



Dying in Kirklees — What matters

Healthwatch Kirklees
End of Life Care report 2023

healthwatch
Kirklees

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If you require this report in another format, please contact Healthwatch Kirklees on 01924 450379 or email: info@healthwatchkirklees.co.uk

Acknowledgements

We'd like to thank every person who has shared their experience with us. We feel privileged to have heard so much detailed, personal feedback (both positive and negative) around End of Life Care (EOLC) and bereavement. We recognise that these can be difficult subjects to discuss and will do our best to represent all the views and themes we've heard to those who have the power to make changes and improvements where needed.

Thank you

From everyone at Healthwatch Kirklees and The Kirklees Palliative Care Partnership

About Healthwatch Kirklees

[Healthwatch Kirklees](#) is your local health and social care champion. We make sure NHS leaders and other decision-makers hear your voice and use your feedback to improve care. We can use your feedback to improve services for everyone, and we have the power to make NHS leaders and other care providers listen to what you have to say. We're entirely independent and impartial and anything you say is confidential.



About The Kirklees Palliative Care Partnership

[The Kirklees Palliative Care Partnership \(KPCP\)](#) is a collective of different organisations in Kirklees that all support people with a life-limiting condition. The Partnership does not directly provide care but works to improve services offered to patients and families.

Note: The KPCP will not exist after Sept 23 and will instead be the 'Dying Well Board'. The Board will be committed to learning from people's experiences and improving services and support for people in Kirklees.

**Kirklees
Palliative Care
Partnership**

Summary

In Kirklees, over 3,800 people die yearly as mentioned in the [Kirklees Joint Strategic Assessment](#).

For three-quarters of these people, death does not come suddenly. Instead, dying is a process that can take years, involving a progressive decline in functioning and frequent interactions with health and social care professionals. This means that there are earlier opportunities in people's journeys to plan for their future care, supported by health and social care professionals.

EOLC can encompass the entirety of a person's journey, from a diagnosis of a life-limiting condition, to its progression, deterioration, care in the last year and care in the last days of life.

The Kirklees Palliative Care Partnership identified a lack of feedback across (EOLC). Healthwatch Kirklees was asked to engage between 1 March 2023 and 28 April 2023 with people who had been bereaved in Kirklees over the last 12-24 months, to gather their feedback on various aspects of care and support throughout their relative's or friend's end-of-life journey. The engagement occurred with those whose friend or relative died suddenly or unexpectedly as well as where the death was expected.

Key findings

Expected or planned for deaths

THE OVERALL QUALITY OF CARE

RATED AS 63/100*

- 89% said that staff were compassionate and showed empathy 'always' or 'most of the time.'
- Just 59% understood the plan for how their friend or relative would be cared for.
- 70% of people had a choice about where they wanted to be cared for at the end of their life and 86% of people died in a place of their choosing.
- People whose friend or relative died at home often reported being left unsupported and experienced delays in administering pain-relieving medication.

The Kirkwood was the most highly rated service for the care given to the person receiving EOLC and their relative or friend.

*ALT text The overall quality of care rated as 60/100 where 0 is poor and 100 is excellent

Key findings

Sudden or unexpected deaths

THE OVERALL QUALITY OF CARE RATED AS 60/100*

- 77% of people said that staff were compassionate and showed empathy 'always' or 'most of the time.'
- 72% of people understood the information given to them at the time their relative or friend was dying or had died. People appreciated being given facts and information in a timely way and in a way they could understand.
- Under-staffing was seen as an issue that affected the quality of care.
- Yorkshire Ambulance service was the most highly rated service for the quality of care they provide.

*ALT text The overall quality of care rated as 60/100 where 0 is poor and 100 is excellent

ASK AND INCLUDE US

People with a learning disability who'd been bereaved told us that they wanted to be told honest, factual information about what was happening to their friend or relative. They want to be able to talk about their feelings. They want to have a plan in place for when their primary carer(s) can no longer care for them. Staff who work with people with a learning disability want more training around dying and bereavement so they can better support people.



Bereavement

LESS THAN 50% OF PEOPLE WERE OFFERED PROMPT SUPPORT

The overall quality of support was rated 53/100 for those who'd experienced an expected death and 40/100 for those whose friend or relative's death was sudden

*where 0 = poor and 100 = excellent

- Less than half of all people were offered support in the first few hours and days following the death of their friend or relative. Most people felt the support offered was not enough at that time.
- The offer of information around grief and loss and access to bereavement support is ad hoc and greatly depends on the services the person is connected with. For example, when The Kirkwood Palliative Care Team was involved in a person's EOLC, the bereaved person was contacted with an offer of support. Those who experience the sudden/unexpected death of a friend or relative, or who have no contact with The Kirkwood Palliative Care Team are often not given information about or access to bereavement support.
- **Those who accessed bereavement support from The Kirkwood spoke very highly of the service they received.**
- Just over 50% of people turned to their friends or family for support when they were bereaved.
- 85% of men reported feeling lonely after the death of their friend or relative compared to 68% of women.
- We heard about a **lack of local support for children and young people** who have been bereaved.

People want:

- **Information**, for example, to help navigate the system following a death.
- Someone to talk to; people want **services to proactively contact them** as they often don't feel able to reach out themselves.
- **Practical support**, for example, returning equipment and medication.



Key recommendations

1. **'Dying Well' to be a priority in Kirklees Health and Wellbeing Strategy.**
2. Use the findings from this engagement as a benchmark and repeat annually to **track progress on quality of care**, particularly where people die in hospitals or at home, and to monitor feedback relating to bereavement support.
3. **Improved support for people dying at home and their carers.**
4. Recognise and **celebrate staff and services demonstrating excellence** in care, particularly examples of compassion and personalised care.
5. **Information about bereavement support** to be provided to anyone who registers a death in Kirklees.
6. **Registrars' Office websites to be updated** with links to bereavement support.
7. Loneliness Strategy in Kirklees to prioritise **supporting those who have been recently bereaved, particularly men.**
8. Readily available information about, and access to, **bereavement support for children and young people.**
9. Most people turn to friends and/or family when they've been bereaved. **Conversations around death and grief should be normalised** so that more people can have supportive conversations with friends, family and colleagues. People should know where they can access additional information and support on these matters.
10. **End-of-life and bereavement training for staff working with people who have a learning disability and neurodiversity.** This will equip staff to have more open and honest conversations with people who experience death.



Background and Engagement

Background

Why we've engaged with bereaved people

The Kirklees Palliative Care Partnership has reviewed the Kirklees Care Charter (Appendix A) and identified a need for feedback about people's experience of End of Life Care across the health and social care system.

There is a need for people's experience to be measured more consistently so that this insight can inform service improvement. Some steps have been taken already to improve the way the Partnership listens to and learns from people's experiences. For example, work has been undertaken to bring providers together to share case studies so that learning can be identified and acted upon.

When considering expected/planned for deaths, KPCP recognises that not everyone who should be on a palliative or end-of-life pathway is recorded as such. Around 0.29% of all Kirklees patients are on a GP practice Quality Outcomes Framework (QOF) end-of-life register, the same as regionally and nationally. This should be higher as around 1% of a GP practice population is expected to die on average each year. This suggests that not all adults nearing the end of life diagnosed with chronic long-term illness are being supported to access EOLC. Taking this into consideration, Healthwatch Kirklees has been asked to engage with all those who have been bereaved, not just those who had an EOLC plan in place, so that all experiences of death, dying and bereavement are captured.

Over the past couple of years, Healthwatch Kirklees has seen an increase in the amount of negative feedback received from people who have experienced EOLC and bereavement. We've heard first-hand the impact that a poor experience of death and dying can have on those who go through this journey with someone. We know that grief and loss can affect people's health and wellbeing immeasurably and that support can be challenging to access for some. Healthwatch Kirklees wants to see people's voices being heard by those with the power to make a difference in the quality of EOLC and bereavement support in Kirklees.

What we already know about engagement on EOLC and bereavement in Kirklees

Some providers of EOLC are audited through the National Audit of Care at the End of Life ([NACEL](#)) which is a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission leading to death in acute hospitals, community hospitals and mental health inpatient. The NACEL audit provides benchmarking for the quality of EOLC across a range of services and provides audit outputs to enable stakeholders to identify areas for improvement.

West Yorkshire and Harrogate Integrated Care System have engaged in Palliative and End of Life Care in 2023 but, at the time of writing, the report is not available. It will be interesting to compare findings in Kirklees with neighbouring places.

The most recent National Survey of Bereaved People was in 2015 [National Survey of Bereaved People \(VOICES\) - Office for National Statistics \(ons.gov.uk\)](#)

Key findings from the National Survey of Bereaved People (2015)

- 3 out of 4 bereaved people (75%) rate the overall quality of end-of-life care for their relative as outstanding, excellent or good; 1 out of 10 (10%) rated care as poor.
- Overall quality of care for females was rated significantly higher than males with 44% of respondents rating the care as outstanding or excellent compared with 39% for males.
- 7 out of 10 people (69%) rated hospital care as outstanding, excellent or good which is significantly lower compared with care homes (82%), hospice care (79%) or care at home (79%).
- Ratings of fair or poor quality of care are significantly higher for those living in the most deprived areas (29%) compared with the least deprived areas (22%).
- 1 out of 3 (33%) reported that the hospital services did not work well together with GP and other services outside the hospital.

