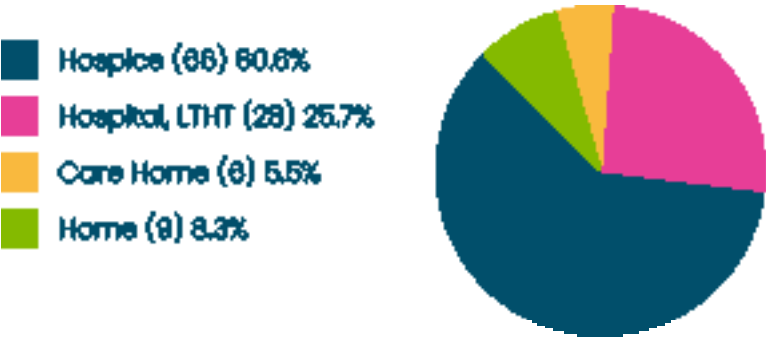
The survey has undergone an accessibility review conducted by our trusted partners and aligns with the established accessibility protocols of Healthwatch Leeds. Below are the compiled findings concerning equality and monitoring questions from respondents across all sectors of services asked about within this survey: hospices, hospital, and community care.

About our respondents

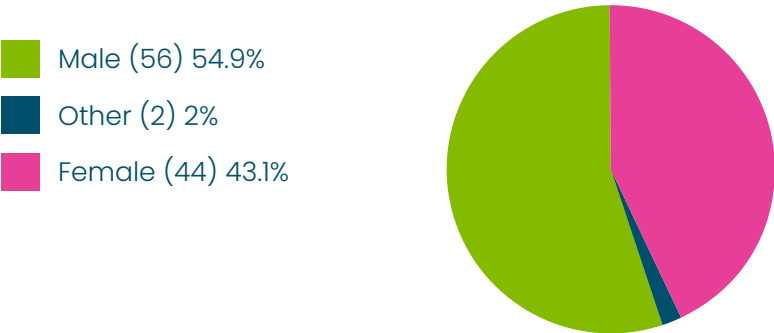
We received a total of 109 responses to our survey. The largest group of respondents (66) said their relative/friend had died in a hospice.

Most friends or relatives who had died were male (56) and 44 were female. Two respondents identified the gender of their deceased friend or relative as 'other'. No further details were disclosed.

Summary of total responses and settings respondents' friends/relatives were cared for

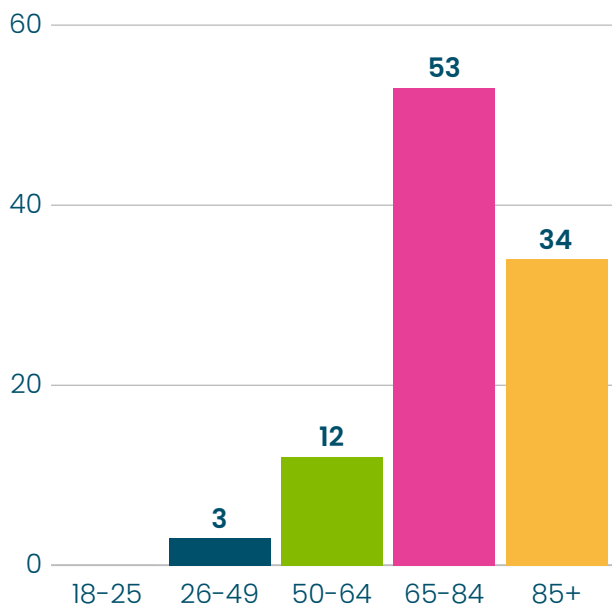


What was your relative/friend's gender?



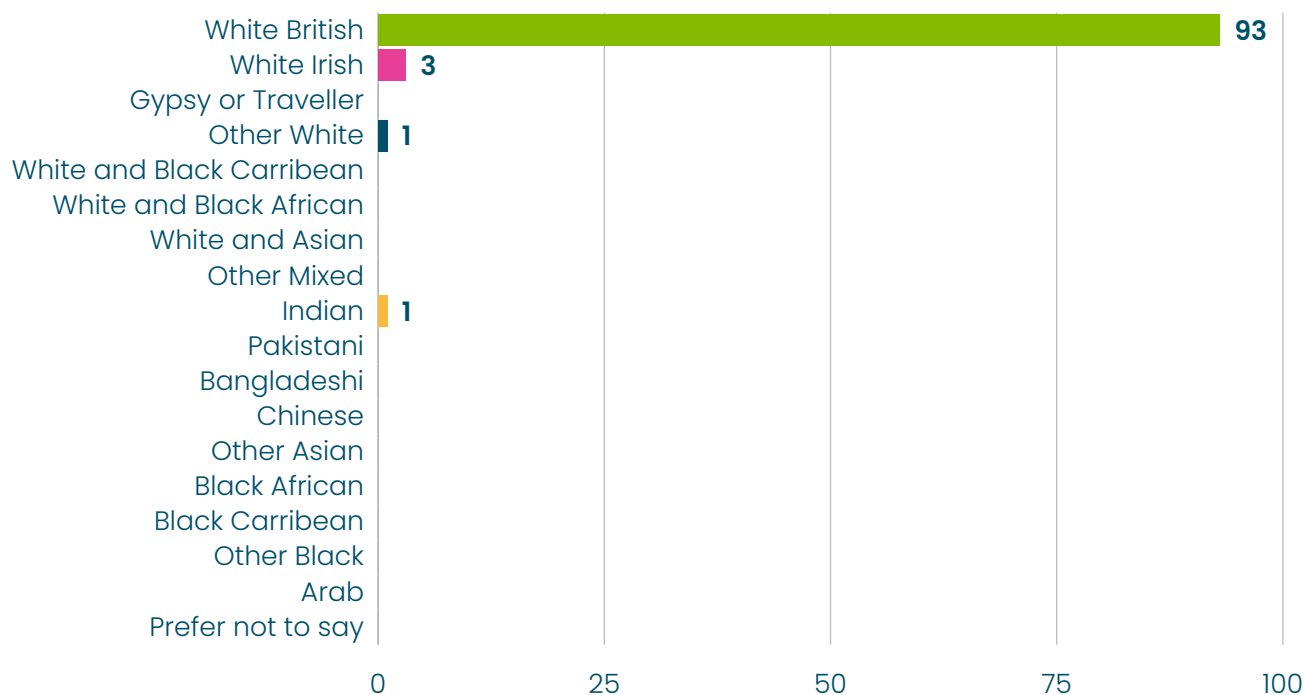
In most cases, respondents' deceased friend or relative was aged 65 and over.

The ages of respondents' friends/relatives



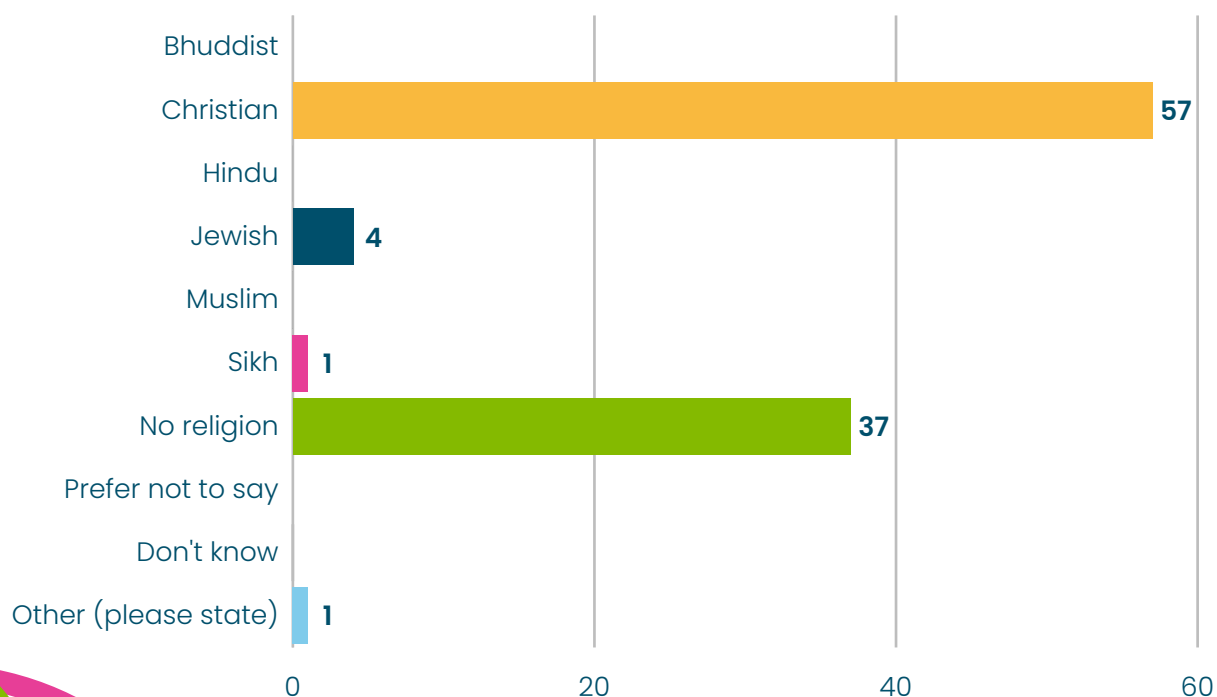
Most of our respondents told us about a friend or relative who was White British.

The ethnicity of respondents' friends/relatives



Most respondents told us about a friend or relative who was Christian. In the case where a respondent had other religions, this was indicated as multi-faith.

The religion of respondents' friends/relatives

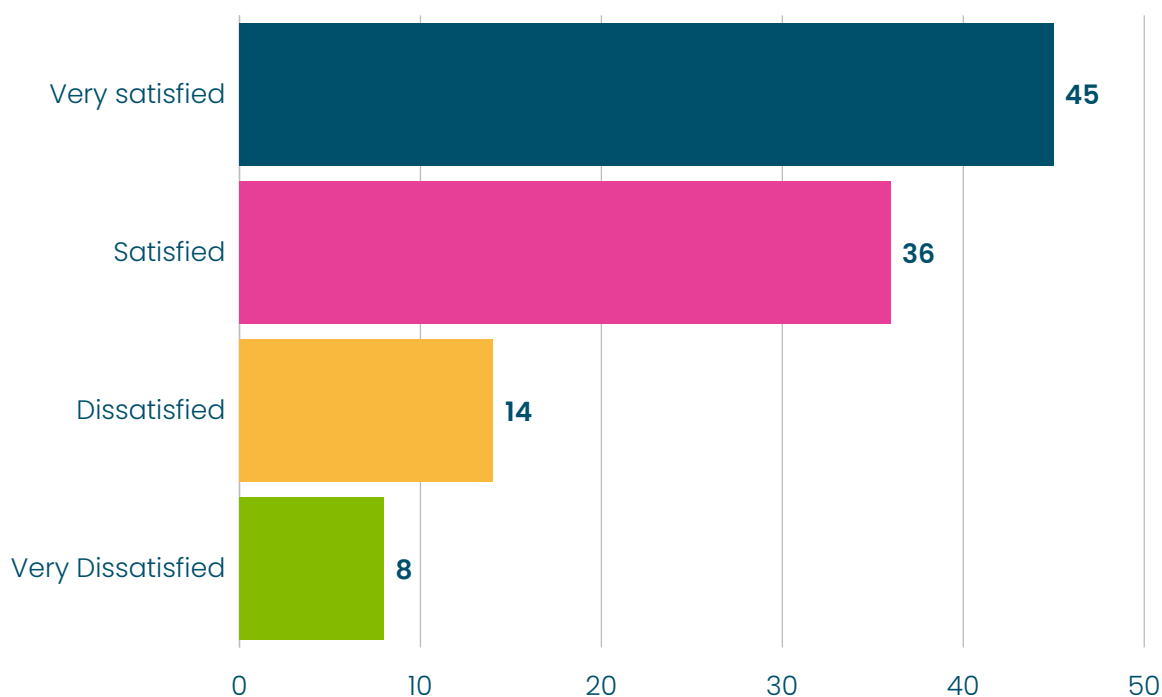


City-wide questions

Two of the survey questions focused on gathering information about the experiences of friends or relatives during the last months of their friends/relatives lives. The following data presents the overall results for these questions across all services. More detailed breakdowns can be found in the individual service sections of the report.

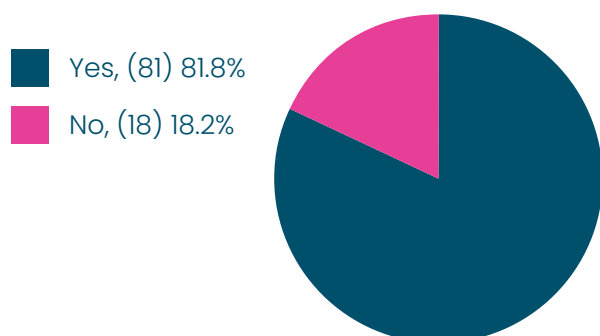
Of the 107 people who answered the following question, 76% were either satisfied or very satisfied with the way services worked together during the last weeks and months of their friend or relative's life.

In the last few months of your friend/relative's life, how satisfied were you with the way services worked together?



Of the 107 people that answered the following question, 75% had the chance to discuss their friend or relative's wishes for their care.

In the last few months of your friend/relative's life, did they (or you) have the opportunity to discuss their wishes about care and treatment with staff providing their care?



Summary of findings

Hospices

- We received 66 responses.
- 100% respondents felt their relative or friend died in the right place.
- Family/friends recognise and credit the person-centred care provided for their loved one at the end of life, particularly their attentiveness to go above and beyond in both caring for and supporting family/friends.
- A respondent recommended ensuring clear signposting and information provision of service upon arrival to family/friends.

Hospitals

- We received 28 responses.
- 75% felt their relative/friend died in the right place.
- Some staff were commended for demonstrating compassion, attentiveness, and patience to both the patient and their family/friends.
- Respondents highlighted the distress when a loved one is constantly moved between wards. They expressed the need for consistency in communicating visiting hours when a friend/relative is at the end of life.

Home

- We received eight responses.
- 80% felt their loved one died in the right place.
- Some people told us that dying at home had been their relative or friend's preference and were glad their wishes were met.
- Some worried about the lack of timely support available and having to wait long periods of time before pain was managed by relevant professional support.

Care home

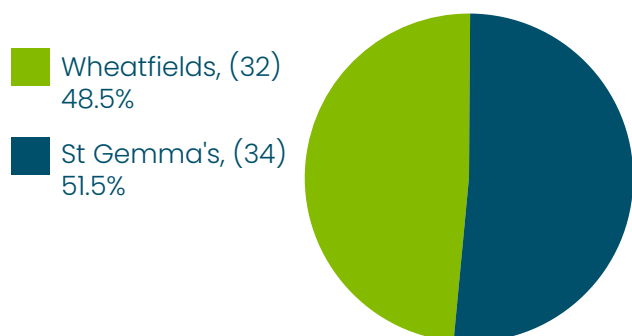
- We received eight responses.
- 80% felt their loved one died in the right place.
- Respondents told us that dying at their care home had been their relative or friend's preference and were glad their wishes had been met.
- Respondents reported the distressing impact that the lack of coordination in care and management of end of life can have, suggesting the way in which services link and work together needs to be continually reviewed and improved.

People who died in a hospice

About our respondents

We received 66 responses from those whose friend/relative died in a hospice. It is worth noting that the responses were closely distributed between St Gemma's with 34 responses, (52%) and Wheatfields with 32 responses, (48%).

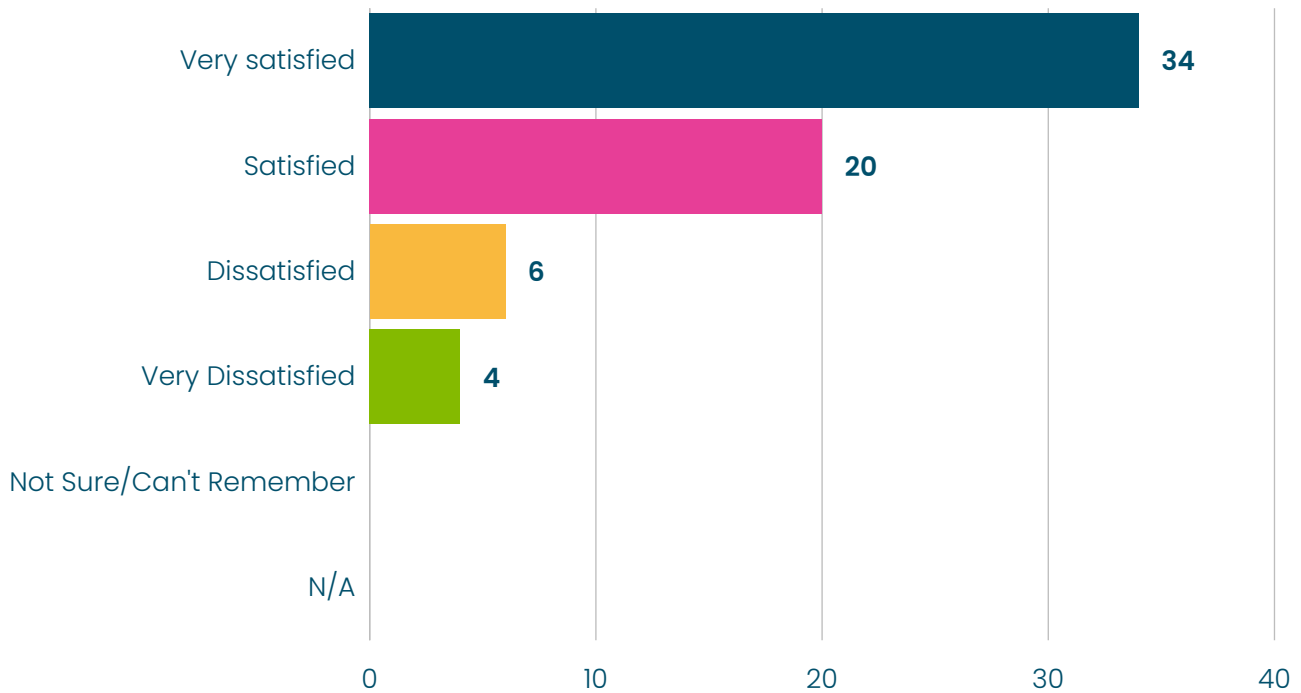
Please tell us which hospice they were cared for in



Services working together

We enquired with the respondents about their level of satisfaction regarding the coordination of services. The majority expressed satisfaction, 31%, or high satisfaction, 53%, although it is noteworthy to mention that there was a comparatively higher percentage (16%) of dissatisfaction reported for this particular question as opposed to others.

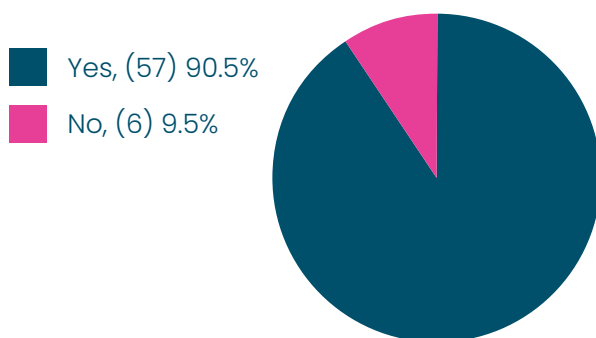
In the last few months of your friend/relative's life, how satisfied were you with the way services worked together? (E.g. GP, Community, Nurse, Homecare, Hospital, Hospice)



Discussing wishes and being involved

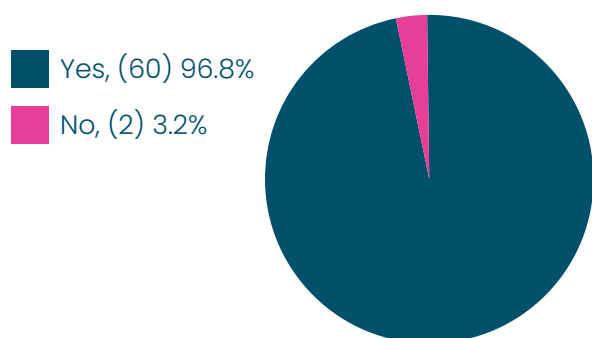
90.5% of individuals or their loved ones were given the opportunity to discuss their or their loved one's care in the final stages.

In the last few months of your friend/relative's life, did they (or you) have the opportunity to discuss their wishes about care and treatment with staff providing their care?



Most individuals were involved in their loved ones care as much as they wanted to be.

Did the service caring for your relative or friend involve you in their care as much as you both wanted?

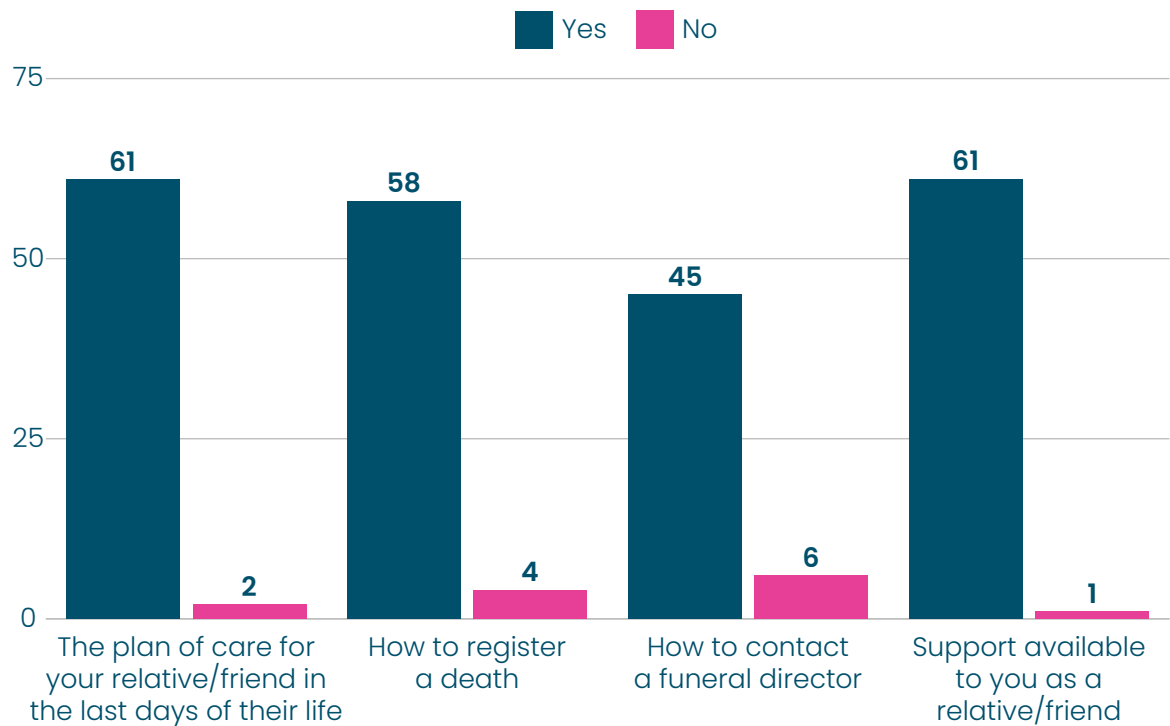


Service information provision

We asked respondents if they were offered information about the following topics:

- The plan of care for their loved one during their last days of life. We found that 96% of respondents answered yes, while 3% said they did not receive this information, and 1% were unsure.
- How to register a death. Out of all participants, 91% confirmed that they were provided with this information, 7% said they did not receive it, and 1% responded "no, n/a."
- The process of contacting a funeral director. According to the responses, 70% of individuals were given instructions on how to reach a funeral director. However, 10% reported not receiving this information, 5% were unsure, and 15% responded with "n/a."
- Available support for relatives and friends. The majority of respondents (95%) stated that they were informed about the support services available to them. Only 2% said they did not receive this information, and 3% were uncertain.