- 3 out of 4 bereaved people (75%) agreed that the patient’s nutritional needs were met in the last 2 days of life, 1 out of 8 (13%) disagreed that the patient had support to eat or receive nutrition.
- More than 3 out of 4 bereaved people (78%) agreed that the patient had support to drink or receive fluid in the last 2 days of life, almost 1 out of 8 (12%) disagreed that the patient had support to drink or receive fluid.
- More than 5 out of 6 bereaved people (86%) understood the information provided by health care professionals, but 1 out of 6 (16%) said they did not have time to ask questions to health care professionals.
- Almost 3 out of 4 (74%) respondents felt hospital was the right place for the patient to die, despite only 3% of all respondents stating patients wanted to die in hospital.

Kirklees Palliative and End of Life Care Ambitions and Care Charter

KPCP present their ambitions and Care Charter here [Palliative and End of Life Care ambitions and care charter](#) and, within this document, 'Dying Well' was suggested as a focus for inclusion in the Health and Wellbeing Strategy for Kirklees.

“We advocate that ‘Dying Well’ should be a key outcome for the Kirklees Health and Wellbeing Strategy and that Palliative and End of Life Care remains an explicit priority within the plan” – From Kirklees Palliative Care Partnership ambitions document presented to Kirklees Health and Adult Social Care Scrutiny Panel

The Charter sets out what people should expect from their care in Kirklees and sets out how organisations are working together to improve the quality of end-of-life care. All organisations within The Partnership have formally adopted the Charter and commit to it by developing and implementing their own individual action plans.

‘Dying Well’ hasn’t been incorporated as a key outcome in Kirklees Health and Wellbeing Strategy 2021–2027, however, it has been identified as a priority for Kirklees and KPCP has started working on the development of a Dying Well Board.

What's missing

People who support a friend or relative at the end of their life have a unique insight into the quality of care provided but we don't routinely seek feedback from anyone who experiences the death or from **anyone** who experiences the death of a friend or relative in Kirklees whether that's an expected or sudden/unexpected death. We also don't know enough about the support bereaved people are offered and what they feel works well or could be improved.

Engagement

What we did

Healthwatch Kirklees were asked to develop a programme of engagement to help address the lack of feedback about EOLC. The plan was to engage with people who have been bereaved in the past 12-24 months, not just as a one-off project but using an approach that could be repeated annually and that could potentially be replicated in other areas.

The engagement took place from 1 March 2023 - 28 April 2023. The survey was left open for a further 2 weeks to give The Kirkwood additional time to share it.

Engagement staff met with people in the community to let them know about the work and to allow them to speak about their experiences face-to-face, to tell us about the things that were/are important to them and what could be improved.

How we engaged

- Social media – including paid-for advertising, organic posting, targeted messaging and support/signposting content
- Face-to-face conversations in a variety of community settings and services
- Telephone calls
- Online survey

Where we shared information about our engagement

- Direct emails to our contacts, including NHS & social care providers, commissioners and voluntary & community services
- Mailchimp to our contacts, including NHS & social care providers, commissioners and voluntary & community services
- An article in Talking News, Kirklees audio newspaper
- Via partner organisation newsletters
- Funeral directors
- Hospital-based bereavement services
- The Kirkwood shared on their social media and directly with their contacts by email and newsletter
- Using posters sent to all GP practices and hospital-based bereavement services
- On social media, tagging key contacts and using paid-for and targeted social media posts and messages



Examples of the most viewed social media content on Twitter and Instagram

To ensure diverse representation from communities in Kirklees, targeted communications went out to people from minority ethnic backgrounds, people with learning disabilities, and other groups/people who may not always find it easy to have their voices heard. A wide range of groups and services were visited by our team.

The places we visited for our face-to-face engagement sessions

- The Friendship Café, Shelley Village Hall
- Carers Count after-carer support group for bereaved carers
- Carers Count Batley, carers get-together
- Young at Heart over 60's, Batley
- The Kirkwood, bereavement support group and newly bereaved group
- The Kirkwood drop-in, Holme Valley Memorial Hospital
- The Kirkwood Chorus group
- Home from Home friendship group, Kirkheaton Community Centre
- Aspire 50+ social group. Crossland Moor
- The Memory Café, Longwood Mechanics Hall
- S2R Friday Friendship Group, Mirfield
- Jubilee Together, a support group for people with a learning disability
- Kirkheaton Parish Centre Lunch Club
- The Branch bereavement journey, Huddersfield
- Carers Group, Dewsbury Moor
- Kirklees Action Network Group, for people with a learning disability

Who we engaged with

Our engagement reached out to anyone who had been bereaved in the past 12-24 months, where the bereaved person and/or their friend or relative lived in Kirklees and was aged 18+.

We asked demographic questions about the person who had died and about the bereaved person completing the survey.

Demographic questions were not asked of people who took part in group discussions.

About the survey

The survey was split into two sets of questions: one for those whose friend or relative died suddenly or unexpectedly and the other for those whose friend or relative's death was planned for or expected.

Questions in the survey were based on the Kirklees Care Charter (Appendix 1), covering the following areas:

- Information provided to the person receiving EOLC and their friend or relative
- Quality of care
- Staff, including showing compassion and treating people with dignity and respect
- Religious and cultural needs
- Choice, particularly around where to die
- Symptom/pain management
- Organisations working together
- Bereavement support

What we know about the person who has been bereaved

About the survey participants

- **Gender:**
79% of survey responses were from women; 16% of responses were from men; and 5% of people who responded preferred not to say.
- **Location:** 64% of responses were from people who live in South Kirklees; 36% live in North Kirklees.
- **Ethnicity:** 76% of responses were from people from White British ethnicity; the rest were from White: any other background (8%); White: Irish (4%); Asian: Asian British Pakistani (2%); Asian: Asian British Indian (1%); Black: Black British Caribbean (1%); Black: Black British any other background (1%); Mixed/Multiple Ethnic Groups: Asian & White (1%); Mixed/Multiple Ethnic Groups: Black Caribbean & White (1%); prefer not to say (5%)
- **Religion or belief:** When asked about religion or belief, 56% of people said they were Christian; 25% said they had no religion; 11% preferred not to say; 4% said 'other'; 2% said Muslim; 1% said Hindu; 1% said Sikh and 1% said 'not known'.

**79% OF RESPONDENTS
WERE WOMEN**



What we know about the person who died

Where the person died:

- At home (planned/chosen place to die) 22%
- The Kirkwood 21%
- In a care home 10%
- At home (sudden/unexpected) 10%
- Other (included hospitals and hospice outside of Kirklees) 10%
- Pinderfields Hospital 8%
- Huddersfield Royal Infirmary 6%
- In a nursing home 4%
- Dewsbury Hospital 3%
- Calderdale Hospital 3%
- Pontefract Hospital 2%
- Prefer not to say 1%

Note: we gathered lots more feedback from group discussions and one-to-one discussions and this feedback was mainly related to services at Mid Yorkshire Teaching NHS Trust, Calderdale & Huddersfield NHS Foundation Trust and The Kirkwood.

The age range of the person who died:

- 18-24 0%
- 25-49 14%
- 50-64 18%
- 65-79 35%
- 80+ 32%
- Prefer not to say 1%

The following responses* were given when we asked about the cause of death:

- Cancer 54%
- Other* 20%
- Alzheimer's and dementia 8%
- Stroke 7%
- Respiratory disease 4%
- Coronavirus (Covid-19) 3%
- Diabetes 3%
- Accident or injury 3%
- Prefer not to say 3%
- Not known 3%
- Influenza & pneumonia 2%
- Liver disease 1%

*Total not = 100% as people could select more than one option

*Other includes: falls, old age, negligence, hypothermia, alcoholism, heart attack, sepsis, deep vein thrombosis, pancreatitis, and organ failure.





Findings

Expected or planned for death

Findings

Please be aware that not everyone who shared their views gave feedback on every area we were seeking feedback on. Due to the sensitive nature of this engagement, people were actively encouraged to share their views on the things they felt comfortable commenting on.

Quantitative data from survey findings are presented in all sections. Qualitative data from group discussions, one-to-one conversations and phone calls are included throughout the report.

144 surveys were completed. Of those, 66 people said the death was sudden or unexpected; 78 people said the death was planned for or expected.

In addition, **we gathered a further 64 pieces of feedback on different services** and bereavement support, through group discussions, one-to-one conversations and phone calls.

Expected or planned for death

Being informed and knowing who to go to, to talk things through or ask questions

79% UNDERSTOOD INFORMATION

50% UNDERSTOOD THE CARE PLAN

- 79% of people understood the information provided at the time the diagnosis of a life-limiting condition was given to their friend or relative.
- 59% understood the plan for how their friend or relative would be cared for.
- Just 50% of people understood how to plan for what might happen next.

Huddersfield Royal Infirmary **“We were never told she was palliative. One junior doctor said that recovery was not an option.”**

Calderdale & Huddersfield NHS Foundation Trust **“The hospital was really bad and I felt really scared because I didn’t know what was going to happen or**

who to ask about things. We got a number for Kirkwood Hospice and they really helped. Until then I don't think we understood what was happening or that she was going to die.”