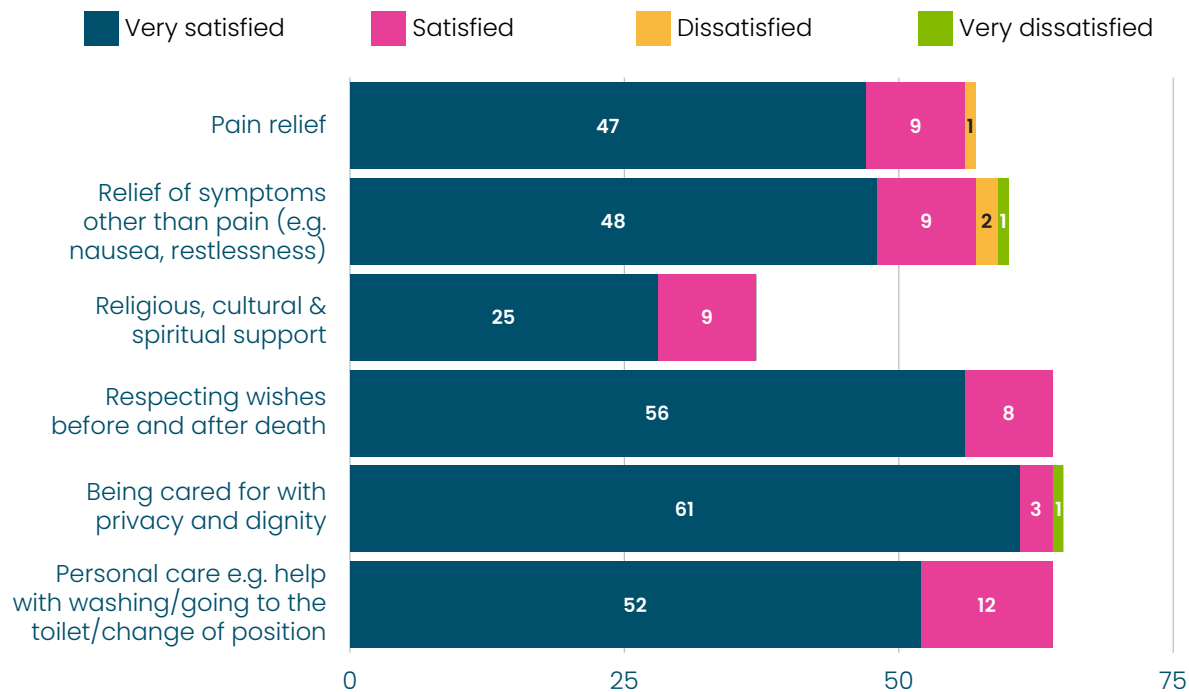
Please tell us if you were offered information about the following



Specific aspects of care

We asked the respondents about certain aspects of the care provided to their friends or relatives. In most cases respondents stated that they were either very satisfied or satisfied. There was a significant high number of “not applicable” responses to the cultural and religious support question. This mirrored the response rates from the equality and monitoring responses.

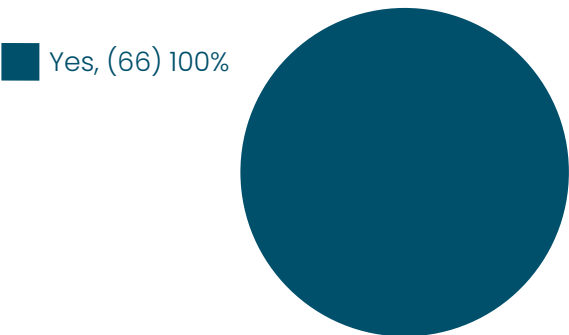
How satisfied were you with the care given to your relative or friend in each of the following areas?



Dying in the right place

All 66 respondents said they felt their relative/friend had died in the right place.

Do you feel that your relative or friend died in the right place?



What worked well and what could have been made better?

We sought peoples insights on what aspects of care went smoothly and what areas could have been better. Of the 53 responses to this question, 91% were overwhelmingly positive.

Of the 53 responses, 30 comments have highlighted the achievement of key values in terms of the quality of care and atmosphere. Specifically, these values include creating a serene, peaceful, and welcoming setting. 56% of comments mentioned valuing the hospice being well-staffed with compassionate professionals who provide exceptional care to both individuals in their final stages of life and their families.



“The hospice was a calm, welcoming environment. The staff including catering and cleaning, could not do enough to make sure things were done to keep my husband comfortable, and to look after me.”

“My husband was cared for with compassion and dignity. The doctors and nurses were very caring towards the whole family. I felt the hospice staff wrapped their arms around all of us.”

“Someone on call 24/7 and for the caring experience they have at Wheatfields hospice.”

Many liked the quality of communication and attentiveness that staff provide to both the individual who is at the end of life as well as their family/friend too. This was captured in the following comments:



“Consideration for relatives who are treated with every care”.

“The care and support the patient and I both received were exceptional making us both feel supported by professionals who cared.”

“His needs were tended to at all times to the best possible degree. As relatives, our whole family were given fantastic attention and information.”

“Sue Ryder (Wheatfields) saw our dad, they really saw him. My mum, my sister and I will forever be grateful for the care given to our dad. There are so many examples of this, I could write a novel but when added together, they made the passing of our dad the best it could be, peaceful, respectful, and full of care. The nurses explained the process exceptionally and were calm and caring throughout. They fed us! Forever grateful, forever a supporter.”

“St Gemma’s took the responsibility for his care from me and provided a calm, safe space for the family to spend with him instead of the increasingly frantic home environment. The staff provided immediate care as he needed it, and also looked after me and the family. I had regular updates of how things were progressing, which I found helpful and reassuring. St Gemma’s allowed us to have a peaceful and supported last week with my husband. I shall always be grateful.”

We requested individuals to provide any additional feedback about their overall experience. Of the 45 responses, two responses provided some areas of constructive feedback:



“Maybe provide a brief info sheet on first arrival of a visitor at St Gemma’s informing on: food, location, hours of visiting, about staying overnight, where staff are located on a floor if they are needed for a chat rather than patient needs (i.e. not using call buzzer).”

“Despite all the planning that went into my relative’s arrival at St Gemma’s, he was not put in the bedroom that has a ceiling hoist. This meant he needed extra equipment, some of which the family provided, as well as practical guidance for its use. We weren’t properly informed about dining arrangements and so many relatives missed out on a full hot meal as the kitchen was closed (I had to chase this up, and the staff then offered a small selection of foods that could be cooked quickly). Overall, we felt well supported at the hospice and the staff were friendly, approachable, and caring. My relative died as peacefully as he could have wished for, and everything went according to the plan in terms of medication and pain relief.”

The remaining 43 responses celebrated and recognised areas of the services that make the experience exceptionally positive:



“All the team are Angels.”

“The care team linked well with the other NHS services.”

“The handover process is commendable at every level of staff. They make it their business to know the detail and ensure continuity despite changing shifts. This is a well-oiled team with exceptional leadership. I am so proud of how they worked together.”

28 of the 43 responses talked about how valuable having ‘kind’, ‘caring’ and ‘supportive’ staff were across the board of care delivered and received:



“We felt that the staff at Wheatfields were sensitive, caring and did amazing work. They ensured my dad died with dignity and that my mum and I were well cared for and consulted throughout his time there.”

“The whole team at St Gemma’s from the Doctors to the staff in the canteen were so kind, caring and thoughtful. They made the most awful time of our lives as a family, just a bit easier. The care given to both my Dad and us as a family was second to none. Keep up the fantastic work.”

“The care at Wheatfields was much better than could have been received at home or in hospital. The hospice was also very supportive of the family, including ensuring that relatives could stay as long as they wished to and offering food and somewhere to sleep if needed.”

“Everyone from the Reception staff to the nursing and kitchen staff were wonderful.”

“All the help and advice we got, really helpful at this sad time, can’t thank everyone for everything you did.”

“Cannot criticise as all involved were exemplary, very kind and supportive to him, and us as a family. They were clear and honest, and their experience showed. What I personally really appreciated was a handwritten letter expressing gratitude for me setting up an online tribute as this note arrived on the morning of the funeral and was a great unexpected source of comfort on an incredibly hard day, so thank you for the person who took the time to do this – so thoughtful.”

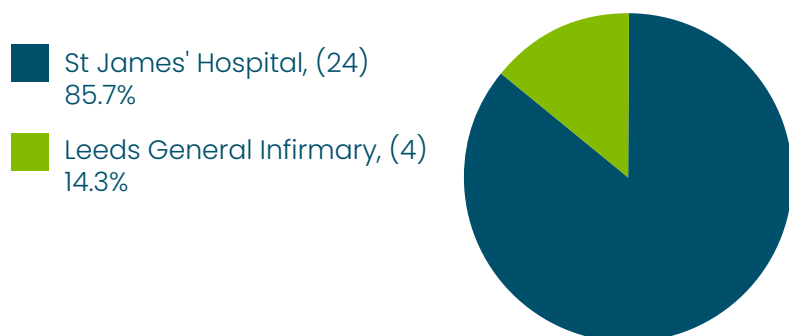
People who died in hospital

About our respondents

We received 28 responses from people whose relative or friend had died in a hospital.

24 people said their loved one had died in St James' Hospital.

In which hospital was your relative or friend cared for?



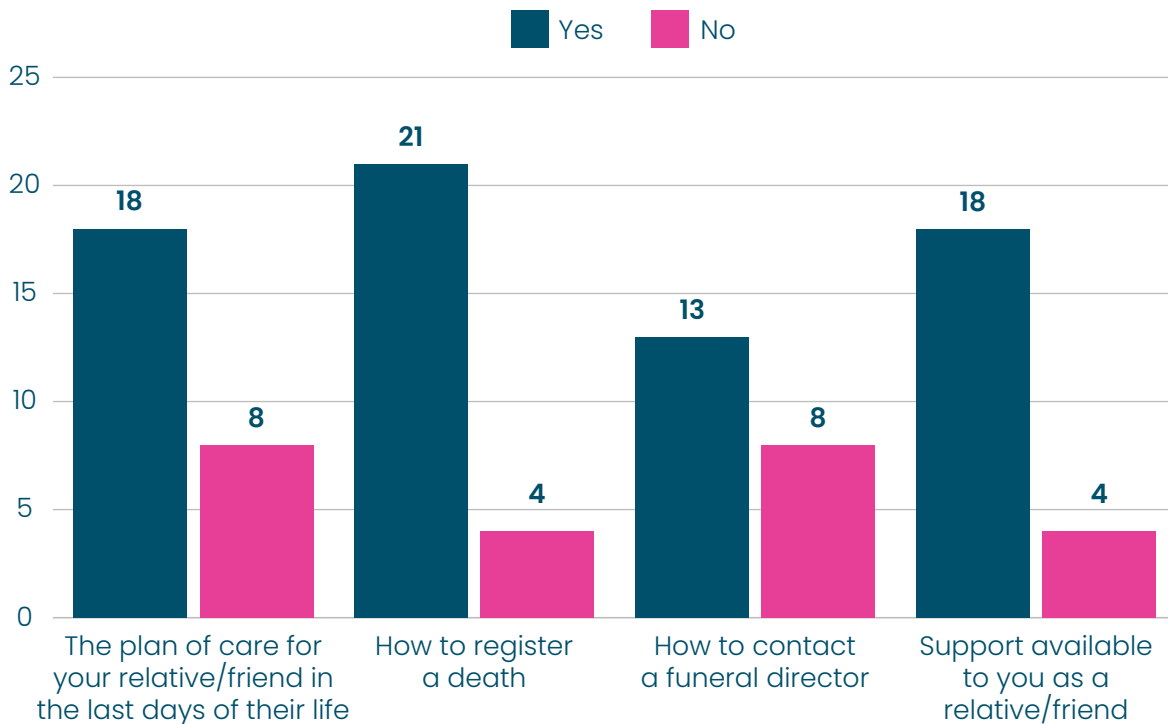
Practical support and information

Most people were offered information about the following:

- The plan of care for their relative/friend in the last days of their life (18 out of 26 people, 70%)
- How to register a death (21 out of 25 people, 84%)
- The support available to them as a relative or friend (18 out of 22 people, 82%)

The number of people who were told how to contact a funeral director was slightly lower. It is important to note that four people said that this issue was not relevant to them. 62% of respondents said they were told how to contact a funeral director (13 out of 21 people).