“We were well supported from the time we were told my wife's cancer had spread and was terminal to when she died. Her GP Meltham Surgery called her the week after the consultant told us it was terminal and spoke with her on the phone and reassured her she could call them whenever we needed them and ask any questions we had.”

“Just basically told it was terminal and left to process that.”

Huddersfield Royal Infirmary “The only thing that upset me was how we were told his condition was terminal. I had been on the ward all day with him and had left in the evening. I received a call from the consultant and he told me over the phone about my husband's condition, and he told me that he had had a conversation with my husband. I was left feeling very upset that my husband was alone when he received this information. When I went to see him the next morning he was very confused and I just knew he hadn't really understood or taken it in.”

61% of people understood who they could contact for information, medical advice and support. 59% of people understood how they could get in touch with someone who would listen and respond at any time of the day and night.

“We were given contact details right from the start which was really useful. I felt the overall care plan was well explained and we were treated as an individual not just another family on your list.”

“We were given a hotline number for the palliative care team to use any time night or day for support, and we did use it many times when he was suffering and needed strong pain relief.”

“Sometimes I just needed someone to talk to. I wasn't suicidal, so wouldn't ring the Samaritans. But there was no one to ring, in the night, when it was all just too much to cope with.”

“I was left to provide round-the-clock care on my own. I wasn’t informed about care or who I could call for support.”

“We would have welcomed information in writing.”

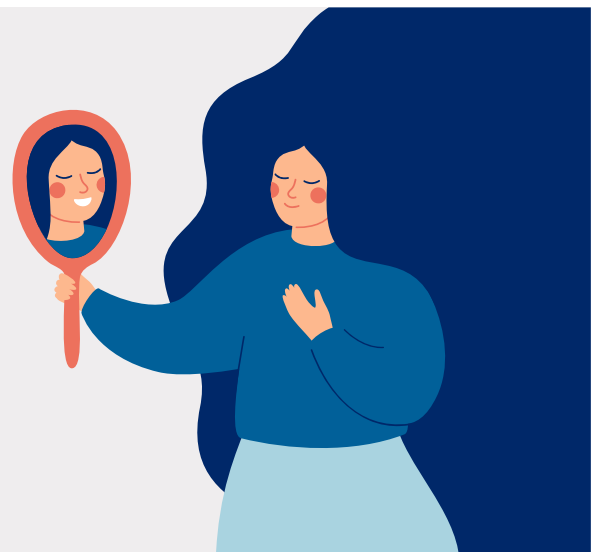
“Needs one person you can talk to, to coordinate things and take pressure off, stop people being passed around. I didn’t know who to contact for what.”

“Occasionally during appointments when making notes comments were made such as ‘Are you going to publish a book when you have finished’, which we found inappropriate. We also experienced some staff who seemed reluctant to discuss timescales and the outcomes of tumour markers and what this would mean. By contrast, others checked understanding and gave our relative a copy of the GP summary which made them feel they were being open and truly working in partnership and modelling shared decision-making. There were a number of occasions when the 24-hour help line answer machine was full so we couldn’t leave a message which is very distressing - on these occasions, our local pharmacy, GP and district nurses were responsive and helpful.”

KIRKLEES CARE CHARTER

I am seen as me

I am informed as early as possible that I have a condition which is life limiting and will shorten my life, although I might continue to live an active life for some time. I, and the people important to me, get the opportunity to have honest, informed and timely conversations.



Having access to care

PEOPLE TALKED ABOUT THE CLARITY OF ACCESS TO APPROPRIATE CARE

A couple of people mentioned that they'd asked if their friend or relative could be moved to The Kirkwood but were told they were not ill enough. It's unclear whether the criteria for accessing The Kirkwood was explained to these people but they didn't feel they had a voice when decisions were made. One person was eventually admitted to The Kirkwood and received good quality care but died after just a few hours there.

Some people mentioned that they felt their relatives didn't get access to appropriate care due to their age or condition.

Huddersfield Royal Infirmary **"I felt she was given up on from day one of being admitted because of her age but she was a very able and fit woman before the accident. I know she had more life left in her if she had been given more of a recovery plan rather than a care plan that restricted her life."**

EOLC at Calderdale and Huddersfield Hospitals **"My relative said 'I'm old now so they don't care what happens.'"**

KIRKLEES CARE CHARTER

I have access to care

The people important to me are supported all the way through my journey. My care reflects my physical, social, psychological and spiritual needs.



Being supported by staff who show they care

89% RECEIVED COMPASSION AND WERE SHOWN EMPATHY

89% of people said that staff were compassionate and showed empathy 'always' or 'most' of the time, and some gave specific examples of where they'd experienced these qualities and values.

“The Marie Curie nurses looked after her with such dignity and kept her at home until the end which was very important to us both as we had spent so much time in and out of hospital we didn't want her final few months to be spent in there too.”

The Kirkwood Hospice **“Just exemplary. Even after my husband passed away, we as a family were still cared for.”**

“The hospice nurses and carers are angels without wings.”

“The staff at Dewsbury Hospital were amazing.”

“Kirkwood staff were always helpful, kind and considerate as were the Marie Curie personnel. Not everyone from the community nursing staff provided the same level of treatment or understanding.”

“The Cleveland House care home staff who looked after my husband were excellent. Very empathetic and had a lovely caring nature about them all. They were so thoughtful with him towards the end and made sure he was comfortable, and kept me informed about everything. It gave me peace of mind when I went home on an evening, he was being so well cared for and they would ring me if he needed me.”

Not all comments around staff attitude were positive.

“Whilst most of the district nurses were kind and supportive there was one who was not and I had to complain about her attitude and that of her line manager after they refused to come out during the day when my relative needed treatment.”

“The NHS were awful some of the nurses very nasty. Some didn’t have a clue about the gastro feeding I had to deal with it. The only hospital worth of praise is St. James Leeds chemotherapy unit.”

We asked people to tell us whether a particular person or service had stood out regarding the care and compassion shown. A special mention goes to:



“Fiona the community palliative care nurse at Kirkwood Hospice”

Calderdale Hospital “I was crying in the coffee shop and a mental health nurse came and sat with me and listened to me and checked I knew where to go and what to do and when I was ready took me back to the ward where Dad had died. He was nothing to with my Dad’s care but just saw I needed someone to be with me and did it without being asked. Just a chance encounter but everyone at the hospital was like this. I never got to say thank you to him”

“The Kirkwood team were terrific from the first meeting. We were well-informed, cared for and looked out for. My husband’s care was exemplary and knowing that made the process that little bit easier for me”

“The Admiral Nurses were fantastic always very supportive and always happy to talk to me on the phone and offer support”

“Palliative care at Pinderfields we’re excellent”

Helen, a nurse at The Kirkwood “Simply a masterclass of empathetic communication on what I look back on as the worse day of my mum’s short illness.....asking where you would like to die? Handled with utter care and compassion.”

District nurses, North Kirklees “One district nurse Nicola was excellent went the extra mile stayed over an hour to make sure the patient was comfortable and was very caring”

Ellie – District nurse Locala “Amazing individual who showed constant care and compassion not only to relative but myself as sole care giver, even starting shift early to ensure syringe driver was given at time needed.”

“Moira and Esther at The Kirkwood.”

“The Marie Curie team were excellent and provided excellent care at all levels.”

“Locala and the district nurses went above and beyond, and Rachel Guest at the hospice was a godsend.”

“The doctor, Emma, at Kirkwood was lovely, very caring and helpful.”

“Community nurses were outstanding. Their caring attitude had a great impact on all the family; we all felt safe in their hands.”

“Kelly The Kirkwood nurse, was so caring and helpful. Couldn’t have done any better.”

“Limitless Care”

“The ambulance crew who sadly arrived too late but were absolutely brilliant in contacting our son’s doctor etc. and making sure I was looked after till sons came.”

Tolson Grange Care Home. **“When my mum was at the end of her life, care staff came to say goodbye to her, even though she’d only lived there a few months.”**

The Kirkwood Palliative Team **“They were so supportive in getting him in and made him so comfortable on his last day, they even allowed him to have a visit from his dog which was so important to him and meant so much to us as a family.”**

Hopton Care Home. **“She was very well looked after there and the staff were excellent.”**

Calderdale & Huddersfield NHS Foundation Trust **“All the staff at Kirkwood hospice and the nurses and staff on the cancer ward.”**

Dewsbury Hospital **“The kidney consultant went out of his way to provide updates and the Kirkwood person who came to our house was very helpful”**

The nursing team at The Kirkwood. **“Nothing was too much for them and they were always so thoughtful and generous They arranged for him to have his favourite music playing in his room for him which was lovely.”**

“Victoria Moxon-Fleetwood, community nurse at Locala”

“Dr Singh, Rose Medical Centre”

Nursing home, unnamed **“One member of staff went above and beyond to spend time with my relative in her final days, talking to her and holding her hand. Staff took care to ensure my relative was not left alone, even sitting with her during their breaks.”**

“The family care team at Kirkwood led by Seamus were excellent throughout my grieving process and months later.”

KIRKLEES CARE CHARTER

I am supported by staff who are prepared to care
All the staff I come across, wherever I am, bring empathy, skills and expertise to give me care which is compassionate.