Please tell us if you were offered information about the following



Specific aspects of care

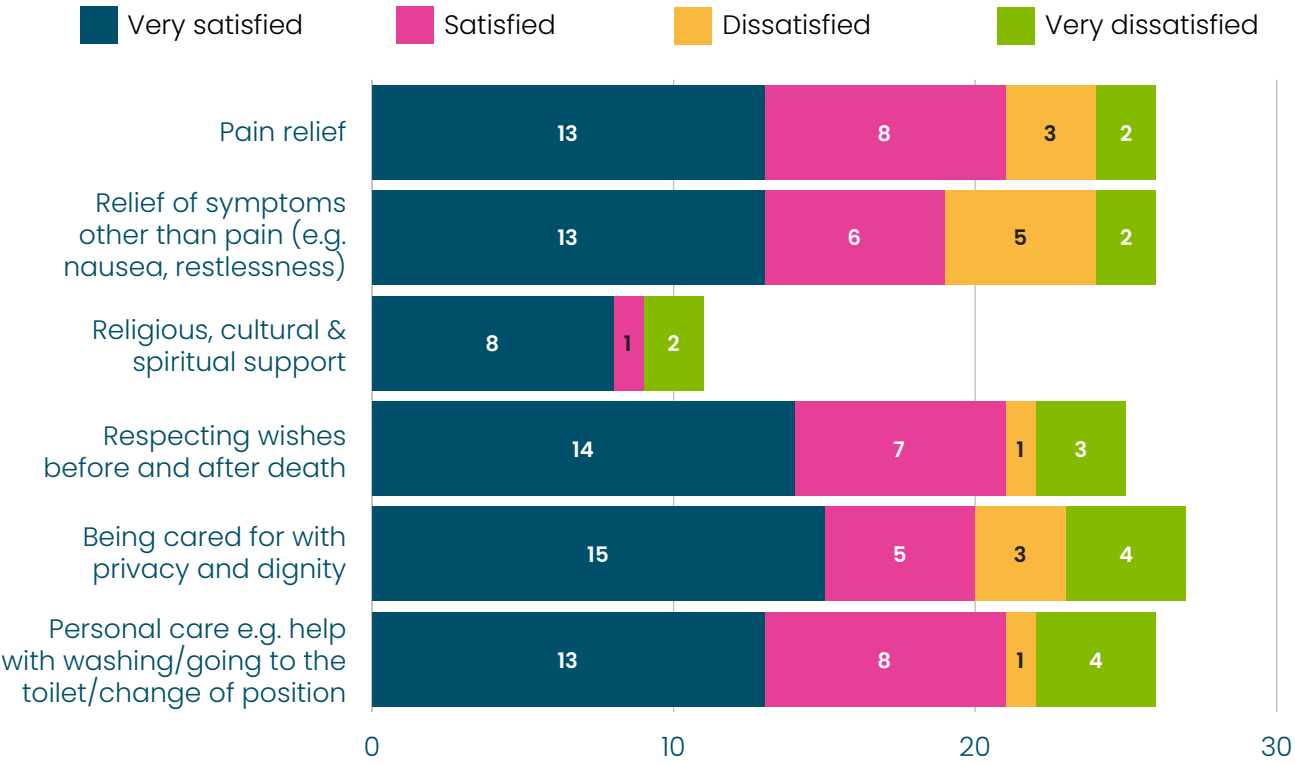
Most people were satisfied or very satisfied with the following:

- Pain relief (21 out of 26 people, 81%)
- Relief of symptoms (19 out of 26 people, 73%)
- Respect for wishes before and after death (21 out of 25 people, 84%)
- Being cared for with privacy and dignity (20 out of 27 people, 75%)
- Personal care (21 out of 26 people, 81%)

The areas with the highest levels of dissatisfaction were relief of symptoms other than pain (7 out of 26 people, 27%) and being cared for with privacy and dignity (7 out of 27 people, 25%).

9 people said they were satisfied or very satisfied with the religious, cultural, and spiritual support offered, while two were very dissatisfied. 16 people said this question was not relevant to them.

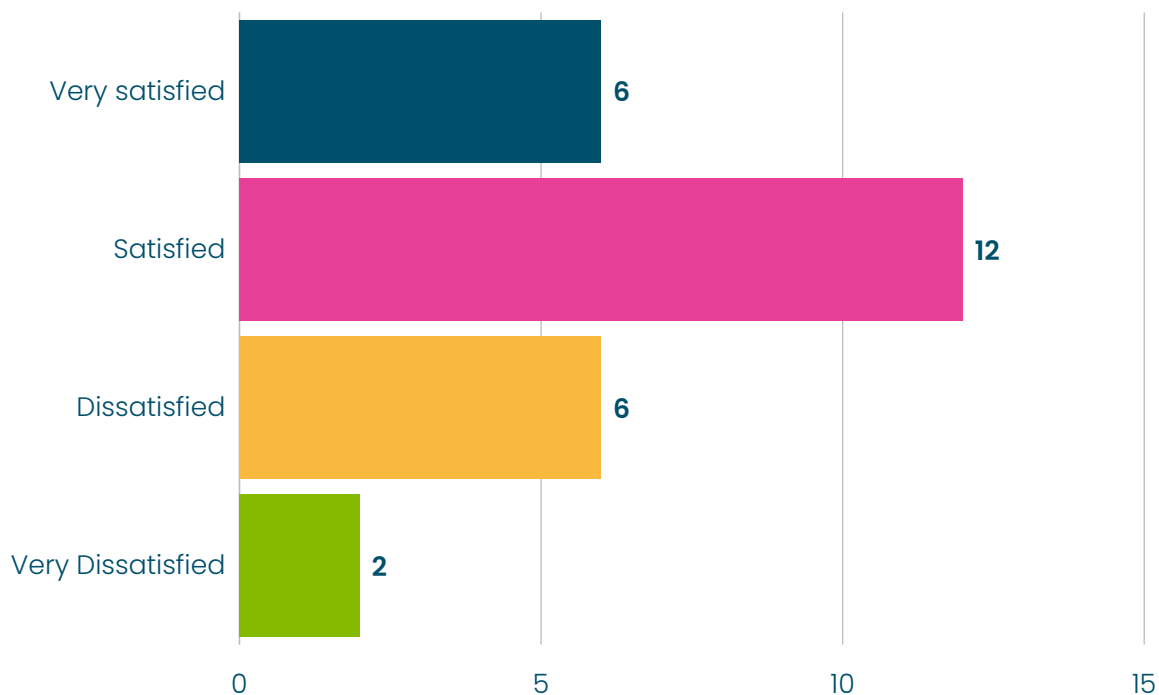
How satisfied were you with the care given to your relative or friend in each of the following areas?



Services working together

Most people were satisfied or very satisfied with the way health and care services had worked together (18 out of 28 people, 69%).

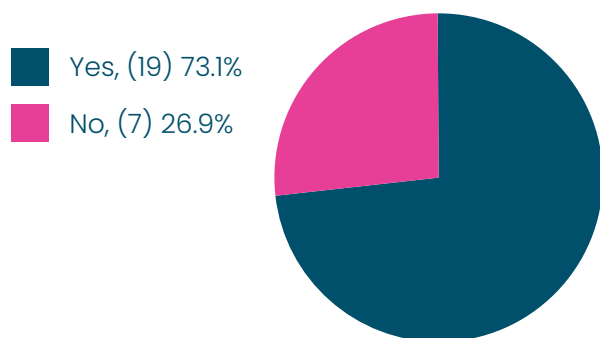
In the last few months of your friend/relative's life, how satisfied were you with the way services worked together? (E.g. GP, Community, Nurse, Homecare, Hospital, Hospice)



Discussing wishes and being involved

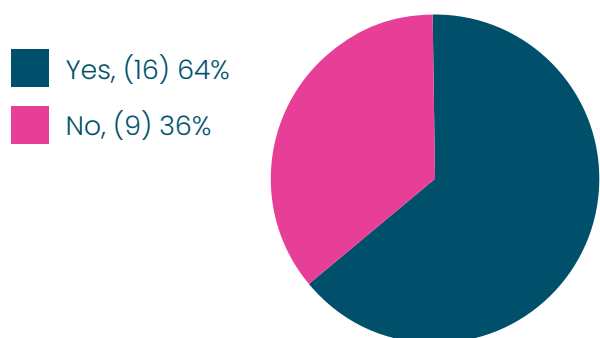
Most people said that they were involved in the care as much as they and their relative or friend wanted (19 people, 73.1%).

Did the service caring for your relative or friend involve you in their care as much as you both wanted?



16 people (64%) said they or their relative or friend had the opportunity to discuss their wishes about care and treatment with the staff providing care.

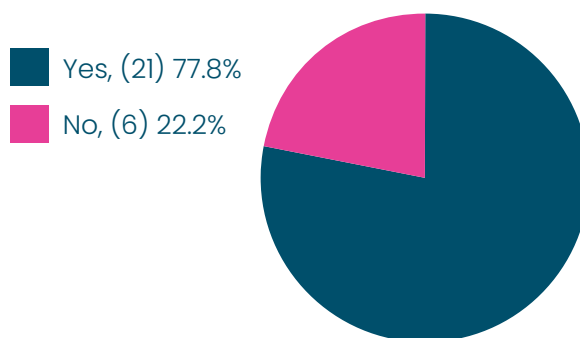
In the last few months of your friend/relative's life, did they (or you) have the opportunity to discuss their wishes about care and treatment with staff providing the care?



Dying in the right place

21 out of 27 responses (77.8%) felt that their relative or friend had died in the right place.

Do you feel that your relative or friend died in the right place?



Support measures (specific to hospital)

We asked people if they received a few support measures that were specific to the hospital.

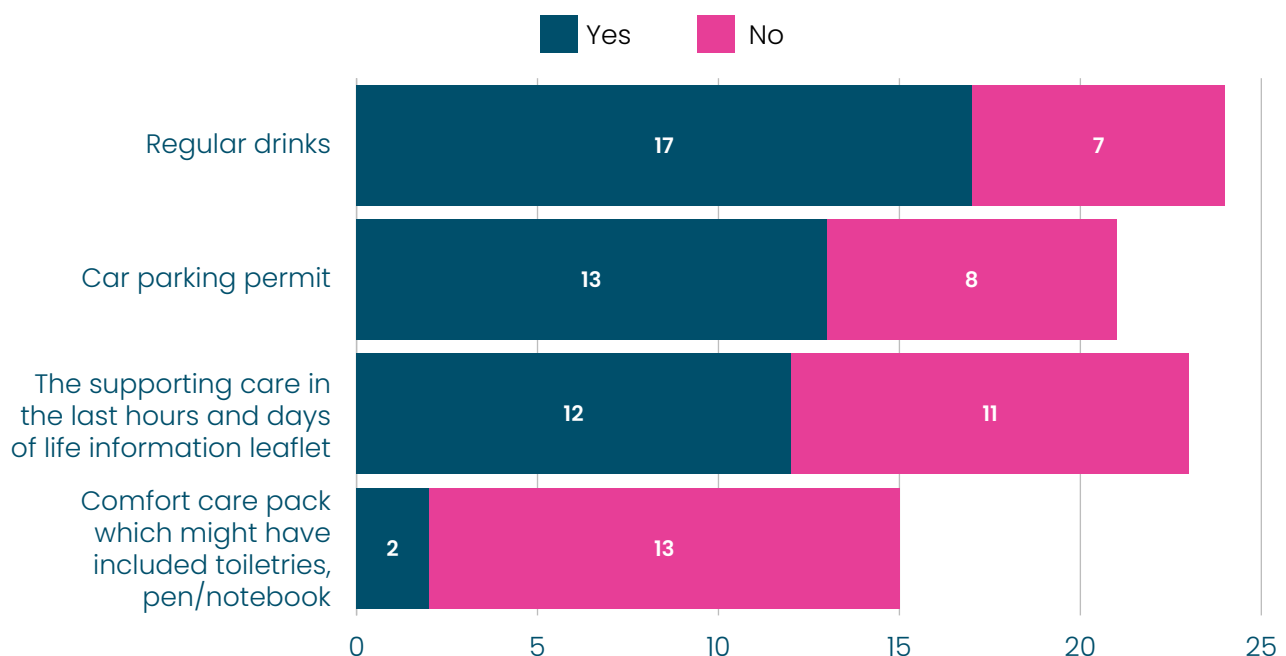
Most people told us they had been offered regular drinks (17 out of 24, 71%). Seven out of 24 people said they had not.

Just over half said they had been offered a car parking permit (13 out of 21, 62%) and over a quarter said they had not (8 out of 21, 38%).

12 people (52%) said they had received the 'Supporting Care in the Last Hours and Days of Life' information leaflet, but almost as many had not (11 out of 23, 48%).

13 people told us they were not sure if they had got a comfort care pack or that this hadn't been relevant to their circumstances. Of the remaining responses, two people said they had received a pack and 13 said they had not.

If your friend or relative died in hospital, please answer the following question. Please tell us if you were offered the following:



Information provision (specific to hospital)

We asked people if they received information specific to the hospital.

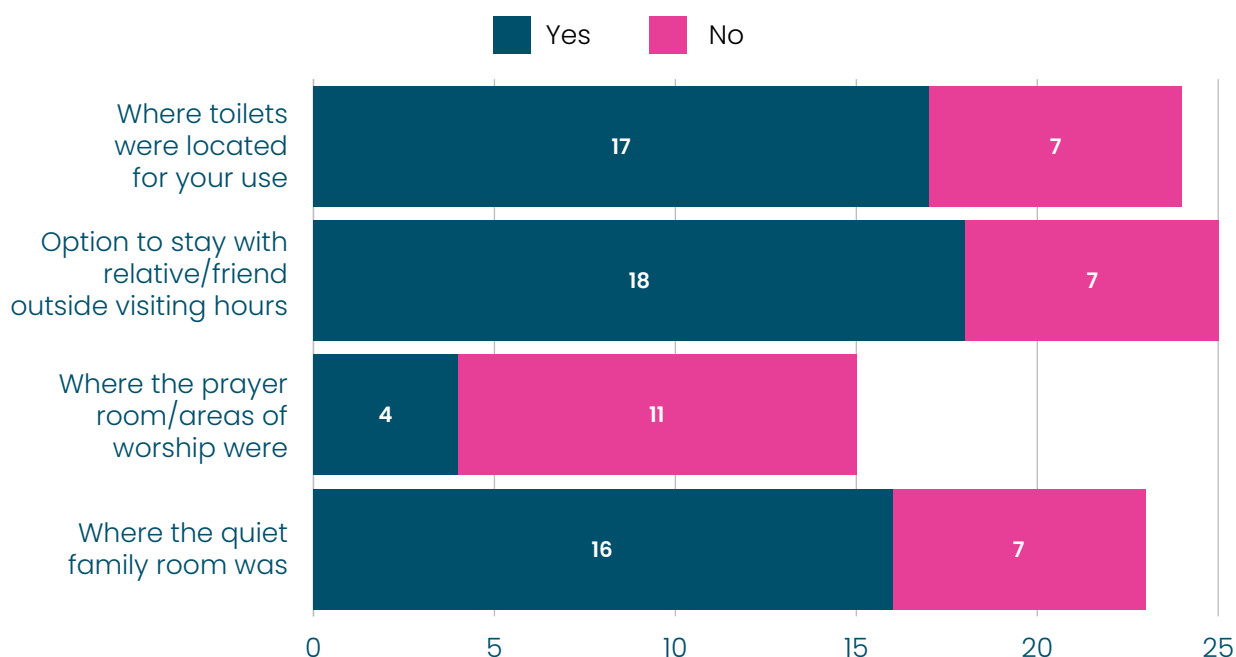
Most people told us they had been told where the toilets were (17 out of 24, 71%). Over a quarter said they hadn't (7 people).

Most people were given the option to stay with their relative or friend outside visiting hours (18 out of 25, 72%).

Most people were told where the family/quiet room was (16 out of 23, 70%). Seven people said they weren't (30%).

13 people told us they weren't sure whether they had been told where the prayer room or area of worship was or that this wasn't relevant to them. Of the remaining responses, four people were told and 11 were not.

Please tell us if you were offered information about the following:



Quality of experience

We asked people to comment on the quality of their experience. Ten people had a positive experience and commented on how the hospital had given their relative or friend privacy. A few examples are given below.



“We were advised by the Dr looking after my mum that it wasn’t ideal to move her on her final days although we wanted somewhere more private for the family to visit and say their goodbyes rather than on a ward with 3 other patients. The hospital staff found mum her own room where this was able to take place.”

“I would have preferred to move mum to a hospice, but she deteriorated very quickly. We were advised that this would be very stressful for mum and the staff kindly emptied a treatment room for us to enable mum to have some peace and offer us the privacy we needed in her last days.”

Five people who had a positive experience also shared comments about how the hospital was able to provide care that suited their relative or friend’s needs around the clock. A few examples are given below.



“He had constant care and pain relief that he would not have had elsewhere.”

“The hospital could give pain relief & other support as and when it was needed plus, given his condition he needed 24-hour support.”

Three out of the 28 respondents referred to dissatisfaction with repeated ward moves, in all three cases, their relative or friend had caught an infectious disease.



“My mum should have been in a home with her family and cat. Instead, she was bounced from ward to ward, infected with norovirus and didn’t get her dying wish to not be in hospital.”

One person also described how their relative’s discharge had been delayed, which resulted in them dying in hospital.

Any further comments i.e. what worked well and what could have worked better?

We asked the respondents to tell us anything else about their experience that they had not already mentioned.

13 of the positive comments related to the staff and their caring and conscientious approach. A few examples are given below:



"I wanted to thank all staff on [the ward] for their compassion, willingness to answer our questions and patience."

"Our family were looked after night and day, and nothing was too much trouble for the staff. Someone was able to stay with mum overnight so she was never left alone from going into A+E on the Sunday to passing the following Wednesday. She was treated with compassion, dignity, and respect as were the rest of the family. Her family have nothing but praise for the wonderful treatment she received during her final days."

13 people provided less positive comments.

Two comments were made about the inconsistency of information provided by staff regarding visiting hours and overnight stays for relatives and caregivers:



"Staying outside visiting hours seemed to depend on which staff were on the ward, I was never offered an option to stay overnight. On the morning my husband died I was in a taxi on the way to the hospital when I received a telephone call, the caller failed to tell me he had already passed away. I feel very angry that I was not there for him at the end and wonder if this could have been avoided. I had made staff aware of my circumstances and the distance involved between home and hospital. If I'd been contacted sooner, I would have been there."

Three comments were made regarding the concern of standards of care being unsatisfactory causing anxiety. Some areas include: appropriate nutrition, adequate monitoring, toileting needs and poor infection control:



“In my mum’s final days before we were told we could be there 24/7, no one helped her eat, boiling hot drinks were left and mum had chronic arthritis in her hands meaning she couldn’t feel heat and couldn’t hold a cup. Food appropriate to her condition was not offered, someone who has fluid on the lungs and is struggling to swallow doesn’t want fish and chips, but no alternatives were available.”

Four individuals provided feedback regarding the insufficient timely responses to promote effective coordination of care, especially during the transfer of patients between different services. It is also apparent that there is a requirement for improved communication. Here are a few instances:

“I felt the palliative care team at the hospital could have acted sooner to move my wife to the hospice. I was not aware until I phoned the hospice that while my wife was in hospital, she was no longer under the care of the palliative care team at the hospital.”

“My relative was fast tracked from hospital and they and their family weren’t referred to the palliative care whilst my mum was in hospital. Even after a social worker had requested a few times for this. The hospital didn’t put in place the community palliative care team as they said they would for my relative to help with medications, etc. when they left hospital, when they were close to dying and had a syringe driver.”

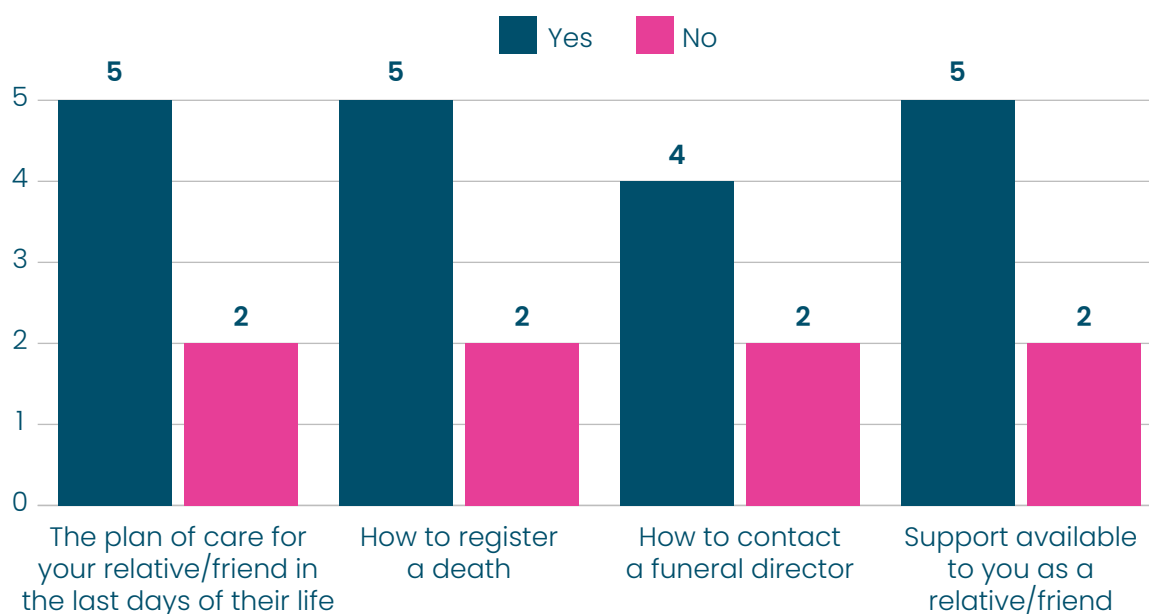
People who died at home

About our respondents

Nine people told us about the experience of a relative or friend who had died at home. When evaluating the provided data, it is essential to acknowledge that the response rate obtained is comparatively low in relation to other services, especially during a period when an increasing number of patients are opting for end-of-life care at home.

Practical support and information

Please tell us if you were offered information about the following:



Most people were told about:

- The plan of care for their relative or friend in the last days of their life (5 out of 7)
- How to register a death (5 out of 7)
- The support available to them (5 out of 7)
- Just over half (4 out of 6) were told how to contact a funeral director

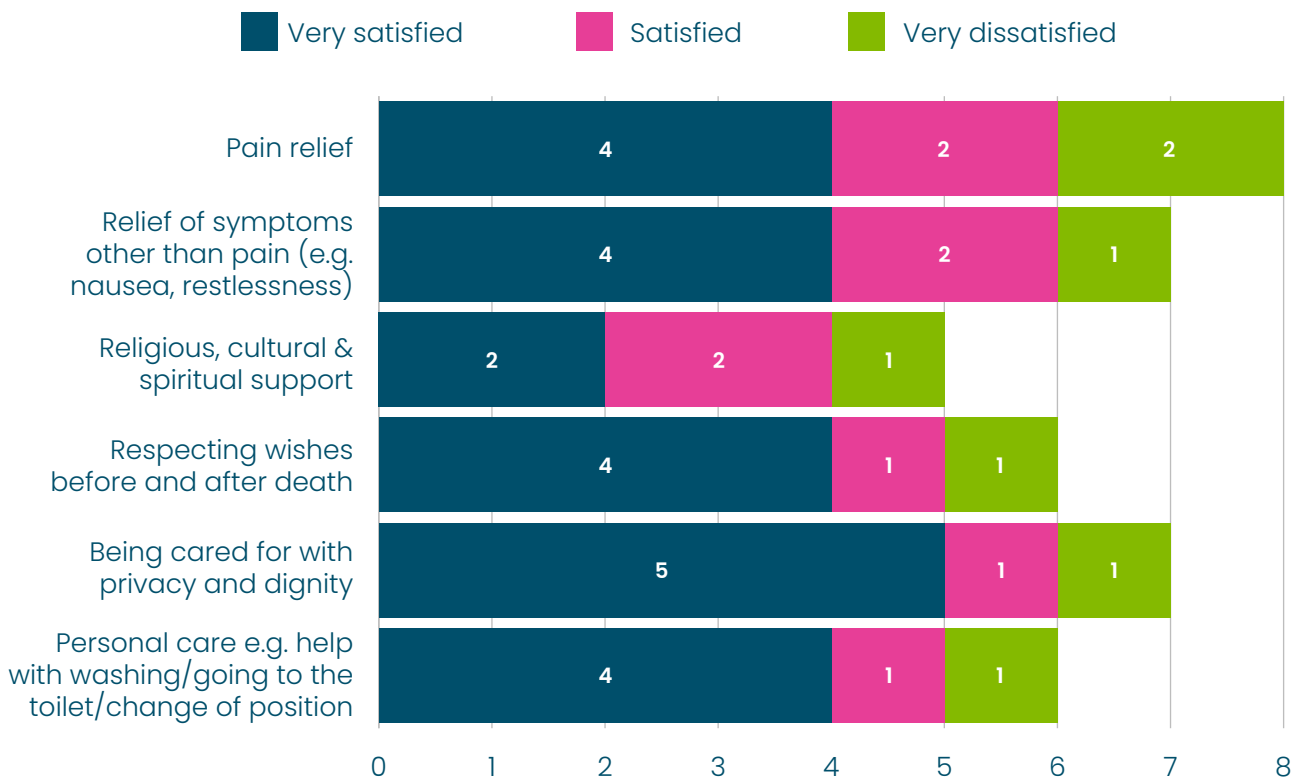
Specific aspects of care

Most people were satisfied or very satisfied with the following:

- Pain relief (6 out of 8)
- Relief of symptoms other than pain (6 out of 7)
- Respecting wishes before and after death (5 out of 6)
- Being cared for with privacy and dignity (6 out of 7)
- Personal care (5 out of 6)

Four out of five people were satisfied or very satisfied with the religious, cultural, and spiritual support offered. Three people said this wasn't relevant to their relative or friend, and one wasn't sure. One person was very dissatisfied.