The quality of care provided, including where different services are involved

The overall quality of care

People were asked to rate the overall quality of care they felt their friend or relative received. The scale was 0-100; 0 = poor, 50 = reasonable, 100 = excellent. The average (mean) rating was **63/100**.



The overall quality of care within 48 hours before the person's death

Using the same scale, people were then asked to rate the overall quality of care in the last 48 hours. The average (mean) rating was **70/100**.



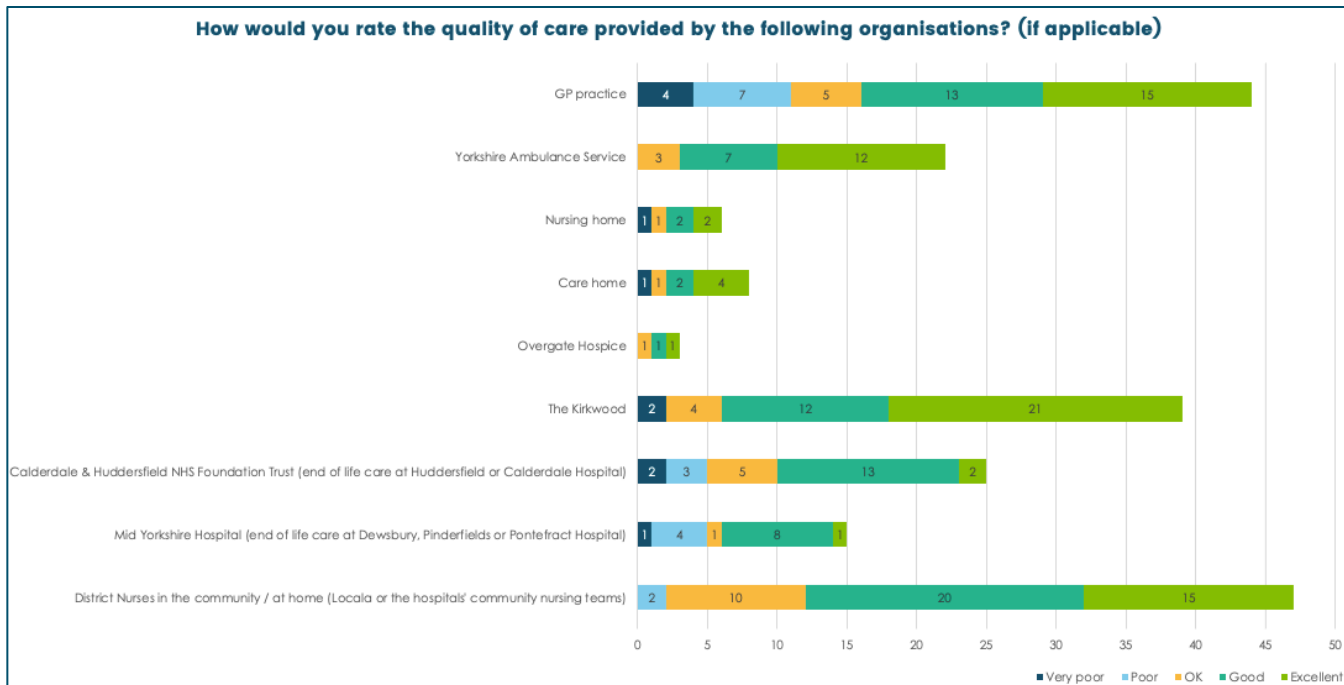
Quality of care for different services

We asked: How would you rate the quality of care provided by the following organisations? (If applicable)

- **GP Practices:**
Four people rated GP practices as very poor, seven said poor, five thought they were okay, 13 rated them good, and 15 said excellent.
- **Yorkshire Ambulance Service:**
Three people rated Yorkshire Ambulance Service as okay, seven rated it good, and 12 gave it an excellent rating.
- **Nursing home:**
One person rated nursing homes very poor, one said okay, two good and two excellent.
- **Care home:**
One person said care homes were very poor, one okay, two good and four excellent.

- Overgate Hospice:**
 Overgate Hospice was rated okay, good and excellent by one person, respectively.
- The Kirkwood Hospice:**
 The Kirkwood received 21 ratings for excellent, 12 for good, four for okay and two for very poor.
- Calderdale & Huddersfield NHS Foundation Trust (Huddersfield or Calderdale Hospital):**
 Two people responded very poor, three said poor, five okay, 13 good and two rated it excellent.
- Mid Yorkshire Hospitals (Dewsbury, Pinderfields or Pontefract Hospital):**
 One person responded good, four poor, one okay, eight good and one excellent.
- District nurses in the community or at home (Locala or the hospitals' community nursing team):**
 Two people gave a rating of poor, 10 people said district nursing was okay, 20 rated it good, and 15 people said excellent.

The chart below shows this information in a visual format, the numbers refer to the number of people responding.



The quality of EOLC in hospitals and the community is variable. Some people experienced high-quality care. Others felt the care provided was lacking in many ways.

“Excellent care from all at Locala and the hospice.”

“He was in Huddersfield Royal Infirmary for about four weeks and to be honest, he might as well have been at home. We constantly had to be there with him and ask for his care. The care he received was very basic. It felt like because there was no treatment plan for him he was almost forgotten about on the ward. We had to constantly ask for information and check if he had been given medication or ask for pain relief. Eventually, we decided to bring him home.”

Huddersfield Royal Infirmary **“When he entered Huddersfield Royal Infirmary, Ward 15, the staff showed little compassion. When I visited, I received very little information about how he had been that day and overnight. If he had eaten, if he had needed additional pain relief etc. I often had to seek out the information and the staff were very matter-of-fact. No compassion care when speaking to me about my dying husband. There were occasions when the staff nurses were about to give medication to my husband I questioned if it was okay with his tumour; they appeared unaware that he had one - had to consult notes. He received a very poor standard of care at the hospital.”**

Huddersfield Royal Infirmary **“The nursing staff were fantastic. He was supported to get washed every day. He always had clean sheets on his bed. I know they may seem like small, trivial things but my husband was a very proud man and it was very important to him.”**

Pinderfields Hospital **“I remember the nurses were very discrete when coming into the room to check on her and administer pain medication etc. They were also very accommodating and allowed visitors to come throughout the night to see her.”**

Where someone died at The Kirkwood, the feedback on the care there was overwhelmingly positive. Also, if the Palliative Care Team at The Kirkwood got involved in someone’s care, whether admitted to The Kirkwood or not, then this was often seen as a turning point for things improving for both the person receiving EOLC and their relatives or friends.

“When he was moved to The Kirkwood, the difference in care and attitude of staff was unbelievable. He was only there for hours before he died but straight away, we felt completely different in that environment. We were welcomed by staff and encouraged to bring his dog in. The Kirkwood went above and beyond to make it a very individual and personalised experience”

“The initial start of the diagnosis was very traumatic from going to the doctors to actually being told at the hospital but after that when The Kirkwood got involved everything was explained and made it a lot easier to understand.”



Services working together

50% FELT SERVICES WORKED TOGETHER WELL WHEREAS DEALING WITH MULTIPLE SERVICES CAUSED PEOPLE TO FEEL STRESS

Just 50% of people felt services worked well together when more than one service was involved with caring for their friend or relative. However, very few comments gave examples of where services hadn't worked well together; some comments highlighted how things had worked in a coordinated way.

“The Kirkwood Palliative Care Team called us when we were back home and arranged to see him the next day, as did an OT who came and arranged for him to have some equipment at home. The district nurses also cared for him at home and all the staff were absolutely fantastic.”

People reported experiencing a lot of stress when different services were involved in caring for their friend or relative. People got involved in trying to plan or coordinate things out of choice or necessity and often met with barriers when doing so.

“We were told by the hospital that it was probably best to move him to a care home but everywhere we rang said they didn't have space. We spent precious time away from our relative trying to organise a care home. Cleveland House agreed to take him but the day before he was due to move, they said he was too ill to take.”

KIRKLEES CARE CHARTER

I receive co-ordinated care

My needs and plans are known by everyone involved in my care and I am helped to achieve them. I know how to reach someone who will listen and respond at any time of the day and night.



Staffing

SERVICES UNDER PRESSURE

STAFF OVERSTRETCHED

There were many comments about services being under pressure and staff being overstretched. People felt this impacted the quality of care and resulted in long waits for things such as home visits or pain relief.

“Very short staffed, had to wait a long time before staff attended. Had to ring each time needed help rather than being put on daily visits.”

“The hospital was too busy to give my friend the time she needed. But they did care and helped when they could.”

“Locala District nursing are short staffed and unable to care for everyone’s needs, but when they do the service is excellent, no one should have to be told that they are not a priority at this moment in time due to staff shortages”

“They probably did their best in difficult times. But there were too few of them. A hospital isn’t ideal for dying people, but no hospice would take him.”

“District nurses are in short supply, so delays in pain relief occurred.”

Review of Care

57% OF CARE

REGULARLY REVIEWED

57% of people said the care of their friend or relative was regularly reviewed.

Management of symptoms and pain

69% PAIN RELIEF WELL MANAGED

69% of people felt their friend or relative's symptoms and pain relief were well managed; most comments relating to pain management were negative, showing that people felt frustrated and upset by delays in administering pain relief.

“GP at Newsome Surgery was very responsive, came and did home visits and managed her pain well.”

“I know my relative died in discomfort in a care home. The Kirkwood should have had input into her pain relief but they did not.”