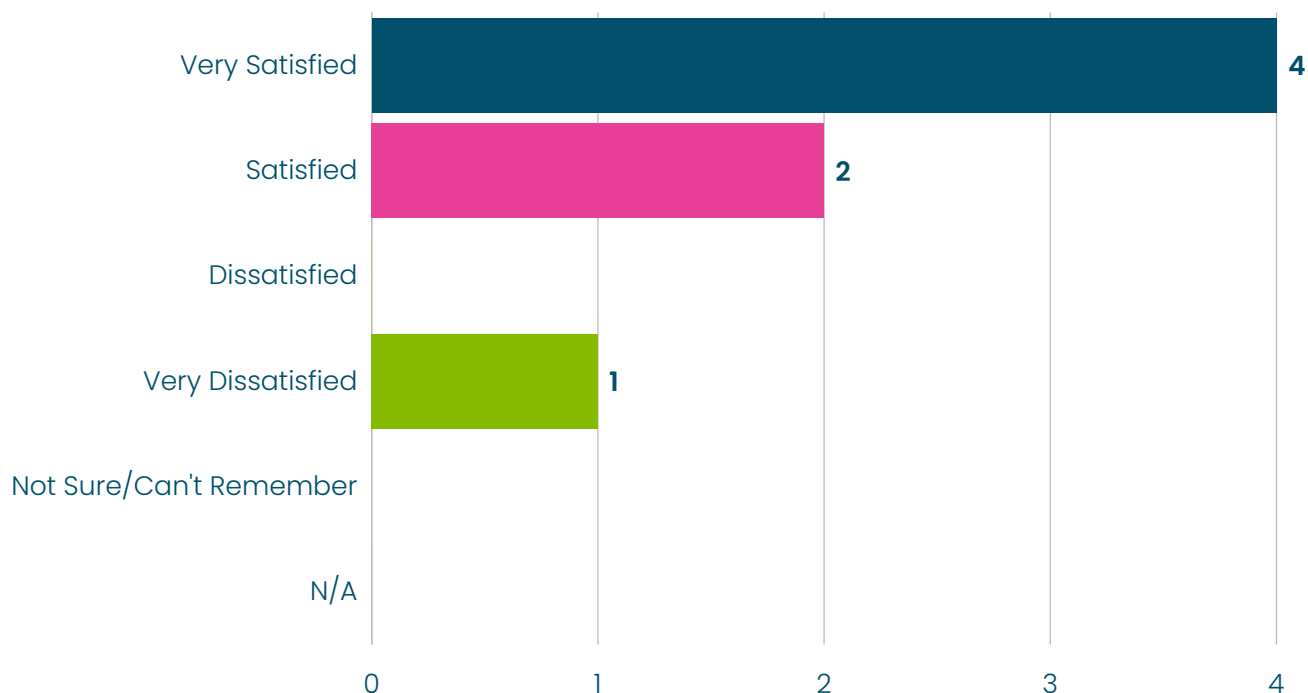
How satisfied were you with the care given to your relative or friend in each of the following areas?



Services working together

Most people (6 out of 7) were satisfied or very satisfied with the way services had worked together.

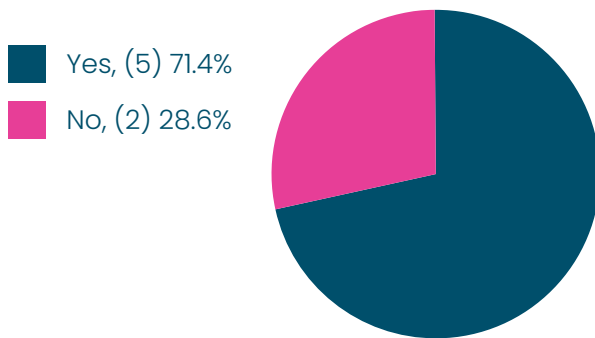
In the last few months of your friend/relative's life, how satisfied were you with the way services worked together? (E.g. GP, Community, Nurse, Homecare, Hospital, Hospice)



Discussing wishes and being involved

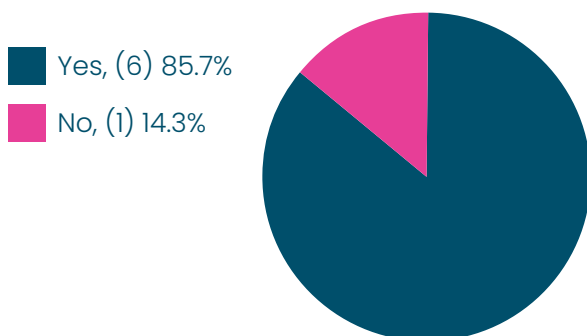
Five people out of seven said that they or their relative or friend had had the opportunity to discuss their wishes about care.

In the last few months of your friend/relative's life, did they (or you) have the opportunity to discuss their wishes about care and treatment with staff providing their care?



Six out of seven people said that the service had involved them in their relative or friend's care as much as they both wanted.

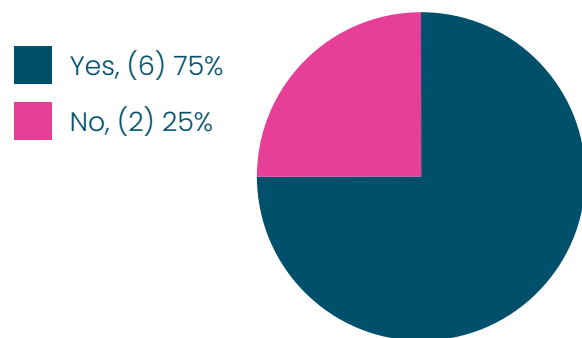
Did the service caring for your relative or friend involve you in their care as much as you both wanted?



Contacting services for advice and support

Most people (6 out of 8) said they were offered information about how to contact services for advice and support in the last days and weeks of their relative or friend's life.

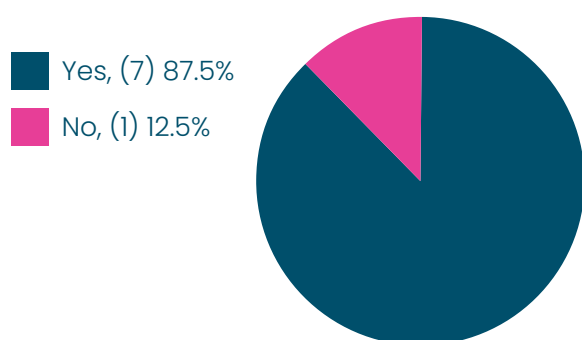
If your friend or relative died at home – please answer the following question. Were you offered information on how to contact services for advice and support in the last days and weeks of your relative/friend's life?



Dying in the right place

Most people felt that their relative or friend had died in the right place.

Do you feel that your relative or friend died in the right place?



Any further comments, what worked well and what could have worked better?

A few respondents left comments about their experience of what worked well and what could have worked better.

One respondent shared the following about their positive experience of a relative or friend dying at home:



“Mum had wanted to stay at home to die. She was fully supported in this decision and support to allow her to do so was provided.”

Two less positive comments included information about inadequate pain relief and how distraught this made loved ones feel:

“Patient had been in remission following cancer treatment. Didn’t get follow up checks because of the “pandemic”, when patient finally got to see a GP about the downturn in condition, it was too late. Told that palliative care nurses would address medication for pain. Palliative care nurse arrived at our home, late, on a Friday and didn’t

have any pain relief. Returned on the following Tuesday, after 3 days of agony and death on Tuesday night.”

“All his wishes were carried out. Our problem was when we tried to contact district nurses via the hub with regard to pain management. Calls were not answered for an extensive length of time; and on one occasion when in severe pain had to wait over 3 hours for someone to actually arrive to administer pain relief. This was the day before he passed away. Causing the family to be distraught over their inability to comfort him.”

One person highlighted that they were not offered information on how to contact services for advice and support in the last days/weeks of their relative's life.

The survey asked the respondents to tell us anything else about their experience that they had not already told us about.

Three comments praised how friendly, supportive practitioners make all the difference when contending with end-of-life care.

“

“The Dr from wife's GP Surgery was absolutely brilliant. She got my wife admitted to hospital really quickly when we didn't know what was going on, this was prior to my wife going into St Gemma's Hospice. Due to the Dr's brilliant care with my wife, I have now changed my GP practice to my late wife's former GP Surgery.”

“Everyone who visited was respectful, professional but also friendly and supportive.”

“The service we received was excellent. It was a personal touch like we [were] with friends.”

One comment fed back the following area of distress:

“

“GP didn't seem to know that he needed to identify my husband's body in the funeral home, and the surgery said they didn't have my contact number – which wasn't true, thus delaying the registration process and causing additional stress.”

People who died in care homes

About our respondents

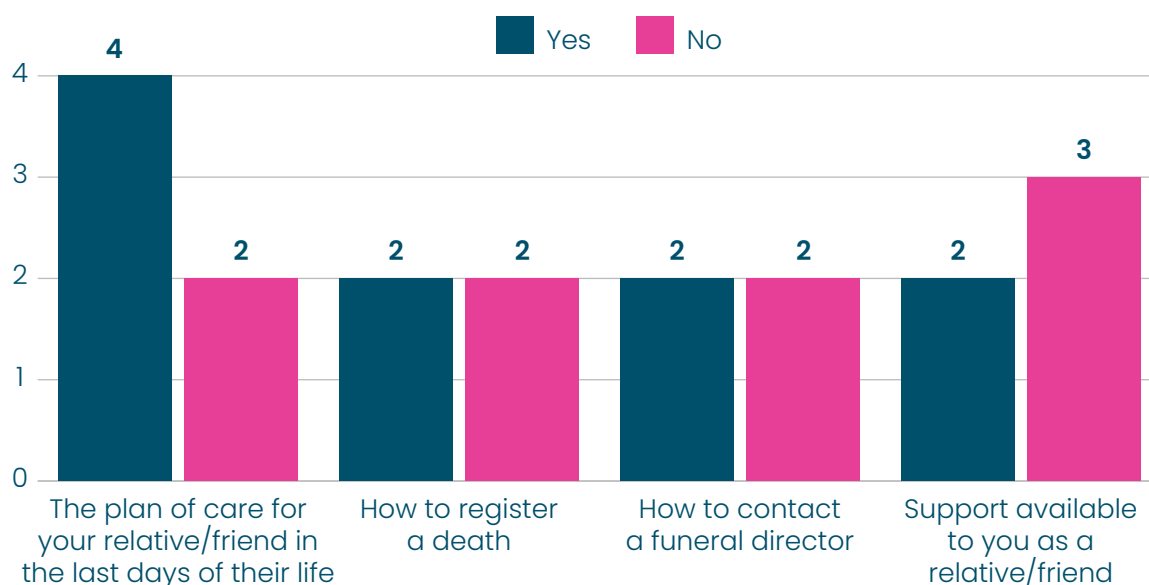
Six people whose friend/relative died in a care home responded to our survey. It is important to acknowledge that we have received a lower response rate for this particular service compared to others. Therefore, we should exercise caution when interpreting the findings, as they may not accurately reflect the views of the majority of the population.

The survey asked the name of the GP practice the person receiving end-of-life care was registered to; all respondents skipped this question.

Practical support and information

During the survey, we enquired about the information that the participants received from the service. The findings showed that 60% of respondents were provided with details concerning the plan of care for their loved ones during the final days of their lives (4). However, there was an equal distribution of respondents who were either informed or not informed about the process of registering a death and how to get in touch with a funeral director (2:2). It is worth noting that a limited number of participants reported being informed about the available support for them as a relative or friend (3).