“Had to fight for medication. Should have had the syringe driver inserted seven days before Mum passed away, didn't get this until 48 hours before she died, although district nurses stated it should have been in place. District nurses had to attend 3/4 times daily to deliver anticipatory medication, sometimes waiting over 5 hours for them to attend.”

“District nurses say they will come whenever but the reality is that they can't as they are understaffed. A syringe driver wasn't in place until really last minute and even then, the dosage couldn't be increased for 24 hours. Four days of unnecessary suffering and I felt incredibly helpless.”

“Delays in pain relief made the experience harrowing to witness.”

People who died at home

LACK OF SUPPORT FOR DYING AT HOME

There were numerous comments from people who cared for their friend or relative at home who felt a significant lack of support.

“End of care for my mum who had dementia – Dr called out twice the week before she died. No one suggested end-of-life drugs, and she was in pain. I was going to ring to ask for the drugs to begin the morning she died.”

“I was left to care for him at home alone with only the support of our GP. I was provided with lots of reading materials from the hospital about what to expect with his condition, etc. but the caring was so full on I didn’t have time to sit and study them. When my husband had a seizure for the first time, I was shocked and worried as I was unprepared for it happening and what to do.”

“My mum and I did most of my dad’s care and I felt like we were almost left alone to do it. There wasn’t much support offered.”

“Palliative care came once. All they said was if he is in pain, call us. So, I coped on my own. He hadn’t spoken or walked for ten years, I understood him. Pity they didn’t.”

“I felt the caring system let us down as I was alone when he died and was only advised by phone how to issue his medication.”

“We had to get on with it on our own. Macmillan was useless, no support never there, didn’t work after 4, no weekends, and no bank holidays. Cancer doesn’t go away during those times. GP at Fieldhead had no interest, never visited, and no appointments could be made. Struggled on our own. I hate them all for that.”

“Promised support but didn’t feel supported.”

“At one point, I rang the palliative care team hotline number to be told they were understaffed and to ring Marie Curie who said they had no one in the area and I would have to manage to lift her, wash her and change the bed myself, even though I was unable to walk unaided at this point.”

“Between being discharged from the hospital we never had a visit from the family doctor. I had to drive him to surgery to get a repeat prescription. The local hospice came to see us and outline what should have happened. Never did only contact was myself ringing for advice when the pain and breathing were getting worse. I was given instructions on increasing medication but no one visited.”

“Getting care in the home is extremely hard. Given that the deceased was a carer for his wife and small family, I felt a lot of pressure and lack of support at times, such as support with home visits or overnight care whilst I rested.”

Staff having the right skills, knowledge and experience

81% FEEL STAFF HAVE THE RIGHT SKILLS

81% of people felt staff had the right skills, knowledge and experience, either ‘all of the time or ‘most of the time’. A few comments related to people experiencing misdiagnosis, medication errors and lack of knowledge of certain conditions.

“The staff did not know much about seizures, and with the staffing ratios being so low in the care home, had I not been there round the clock I don’t think they would have known she had suffered several seizures. When I did call for help they didn’t know what to do. Fortunately, I did but they didn’t know that I did. This is a worry.”

“Local staff nurse who needs more training on EOL care in the community and how to speak with families. GP – misdiagnosed.”

“Struggled with GP. Lack of communication when prescriptions are ready, no sense of urgency. At one point, wrongly prescribed meds.”

Choice, dignity and respect

70% FELT THEY HAD A CHOICE ABOUT CARE AT THE END OF LIFE

70% of people felt their relative or friend had a choice about where they wanted to be cared for at the end of their life. 86% of people died in a place of their choosing. People appreciated efforts made by some professionals to ensure preference was supported wherever possible. People were disappointed if their friend or relative's choice couldn't be facilitated. Still, they generally understood that it was not always possible to support someone's choice if they'd become too ill to move or a move wasn't in the person's best interest.

A few people expressed that their friend or relative didn't want to die in the hospital and, if they couldn't go home, they preferred to go to a care home or The Kirkwood.

Pinderfields Hospital **"It was a very distressing conversation but the consultant was very empathic and respectful. He spoke to my husband directly and asked him where he would like to be and he said he wanted to go home. The consultant arranged for him to be discharged."**

"She went into the hospice but wanted to go home and they were nice about it all, so they sorted it all and we're so nice to me because I had so many questions. The lady who organised it all had thought of stuff we hadn't like sheets and where to be in the house because there wasn't space upstairs. It was really good, and they even got an ambulance."

"He wanted to die at home but was too ill."

Care Home **"I knew he wouldn't want to be in a hospital and this was the next best thing to home."**

"Initially my husband wanted to be at home. But his health declined quickly and the care he needed was beyond my capability. So, he chose to be in The Kirkwood. From the moment we got through the doors we both knew we were in the right place."

“My mum wanted to be in The Kirkwood but died in hospital. She was admitted due to deteriorating health, plans were being made for her to go home but she didn’t make it out.”

“It was very important for my husband to stay at home as that’s where he wanted to be at the end, and without the palliative care team and the district nurses, that would not have been possible. They were so responsive to all our requests for help, we couldn’t have asked for more.”

78% felt their friend or relative was treated with dignity and respect. Comments reflect occasions when this was evident before and after their death.

“What I saw was a display of sheer compassion, respect and dignity given to my Mum in the short time she was at The Kirkwood (less than 24 hours). I saw one of the care workers who had been caring for my Mum walk past with her hands clasped in front of her and held out. It quickly dawned on me that she had removed my Mum’s jewellery from her body and was taking it to be kept safe. Just seeing her treat my Mum’s personal and treasured possessions quietly and dignifiedly will stay with me forever.”

“She was listened to at every opportunity. One example was that my relative liked to sit in the garden, so Simone, the Marie Curie nurse, arranged for us to have a ramp delivered, which meant I could still wheel her out in her chair daily.”

“Before her discharge, we had an advanced care planning meeting with the Macmillan Cancer Support at Pinderfields team. They were very respectful of her wishes and really let her choose what she wanted. They allowed us to ask so many questions and were so patient and understanding with us.”

Some commented on a lack of dignity for their friend or relative.

Huddersfield Royal Infirmary **“He was often sat in his own urine until someone noticed him, which was usually me or one of the family. This made us worry about how long he had been left in that state. There was just no dignity in it.”**

Spiritual, cultural and religious needs

60% OF

RELIGIOUS & CULTURAL NEEDS MET

60% felt their friend or relative had their religious or cultural needs met; 27% were unsure.

The few comments regarding this aspect of care were generally positive.

“We had gone to church together every week since we were married. In the last few years of his life he wasn’t up to it but I would pray with him every day, and before he got too ill, we would sing hymns together. I told one of the nurses this and the following day I went to see him after church. I found him propped up in bed watching songs of praise on BBC iPlayer. He looked so content, it’s a lovely moment that will stay with me forever.”

KIRKLEES CARE CHARTER

I am confident that my wellbeing and comfort come first

I can choose to stay where I prefer and avoid unnecessary visits to hospital. My care is regularly reviewed and my symptoms are managed as well as they can be.





Findings

Unexpected or sudden death

Findings

Unexpected or sudden death

Most people who had experienced a friend or relative's sudden or unexpected death gave feedback on emergency and hospital services.

Being informed

72% understood information

62% felt able to ask questions

People talked to us about knowing who to go to, to talk things through or ask questions:

72% of people understood the information given to them at the time their relative or friend was dying or had died. People appreciated being given facts and information in a timely way and in a way they could understand. When this didn't happen, some people felt confused and misled.

Huddersfield Royal Infirmary **"I asked [the doctor] if he [thought] that he would die but he was very vague and said things like 'we are doing what we can for him' and 'we are working on getting him better.' I think he knew it wasn't the case and wanted to give us hope but I would have preferred to been told the reality of things sooner."**

Huddersfield Royal Infirmary **"We never really understood what was happening and information was passed to us in dribs and drabs."**

Pinderfields Hospital **"My sister died from pancreatitis. It happened very quickly, so it was a lot to take in but we were kept informed of everything at every stage, and every question we asked was answered."**

Calderdale Hospital **"She continued to deteriorate in ability, yet no health professional spoke to the family about her dying until it was actively happening. It felt very poor support all round. We later had access to her**

health records and could see she'd become severely unwell five days before she died. At no point on the night or the following days were any of the family informed she had been worse and this only came to light to the family when we read her records after the event."

District nurses, Huddersfield **"They gave us a number to call if we needed them and were really caring and made sure we knew we could call them at any time. We called the number a couple of times to ask questions and to call them out late evening."**

62% felt able to ask questions about what was happening. Those who didn't feel able to said that their questions appeared inconvenient for staff.

Calderdale Hospital **"The nurses on the ward were incredible, very caring for my relative, and helpful to the family when we visited. However, the team overall from the ward did not consistently communicate with the family. We were only given information if we asked, nothing was forthcoming, and we were made to feel like we constantly bothered staff when, as family members, we were just worried and scared for our relative and wanting to know what was happening."**

Dewsbury Hospital **"Communication from the hospital staff was always very vague. We had to ask for more specific information constantly. We were never stopped from asking questions, but I feel like information wasn't easily offered to us."**

Being supported by staff who show they care

77% received empathy

Exemplary services were highlighted

77% of people said that staff were compassionate and showed empathy 'always' or 'most of the time', and some gave specific examples of where they'd experienced these qualities and values.

Pinderfields Hospital **"By the time we had got to the hospital she was very, very ill and I don't imagine would know what was going on but I remember all the staff being so lovely and talking to her throughout their work. They let me stay by her side the whole time and hold her hand the whole way. They were very caring towards me."**

Pinderfields Hospital **"The staff at Pinderfields ICU [Intensive Care Unit] were fantastic; they were working under such pressures but always showed us so much compassion and took the time to talk to us."**

Dewsbury Hospital **"The doctors and nurses on the ward were excellent...very caring and gentle with him...all the staff were very calm and caring...all so lovely."**

However, some of the comments from people who'd experienced the sudden death of their friend or relative were negative.

Huddersfield Royal Infirmary **"It felt like there was something lacking in terms of empathy. I remember asking one of the nurses if he could hear us talking to him and we were told 'Probably not' with a shrug and she walked out the room. It felt like he was a lost cause and so didn't require anything more than a bed and basic level of care until he was no longer there."**

We asked people whether a particular person or service had stood out regarding the care and compassion shown. A special mention goes to:



- Stroke Ward 7A, Calderdale Hospital
- My Homecare Huddersfield – “Carers were invaluable”
- Staff in the hospice were the best
- Admiral nurses
- A&E at Pinderfields

“My wife was rushed to hospital. We were in the back of an ambulance and before they set off the paramedics said they were taking her to Dewsbury but halfway there they decided it was better to take her to Pinderfields. My son was following us along from home to the hospital and he went straight to Dewsbury not knowing we had diverted and I had no way of letting him know. When we arrived I told one of the nurses in the emergency department and even though they were very busy she was fantastic and rang DDH for me and got a message to him. He got there in time to see his mother before she died so that meant a lot to us.”

“Palliative Care at Pinderfields”

“Yorkshire Ambulance Service – paramedics did their best.”



**The quality of care provided
(including where different services were involved)**

67% positive responses for staff skills, knowledge and experience

The overall quality of care

People were asked to rate the overall quality of care they felt their friend or relative received.

The scale was 0-100; 0 = poor, 50 = reasonable, 100 = excellent.

The average (mean) rating was **60/100**.



67% felt that staff had the skill, knowledge and experience to care for their friend or relative 'always' or 'most of the time'.

“Unable to express how a 44-year-old man with a good prognosis could have been so let down. Nobody checking his progress. Can’t believe in 2022, this could have happened. Cancer tea and Macmillan nurse were very poor in knowing that things were going downhill.”

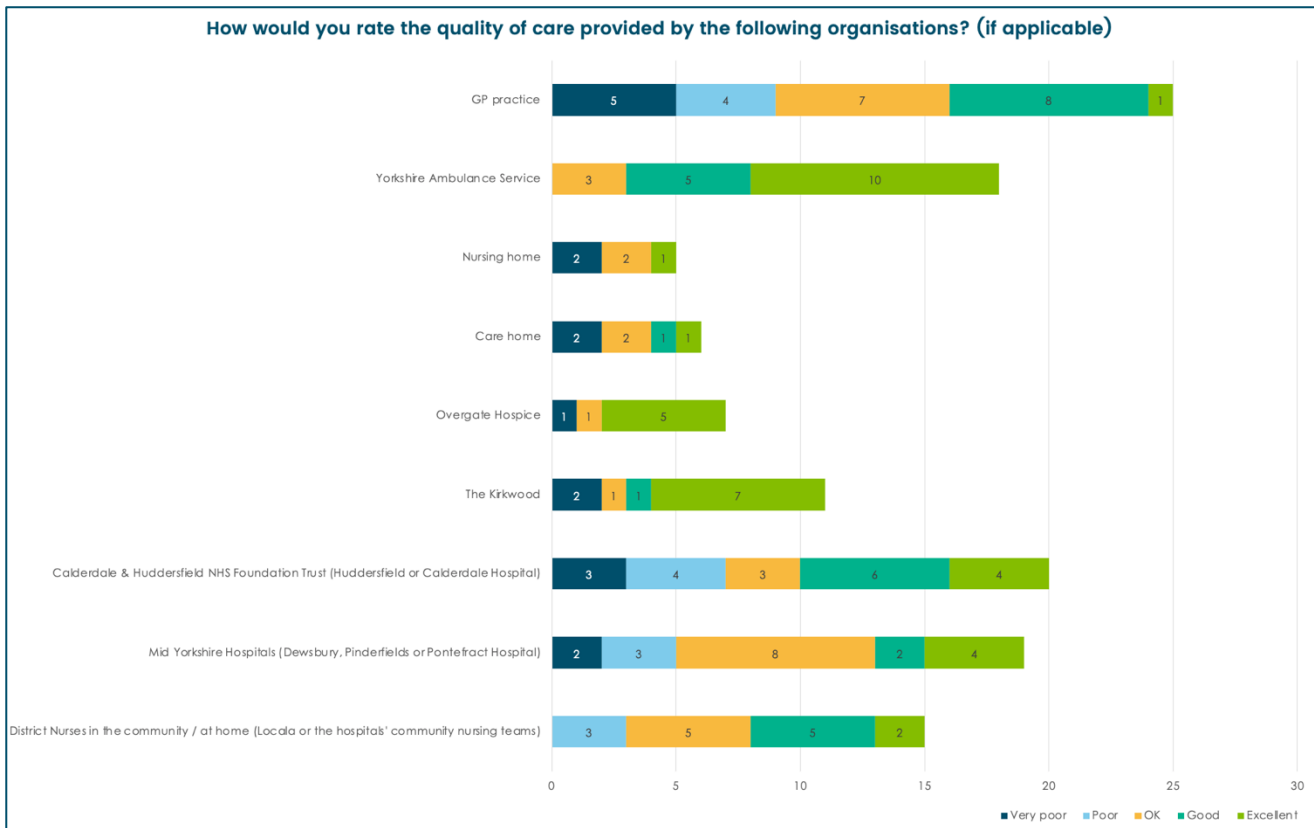
Huddersfield Royal Infirmary **“My relative was not given the right treatment to start with and was sent home saying nothing was wrong despite him insisting that something was not right, then he suddenly became very ill and died suddenly, which I feel could have been prevented had he had the right treatment in the first place.”**

Quality of care for different services

We asked: How would you rate the quality of care provided by the following organisations? (If applicable)

- **GP Practices:**
Five people rated GP practices as very poor, four said poor, seven thought they were okay, eight rated them good, and one said excellent.
- **Yorkshire Ambulance Service:**
Three people rated Yorkshire Ambulance Service as okay, five rated it good, and 10 gave it an excellent rating.
- **Nursing home:**
Two people rated nursing homes very poor, two people said okay, and one person said excellent.
- **Care home:**
Two people rated nursing homes very poor, two people said okay, one person said good, and 1 said excellent.
- **Overgate Hospice:**
Overgate Hospice was rated very poor or poor by one person, and five people rated it excellent.
- **The Kirkwood Hospice:**
The Kirkwood received seven ratings for excellent, one for okay and good, respectively and two for very poor.
- **Calderdale & Huddersfield NHS Foundation Trust (Huddersfield or Calderdale Hospital):**
Three people rated these hospitals very poor, four said poor, three okay, six good and four rated it excellent.
- **Mid Yorkshire Hospitals (Dewsbury, Pinderfields or Pontefract Hospital):**
Two people rated these hospitals very poor, three said poor, eight said they were okay, two people good, and four rated them excellent.
- **District nurses in the community or at home (Locala or the hospitals' community nursing team):**
Three people gave a rating of very poor, five people said district nursing was okay, five rated it good, and two people said excellent.

The chart below shows this information in a visual format, the numbers refer to the number of people responding.



When rating the quality of care provided by different services, **Yorkshire Ambulance Service received the most 'excellent' ratings**, but this service was rarely mentioned in the comments.

Pain management

Only half of people felt that symptoms and pain relief were managed well but no comments highlighted any particular issues or concerns around these aspects of care.

Services working together

Some people shared feedback on difficulties when more than one service was involved in caring for their friend or relative.

Calderdale Hospital **“So many mistakes whilst an inpatient at the hospital, care not co-ordinated or monitoring her wellbeing whilst in, which had a significant impact on her. She was delirious due to them not making sure she was drinking properly, meds not taken, and falls and sores. Then couldn’t be discharged if didn’t have oxygen, so was delayed. Then they changed their mind and discharged her but no PPE for carers. The social worker was**

only interested in what money she had to pay for care privately. We as a family co-ordinated and organised everything.”

Mid Yorkshire NHS Teaching Trust, The Kirkwood, unnamed GP practice **“Her GP was excellent in providing information and joining up the services. The hospitals and hospice didn’t work together, but the GP did a good job.”**

Pinderfields, The Kirkwood and unknown GP practice **“Communication between the hospital, hospice and GP. was poor with no joined up working. It feels as if people are under too much pressure to care and have to do their best to get through each day.”**

Acute hospitals and The Kirkwood **“Generally good, although not all the services talked to each other, so we had to repeat ourselves quite a bit when visiting new services.”**

Staffing

Some people felt that the quality of care was impacted by staff being overstretched due to understaffing.