Please tell us if you were offered information about the following:



Specific aspects of care

We asked respondents about how satisfied they were with specific aspects of their friend/relative's care. The majority of responses were satisfied or very satisfied. There was a slight increase in reports of dissatisfaction regarding pain relief.

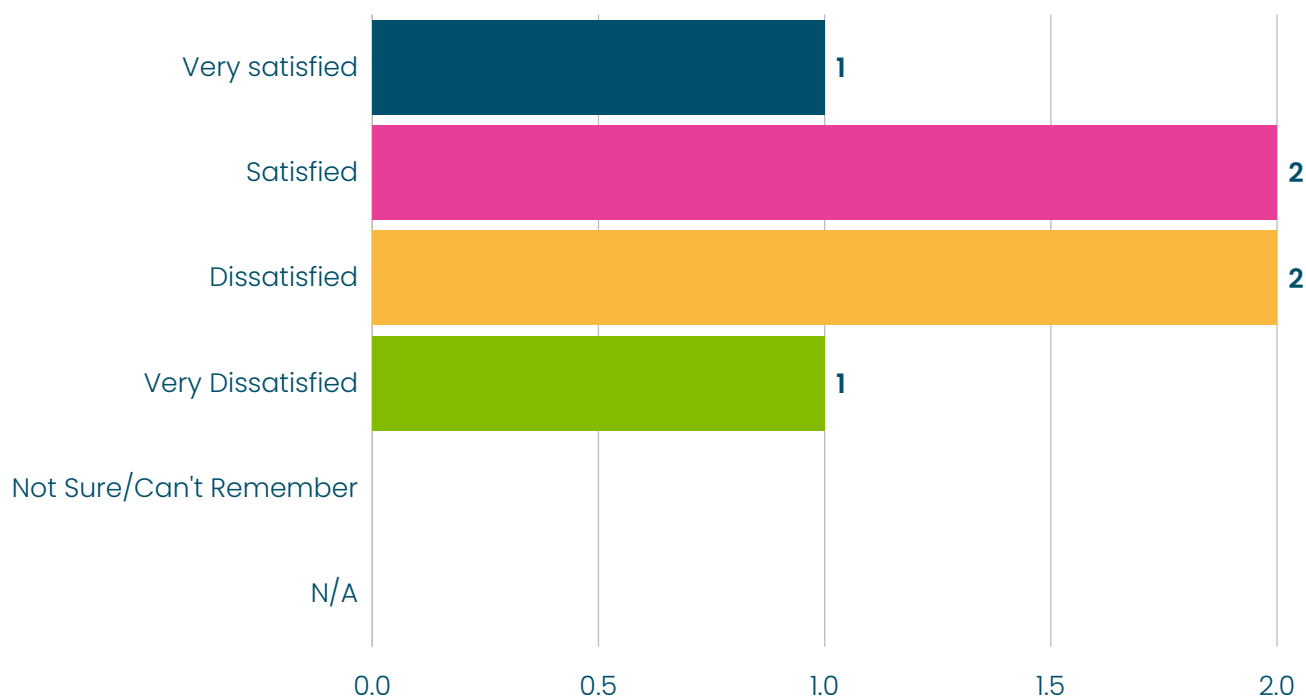
How satisfied were you with the care given to your relative or friend in each of the following areas?



Services working together

There was an equal ratio of respondents who were satisfied (2) and dissatisfied (2) with how services worked together within the last few months of their loved ones' life. Equally this same principle applied for those who were very satisfied (1) and very dissatisfied (1).

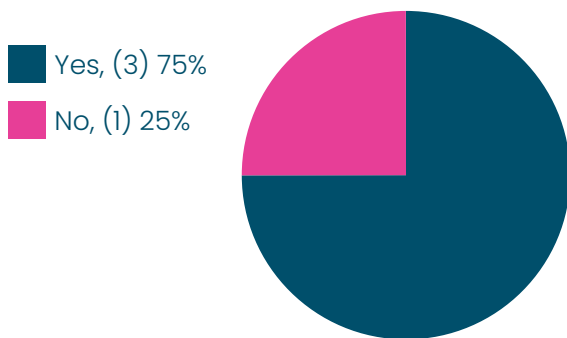
In the last few months of your friend/relative's life, how satisfied were you with the way services worked together? (E.g. GP, Community, Nurse, Homecare, Hospital, Hospice)



Discussing wishes and being involved

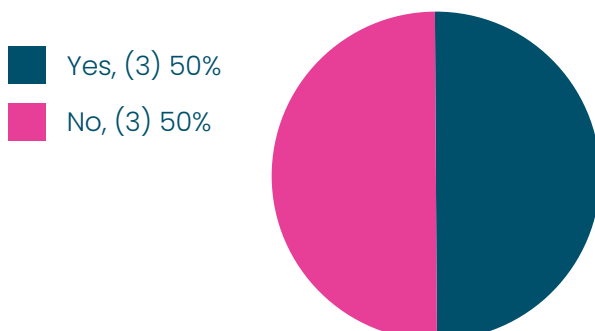
Half the respondents (3) had the opportunity to discuss their wishes about care and treatment with staff providing their friend/relative's care.

In the last few months of your friend/relative's life, did they (or you) have the opportunity to discuss their wishes about care and treatment with staff providing their care?



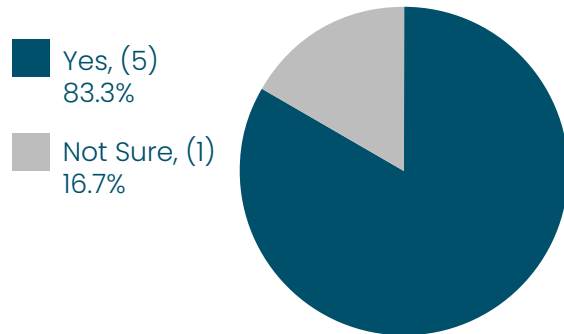
There was a 50% split between those surveyed reporting that they or someone they know has or has not had the chance to talk about their loved one's preferred care and treatment during the final months and weeks of their life.

Did the service caring for your relative or friend involve you in their care as much as you both wanted?



Dying in the right place

Do you feel that your relative or friend died in the right place?



Among the five responses received, four individuals stated that they held the belief that their friend or relative died in an appropriate location.

“

“I could no longer cope with him at home.”

“She was in a familiar place with people that she knew.”

“Derek was transferred to a local care home one week before he died after spending 7 weeks in hospital. Very happy that he died in a nice environment.”

“My husband was cared for in the nursing home as if he was a member of one of the staff member’s family. They were caring and called GPs whenever necessary and called me with information relating to his care whenever needed. It was a peaceful end, and the staff were excellent, telling me what to expect and when.”

Any further comments, what worked well and what could have worked better?

We asked respondents to feedback on any further comments, including areas that worked or did not work so well.

One person highlighted just how well the coordination of care was, crediting how this was ‘second to none’ in comparison to their ability to look after their loved one within their final few days:



“I do not feel the care at home would have been anywhere near as well organised or coordinated. Having experienced care at a nursing home for my husband I can say that home care for end of life would fall short in so many ways.”

Two individuals provided feedback regarding the challenging situations they encountered while their friend or relative was residing in a care home. The crucial aspect that emerged from their comments was the necessity for efficient care coordination and adequate support. These factors are essential to minimise the discomfort experienced by the relative and provide reassurance to their family and friends during this challenging period.



“Despite being on end-of-life pathway my Mum was not prescribed morphine so when she became very uncomfortable, we spent well over half an hour on the phone trying to get this sorted which we did not manage to do. It felt such a sad thing though fortunately my brother and sister were there too she was not left alone.”

The following comment highlights the impact of care needs that were not met within a care home. The impact of insensitivity of staff members and lack of communication are further detailed:



“The nurse in the nursing home didn’t know how to use the syringe driver and was informed by the hospital during the start of hours that no one was available to help or refer my relative to the community palliative team until 9am the next day. The nurse was going to leave it till the next day to do anything and not ensure my relative had the care in place that they needed. I needed to do this myself. Some of the nursing home staff were very insensitive at this very sensitive time for my relative and their family. Throughout the time my relative stayed in this expensive and rated nursing home, the communication was really poor, they didn’t keep us up to date with how our relative was, didn’t answer emails, phone calls, inform us of the medical issues/visits. There’s other things, all of which had a huge impact on my relative and myself. So distressing, exhausting, stressful, to say the least.”

Recommendations

Here is a summary of the suggestions made, as outlined in the findings of this report. These recommendations will serve as the foundation for an action plan, which will be made accessible to the public and can be accessed via the following webpage: <https://www.leedspalliativecare.org.uk/professionals/resources/lpcn-documents/>

Across the city, it is vital to share the positive feedback we have received regarding the care and compassion demonstrated by staff across all services towards patients and their caregivers. It is vital to communicate this feedback to all staff involved in the services explored within this report to emphasise the importance of recognising early end-of-life care needs and maintaining continuity of care and support, especially during the final weeks of life.

Effective coordination of care among various healthcare providers is crucial for providing a smooth experience for patients, families, and caregivers. All services need to work together to ensure there is efficient coordination leading up to a person’s end-of-life journey, even in cases where the initial plan may not have been successful.

Hospices

- Express gratitude towards all staff for their sincere kindness and compassion which is consistently demonstrated towards the families/friends in which they serve.
- Continue with a person-centred approach and the positive atmosphere that has been created within the hospices.
- Ensure signposting and information provision are being relayed upon admission.

- Embed TALK campaign across clinical areas to ensure the communication needs for dying patients and their families are met in a compassionate way.
- Continue to raise the importance of aiming to minimise ward moves for patients at the end of life. Ensure any moves are communicated sensitively to patients and families.
- Ensure the results of this survey are reported through the Trust's end-of-life care governance structures.

Hospitals

- Refresh awareness for all staff regarding the importance of utilising the SUPPORT Campaign for families/friends. This campaign is aimed at providing assistance and support to the families of patients who are nearing the end of their lives. This comprehensive initiative encompasses providing information about various provisions such as car parking permits, comforting care packs, access to toilet and shower facilities and designated family/prayer rooms. It also incorporates the importance of ensuring families receive regular updates and information regarding the provided care and visiting hours outside of regular working hours.

At home

- Priority should continue to be given to enhancing communication regarding care plans, ensuring that all individuals involved are informed about the available support, what to expect, and how medications can help manage common symptoms at the end of life.
- Continue education programmes for community staff to ensure all are trained and competent with the end-of-life care processes and procedures.
- Promote the available information regarding post-death care, ensuring that individuals are well-informed about the necessary procedures and steps to take after the passing of a loved one.

- Share this report with Neighbourhood Services to highlight the impact of waiting times and the importance of communication with family members when there is a delay in visits at the end of life.

Care homes

It is recommended that the findings be shared through city-wide forums and that services collaborate with care homes to gain insight into people's experiences and identify opportunities for improvement in the following areas:

- Effective communication with families regarding their loved one's wishes, and how these wishes can be supported.
- Information about the available support for family and carers.
- Encouraging family involvement in their loved one's care.

Next Steps

The report will be shared with Leeds Palliative Care Network and by each individual organisation locally through their clinical governance and quality assurance structures. The report will be made publicly available through Healthwatch Leeds and the Leeds Palliative Care Network website. All providers will collaborate to determine the necessary actions in response to the recommendations from this report. We will work together to monitor progress and plan ongoing surveys for bereaved carers, with the objective of addressing accessibility and low response rates from marginalised communities. A review will be conducted to assess the content and future distribution of the survey, prioritising the assessment of issues deemed important to the families of dying patients.

Acknowledgement

We would like to express our sincere gratitude to all the relatives and friends who graciously participated in this survey and took the time to provide their valuable feedback, particularly during a challenging period for them. Your input plays a crucial role in guiding the development of our services and ensuring that any concerns are promptly resolved as they arise.

Appendices

Appendix 1: Relief of pain & other symptoms

In total, 96 people responded to the question about relief of pain and 98 responded to the question about management of other symptoms.

The breakdown of their responses is as below:

Place of Death	Pain	%	Symptoms	%
Hospice	56/57	98%	57/60	95%
LTHT	21/26	81%	19/26	73%
Home	6/8	75%	6/7	86%
Care home	2/5	40%	3/5	60%
Total	85/96	88%	85/98	87%

Appendix 2: Standard Operating Procedures of the Bereaved Carers Survey Project



Leeds Bereaved Carers Survey Quarter 4 2022-2023 Standard Operating Procedures (SOP)

1. Title

Leeds Bereaved Carers Survey – Year 6.