Huddersfield Royal Infirmary **“Although the staff were lovely and very caring, there were not enough nurses to tend to her.”**

“Locala District nursing is staffed and unable to care for everyone’s needs, but the service is excellent when they do. No one should be told that they are not a priority at this time, due to staff shortages.”

Dewsbury Hospital **“The staff cared for my dad reasonably well but they constantly felt rushed and not the most welcoming to us as visitors. My mum has dementia, so she would often ask questions. It felt like we were a burden to the staff being there and asking for information.”**

Macmillan at Pinderfields Hospital **“Macmillan is overrun. Macmillan nurses at the hospital seem overwhelmed with the volume of work.”**

Choice, dignity and respect

63% treated with dignity

57% of religious & cultural needs met

When deaths are unexpected or very sudden, choosing where to die is often not an option due to the pace of events. However, a few people mentioned that they'd requested a move from hospital to home as they felt their friend or relative would have wanted this.

Huddersfield Royal Infirmary **“At first we were told she was too weak to move. We knew how important it would have been for Mum to be at home, and eventually, we managed to arrange this.”**

63% of people felt their relative or friend was treated with dignity and respect.

Person died outside of Kirklees **“The intensive care nurse assigned to my friend was an extremely compassionate person. He also talked to my friend whenever he had to do an intervention to explain what he was doing to her even though she was unconscious, brushed her hair and treated her with dignity.”**

Spiritual, cultural and religious needs

57% felt their relative or friend's cultural or religious needs were respected and fulfilled. Just over 10% of people felt this wasn't the case, and the rest of respondents didn't know or preferred not to say.

Huddersfield Royal Infirmary **“We were well supported by the nursing staff. We have a big family and they allowed us all as much time as we needed to come and see him. They arranged for a priest to come and pray with us, which was really important to my mum and gave her a lot of comfort.”**



Findings

Learning disability
and Neurodiversity

MEMBERING CLUB

Feedback from people with a learning disability

PREPARATION AND TRANSPARENCY

A group discussion with people with a learning disability revealed a lack of transparency in the conversations people had with them about the situation their friend or relative was experiencing and the lack of support offered to them after they'd experienced a death.

“I was told the day before my mum died that she was ill in hospital and wouldn't be well enough to come home. I got to see her once before she died. I wanted to be told straight away.”

Some people experienced an abrupt change in their living arrangements following the death of their primary carer and others mentioned advance care planning in readiness for a change in circumstances.

“When my grandma died, I was moved into Bridgewood the next day. I didn't know anyone. I didn't talk to anyone. I felt lonely. I wanted to go home.”

“When me and my wife were both diagnosed with cancer five years ago, the adult social care team contacted us and advised us to start looking and planning for where our two adult children with LD would live.”

“I started to talk to my mum and dad about what would happen to me when they died. This is when we started to plan for my future and I decided I wanted to live in a flat on my own. I feel more prepared and independent now.”

“After his dad died, he was placed in emergency accommodation in Dewsbury the next day. He had not been to the area before and didn't know anyone. He was traumatised by the experience of having to cope with such a huge change to his life on top of the grief.” – Support worker

When discussing bereavement support, the people we spoke to with a learning disability clearly expressed a wish to talk about their feelings and how beneficial it was when they had the opportunity to do so.

“I would have liked to talk about how I felt but no one asked me.”

“When my mum died, I didn’t talk to anyone about it. No one offered me counselling. I would have liked to talk about how I felt but no one asked me.”

“My support worker contacted the West Yorkshire Grief & Loss Service and I spoke to them for a while. It helped me to talk about my sister and missing her. When my auntie died, I talked to people about it straightaway, which was better.”

Support workers told us they sometimes felt ill-equipped to support the people they worked with properly. They wanted more awareness of the signs and behaviour changes that might be displayed when someone is experiencing grief and training on how to support people through difficulties. None of the professionals we spoke to (four staff) had ever had any formal training on bereavement support, but they’d all been in a position where they had to provide such support on multiple occasions.

Feedback from people who are neuro-diverse

‘PROTECTED’ FROM THE REALITY

One person told us that the impact of her relative dying had led to increased anxiety and being unable to leave the house for three months, with little understanding from others, **“I feel like people dismissed my grief and anxiety after some time had passed like I should be over it now.”**

Similar to the feedback from people with a learning disability, another neuro-diverse person said that others had tried to protect them from the reality of what was happening to their relative by not telling the truth, **“No one told me she was ill until she was in hospital dying.”**

Someone else told us they felt some of the staff they had contact with didn’t know how to communicate with someone with autism and a learning disability.



Findings

Bereavement support

Bereavement support

Experiencing the death of someone close to you is a very personal, often life-changing, time; nobody knows how they will feel or how they might be affected at the time of the death and in the weeks, months and years that follow.

Our engagement captured the views and experiences of the care given to people at the end of their lives from the perspective of someone who has been bereaved. We also needed to ask people about the support the bereaved person was offered and/or accessed. The following findings relate to people who had experienced the sudden, unexpected death of a friend or relative and deaths that were expected and planned for.

The overall quality of support you received as someone experiencing the expected or unexpected death of a friend or relative?

The overall quality of support

People were asked to rate the support they received overall. The scale was 0-100; 0 = poor, 50 = reasonable, 100 = excellent.

Those who had experienced a **sudden or unexpected death** gave an average (mean) rating of **40/100**



Those who had experienced an **expected or planned for death** gave an average (mean) rating of **53/100**



Support offered in the hours and days immediately after the person had died

A follow-up call would be appreciated

There was an almost equal split between the number of people who were and were not offered support immediately after their friend or relative died (44% and 45%, respectively).

35% of people felt the support offered at that time was enough, and 45% of people didn't feel it was enough.

Understandably, it's often difficult for people to take in what's been said to them immediately after the death of a friend or relative and when written information is provided, people don't always feel able to look at it. Many people commented that a follow-up phone call would have been much appreciated.

“No support was offered at the time. The paramedics left the house when they had finished their checks. No contact from GP or private carers.”

“No support was offered and as I'd helped care for her at the end of her life, some support for me was needed, but as I wasn't a relative or spouse, I wasn't offered anything.”

“I was offered support from The Kirkwood's bereavement service.”

“I remember they took us to the family room after she had died and we sat for a bit with one of the nurses. She was very comforting and gave my son some information to take away with us. On reflection, I feel there should be follow-up support, not just at the time of the death, given the different stages of grief.”

“It was difficult to make the first step and get in touch. Would have been easier if someone contacted us to ask us if we needed support.”

Huddersfield Royal Infirmary **“I needed Muslim-specific support. That was not available.”**

Dewsbury Hospital “I just wanted someone to talk to. I was just left with my mum for as long as I wanted, which was good, and the nurses were good in offering tea, etc. but no one even spoke to me when I left the ward.”

“Bereavement Team at Calderdale Hospital were in contact soon after. The hospital and the nursing home gave me pamphlets to take away. I can’t say I looked at them very much.”

“Initially, after her death, I was too overwhelmed. I think it hit me very suddenly .how quickly she had gone from being well to dying, so I don’t think I took anything on board beyond the information they were giving us about her condition. So, if anyone did speak to us about bereavement support, I cannot recall what was said. I remember sometime after someone from Rosewood contacted us and offered counselling sessions, which I took up sometime later.”

Huddersfield Royal Infirmary “When I was at the hospital I was given some leaflets on available bereavement support but no one discussed any of it with me. When you are in that situation, you come away with a myriad of leaflets and you sort of put them down but never really have the time to sit and read them or absorb what is there.”

What support people felt would have been most useful to have in the first few hours and days following the death of their friend or relative

A check-in

and help with the process

People talked about the information and guidance they would have appreciated in the period soon after their friend or relative had died. They talked about wanting someone to talk to but often not feeling able to initiate that contact. Some mentioned practical tasks they would have appreciated support with or more time to deal with.

“One-to-one support within the first couple of weeks. I felt very alone and frightened by my grief; it was overwhelming and there were times I didn’t think I could make it to see another day.”

“Someone sitting down with us to discuss the process of what happens next and what we need to do.”

“I found it very warming that my grandma’s community palliative care nurse rung us after death for a wellbeing call despite her dying in hospital.”

“A call from the GP would have been nice, given that she had been a patient for decades.”

“Although Mum was frail and elderly when she died, it felt quite harsh that her medical records were taken off my access fast and we had to clear her room, etc. All understandable but doesn’t help with grieving.”

“Arranged with Medequip for his equipment to be collected. They do a brilliant job and we were grateful for their support. I just would have liked the bed to be taken away sooner as for those 10 days it was very distressing having the constant reminder.”

To summarise, people would have found the following most useful in the initial hours and days after their friend or relative died:

Information

- Information about what needs to happen when someone dies, what’s the process?
- Information about sudden deaths and grief.
- Navigating the system.
- Help to understand probate.

Someone to talk to

- Face-to-face, not just phone calls or leaflets.
- Check-in to ask how people are.
- Contact from services to the bereaved person rather than the other way round; people often didn’t feel able to make calls but would have appreciated someone calling them.

- A call from the person's GP practice. Particularly where the person who died had been a patient at a practice for several years.
- A place to meet people who had been through similar experiences, sharing ways to cope.
- Specialist support from someone who has skill and experience communicating with people with a learning disability and/or who are neurodiverse.