2. Purpose

To measure the quality of the care we delivered to patients who have died within Leeds. We are undertaking a city-wide survey of bereaved carers of adults who died between **1st February 2023 and 30th April 2023**. The focus of the survey is the care of patients in the last days of their lives.

The survey has been developed by stakeholders from Leeds Palliative Care Network (LPCN) with the involvement of Healthwatch and St Gemma's Academic Unit for Palliative Care (AUPC) to measure the care delivered to patients and their families in the following care settings: Leeds Teaching Hospital Trust (LTHT), St Gemma's Hospice, Wheatfields Hospice, Primary Care including Leeds Community Healthcare NHS Trust (LCHT), Care Homes and The Mount Leeds (LYPFT).

The Survey will be agreed by the working group and signed off by the LPCN executive group.

3. Roles and Responsibilities

Leeds Palliative Care Network Lead: Gill Pottinger

Leeds Palliative Care Network Manager: Diane Boyne

City-wide Survey Leads: Helen Syme, Claire Iwaniszak & Elizabeth Rees

Leeds Teaching Hospitals NHS Trust:

Management Lead: Elizabeth Rees Lead Nurse for Palliative and EoLC

Project Lead: Helen Syme Bereavement Nurse & Claire Iwaniszak Nurse Specialist EoLC

St Gemma's Hospice:

Hospice Lead: Clare Russell

Wheatfields Hospice:

Hospice Lead: Natalie Sanderson

Primary Care:

Primary Care Leads: Dr Gill Pottinger Clinical Lead for EOL Leeds CCG, Lisa Kundi
Primary Care Commissioning Manager.

LCHT Leads: Sarah McDermott Clinical Service Manager

LYPFT Project Lead: Catherine Burns

Carers Leeds Representative: Sian Cartwright

Healthwatch Leeds:

Management Lead: Stuart Morrison

Project Lead: Rameesah Ahmed

4. Distribution of survey

- I. Leeds Register Office will offer paper copy of survey and freepost envelope to Informant (person registering the death).
- II. Survey will contain link to online survey and information about how to complete via post or telephone by contacting Healthwatch Leeds.
- III. The Leeds Hospices will also prompt completion by sending a letter to their service users.
- IV. LTHT will add flyers to condolence cards sent within this time period.
- V. LCHT will give flyer at bereavement follow up visit.

5. General procedure Leeds

- I. Completed surveys to be submitted via post, completed over the phone or online to Healthwatch Leeds.
- II. To run survey for three months for adult deaths that occur between 01/02/23 and 30/04/23.
- III. Healthwatch will highlight any significant concerns raised to the project lead(s) for each organisation within one week of receipt. Details on how to raise a complaint or concern are included in the survey.
- IV. Survey analysis will be undertaken by Healthwatch.
- V. Healthwatch Leeds will assist stakeholders in developing a report for Leeds Palliative Care Network which will be published on both websites by the end of 2023.

6. Accessibility of survey

To include in the report measures and reasonable adjustments taken to ensure the report is as accessible as possible. These include options to complete the survey over the phone, with an interpreter and measures to publicise the survey more widely.

7. Data Collection

Responses will be sent to Healthwatch. Data collection will close 30th June 2023.

In order to calculate a response rate: at the end of the survey period, Leeds Registrar Office will inform the group of the number of deaths within Leeds, organisations to provide own data for survey period.

8. Data Analysis

Healthwatch will provide quantitative and qualitative analysis of the survey.

A template will be used to produce a report, to include information about accessibility of report and SOP.

9. Storing of Data

Surveys are anonymous, no personal details are taken therefore no identifiable information is recorded or stored. If assistance is requested from Healthwatch with completing the survey, any details taken would be destroyed once used for that purpose.

10. Communication Plan

LPCN communication team to email partners and key contacts to encourage eligible people to complete survey. Healthwatch to share information with 3rd sector organisations through email, conversation and attending meetings. Group members to publicise survey within their own organisations.

Appendix 3: The Survey

The following wording was used to introduce each version of the survey, a copy of the survey then follows.

On behalf of the Leeds Palliative Care Network, we would like to extend our sincere condolences to you and your family at this time.

We would appreciate it if you feel able to complete this short survey (5 – 10 minutes) about your experience of the care you and your relative received at the end of their life. This survey is open to people whose relative or friend died between February and April 2023 in Leeds.

Any information we receive will be used anonymously to improve care across Leeds. Results of the survey will be available towards the end of 2023 on the Leeds Palliative Care Network website and the Healthwatch Leeds website.

Please complete the survey by the end of June 2023.

If you would prefer to answer the questions by telephone or need further assistance to complete the survey please contact Healthwatch Leeds on 0113 898 0035 or email at info@healthwatchleeds.co.uk

(For copy of the survey, please see next page).



Leeds Palliative
Care Network

Your
healthwatch
Leeds

The Old Fire Station
Gipton Approach

Leeds
LS9 6NL

0113 898 0035

info@healthwatchleeds.co.uk

<https://healthwatchleeds.co.uk>

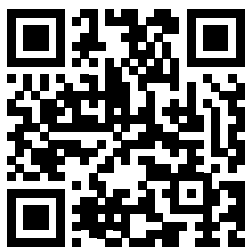
On behalf of the Leeds Palliative Care Network, we would like to extend our sincere condolences to you and your family at this time.

We are committed to improving the experiences of people at end of life and their friends and family. To do this it is really important to hear the views of people who used our end-of-life services.

We would appreciate it if you feel able to complete this short survey (5-10 minutes) about your experience of the care you and your relative received at the end of their life. This survey is open to people whose relative or friend died between February and April 2023 in Leeds.

Any information we receive will be used anonymously to improve care across Leeds. Results of the survey will be available toward the end of 2023 on the Leeds Palliative Care Network website and the Healthwatch Leeds website. Please complete the survey by the end of June 2023.

If you would prefer to answer the questions by telephone or need further assistance to complete the survey please contact Healthwatch Leeds on 0113 898 0035 or email at info@healthwatchleeds.co.uk or text 07717 309 843.



The survey can also be completed online by scanning the QR code or at the following link:

<https://www.surveymonkey.co.uk/r/Carers2023>

Where possible please complete the survey online.

Leeds Palliative Care Network Bereaved Carers Survey

1a. Where did your relative or friend die? (Please tick)

- ☐ St Gemma's Hospice
- ☐ Wheatfields Hospice
- ☐ Home
- ☐ Care Home
- ☐ The Mount
- ☐ Leeds General Infirmary
- ☐ St James' University Hospital
- ☐ Other hospital (Please specify)

1b. If your relative or friend died in hospital, please tell us which ward your relative or friend was cared for in, if you know it for example J30 or L2 (Please write your answer in the box below).

2. In the last few months of your relative or friend's life, did they (or you) have the opportunity to discuss their wishes about care and treatment with staff providing their care?

- ☐ Yes
- ☐ No
- ☐ Not sure/Can't remember
- ☐ N/A

3. In the last few months of your relative or friend's life, how satisfied were you with the way health and care services worked together? (E.g. GP, Community Nurse, Homecare, Hospital and Hospice)

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Dissatisfied
- ☐ Very Dissatisfied
- ☐ Not sure/Can't remember
- ☐ N/A

4. Did the service caring for your relative or friend involve you in their care as much as you both wanted?

- ☐ Yes
- ☐ No
- ☐ Not sure/Can't remember
- ☐ N/A

5. Please tell us if you were offered information about the following: (Please tick one box per row)

Offered information	Yes	No	Not sure	N/A
The plan for care for your relative/ friend in the last days of their life	☐	☐	☐	☐
How to register a death	☐	☐	☐	☐
How to contact a funeral director	☐	☐	☐	☐
Support available to you as a relative or friend	☐	☐	☐	☐

6. How satisfied were you with the care given to your relative or friend in each of the following areas? (Please tick one box per row)

Areas of care	Very satisfied	Satisfied	Dissatisfied	Very dissatisfied	Not sure/ can't remember	N/A
Pain relief	☐	☐	☐	☐	☐	☐
Relief of symptoms other than pain (e.g. nausea, restlessness)	☐	☐	☐	☐	☐	☐
Religious, cultural, and spiritual support	☐	☐	☐	☐	☐	☐
Respecting wishes before and after death	☐	☐	☐	☐	☐	☐
Being cared for with privacy and dignity	☐	☐	☐	☐	☐	☐
Personal care e.g. help with washing/going to the toilet/change of position	☐	☐	☐	☐	☐	☐

7a. Do you feel that your relative or friend died in the right place?

- ☐ Yes
- ☐ No
- ☐ Not sure

7b. Please use the comment box below to tell us why you feel this way.

8. If your relative or friend died at home – please answer the following two questions. Please skip to the next question if your relative or friend died somewhere else.

1. Please tell us their GP practice (please state in the box below).

2. Were you offered information on how to contact services for advice and support in the last days and weeks of your relative/friend's life?

- ☐ Yes
☐ No
☐ Not sure/can't remember
☐ N/A

9. If your relative or friend died in hospital – please answer the following two questions. Please skip to the next question if your relative or friend died somewhere else.

1. Please tell us if you were offered any of the following:

	Yes	No	Not sure/ can't remember	N/A
Regular drinks	☐	☐	☐	☐
Car parking permit	☐	☐	☐	☐
The supporting care in the last hours and days of life information leaflet	☐	☐	☐	☐
Comfort care pack which might have included toiletries, pen/notebook	☐	☐	☐	☐

2. Please tell us if you were offered information about the following:

	Yes	No	Not sure	N/A
Where toilets were located for your use	☐	☐	☐	☐
Option to stay with relative/friend outside of visiting hours	☐	☐	☐	☐
Where the prayer room/areas of worship were	☐	☐	☐	☐
Where the quiet/family room was	☐	☐	☐	☐

10. Please use the space below to tell us anything else about your experience that you have not already told us about:

Equality monitoring form (optional)

Please complete this section with your relative/friend's information. By filling in this equality monitoring section you will help us ensure that we get feedback from all our communities. Filling in this section is optional.

What was your relative/friend's gender?

- ☐ Male
- ☐ Female
- ☐ Not sure
- ☐ Other (please state in the box)

What was your relative/friend's age when they died?

- ☐ 18 – 25
- ☐ 26 – 49
- ☐ 50 – 64
- ☐ 65 – 84
- ☐ 85+
- ☐ Not sure

What was your relative/friend's religion?

- ☐ Buddhist
- ☐ Christian
- ☐ Hindu
- ☐ Jewish
- ☐ Muslim
- ☐ Sikh
- ☐ No religion
- ☐ Not sure
- ☐ Other (please state in the box)

Please could you indicate which ethnic group in your opinion they belonged to:

- ☐ White British
- ☐ White Irish
- ☐ Gypsy or Traveller
- ☐ Other White
- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Other Mixed
- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Other Asian
- ☐ Black African
- ☐ Black Caribbean
- ☐ Other Black
- ☐ Arab
- ☐ Not sure

If any other ethnic background, please state in the box below:

Thank you for taking part in this survey.

If you want to raise a concern or complaint, please contact the organisation directly or you can contact Healthwatch Leeds on 0113 898 0035 or email:

info@healthwatchleeds.co.uk

If you'd like to receive a copy of this report when it's completed, please sign up to the city-wide network. To do this, go to the following webpage: **[www.](http://www.healthandcareleeds.org/have-your-say/shape-the-future/join-our-network/)**

[healthandcareleeds.org/have-your-say/shape-the-future/join-our-network/](http://www.healthandcareleeds.org/have-your-say/shape-the-future/join-our-network/)

Or contact Healthwatch Leeds by calling 0113 898 0035, email

info@healthwatchleeds.co.uk or text 07717 309 843.



**Committed
to quality**

We were awarded a committed to quality marque from Healthwatch England. To obtain this we did an in depth audit which will be reviewed.

Your **healthwatch** Leeds

Healthwatch Leeds
Community Interest Company 9542077
Ground Floor
The Old Fire Station
Gipton Approach
Leeds
LS9 6NL

www.healthwatchleeds.co.uk

Call: 0113 898 0035

Email: info@healthwatchleeds.co.uk

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