Practical support

- Quicker appointment to register death so funeral could be arranged.
- Support with sorting out funerals and finances.
- Practical help and advice for collection of drugs/removal of equipment.
- Timely collection of equipment/beds from people's homes.
- Allow adequate time for bereaved family/friends to make necessary arrangements to deal with things such as removing belongings from rooms.

KIRKLEES CARE CHARTER

I have access to care

The people important to me are supported all the way through my journey. My care reflects my physical, social, psychological and spiritual needs.

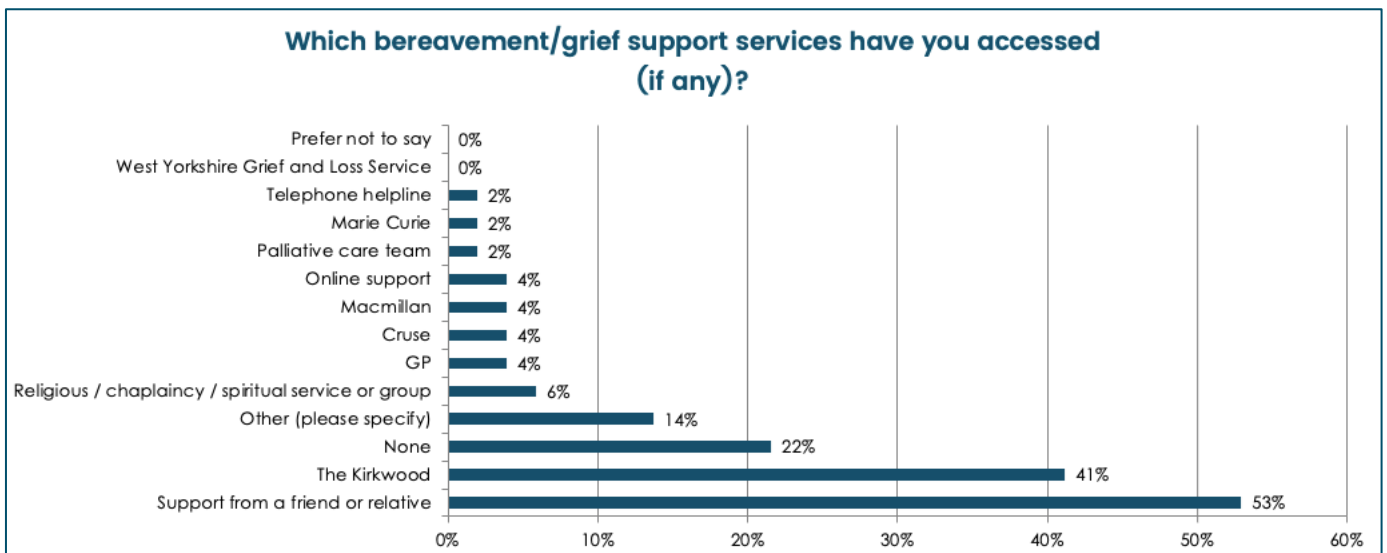


Information provided about bereavement support

Less than 50% received bereavement information

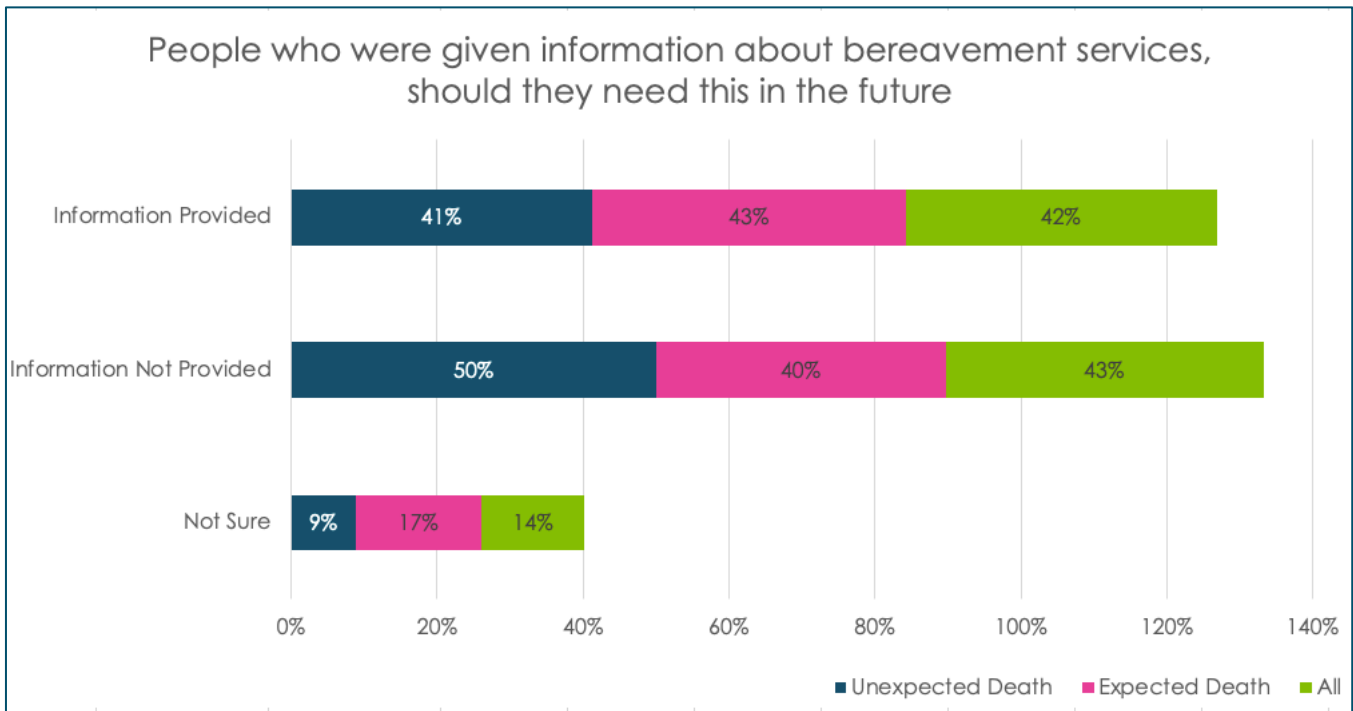
Less than half of all people were provided with information about bereavement services; this was slightly higher for those who had experienced a sudden or unexpected death.

When we asked which sources of support they'd accessed (if any) for their bereavement, most people (53%) got this from a friend or relative; this was the case for both men and women. Just over 40% accessed bereavement support at The Kirkwood.



As shown above other sources of support included 22% response for none, 14% other, 6% religious support, 4% for GP, Cruse, Macmillan and online. 2% from Palliative care teams, Marie Curie or a telephone helpline and 0% for West Yorkshire Grief and Loss service or other.

The chart below shows that for unexpected death 41% of people were provided with bereavement information, 50% did not receive any bereavement information and 9% were unsure. For expected deaths 43% of friends or relatives received bereavement information, 40% did not and 17% were unsure. Combining these totals we find that 42% of people overall received bereavement information, 43% did not and 14% were unsure. (People could select more than one response.)



Some people told us they didn't know where to go for support, or they found it difficult to talk about their loss and feelings.

“I felt lonely and didn't know where to go for support. I didn't want to bother my GP with it.”

“My friend died of alcoholism, which is highly stigmatised. I felt this was an added trauma to the grief I experienced. I feel alcoholism is misunderstood and people did not know how to respond to me. I feel often people do not know how to respond to grief anyway – death is not often talked about in our culture and the addition of alcoholism made the topic even more difficult for others. I felt people just avoided the topic, didn't know how to help me, felt it was my friend's fault that she died. There were many unanswered questions for me about her death. I also have a chronic condition and the grief made it worse for months. Mentally it was also difficult for me.”

“Bottled everything up for a long time as it was sudden. Still don't think I am anywhere near grieving.”

“I would have appreciated a call from someone who knew about end-of-life and bereavement support, to reassure me about my feelings of anger and guilt.”

We didn't engage with **children and young people** but a few people mentioned a lack of support for children and young people who had lost a parent.

“The children have been very let down by the lack of support. They were given a memory box at the hospital but then there's nothing; GP said there's at least a 9-month waiting list for support for them.”

“We have not been offered any help. I have since found help for the children at Winston's wish.”

The Kirkwood's bereavement support was mentioned positively on multiple occasions. Where people were already known to The Kirkwood, they were proactively offered bereavement support following the death of their friend or relative and this was very much appreciated.

“After my relative died, I was contacted by The Kirkwood within a couple of days and offered bereavement counselling, which I took up. I had a one-to-one session with Katherine who was very supportive. She also suggested I join the 6-week newly bereaved course.”

“I am so grateful for the support I received from The Kirkwood bereavement team, I honestly don't know how or even if I would have survived without them. The one-to-one support I received was truly invaluable to me.”

Impact of bereavement on loneliness and finances

85% of men felt lonely

68% of women felt lonely

We asked two specific questions about **loneliness** and **finances** following the death of a friend or relative as we noted that in Kirklees Joint Strategic Assessment, more men were likely to feel lonely following the death of someone close to them and more women were likely to experience a financial impact.

Loneliness

In our engagement, **68% of people said they'd felt lonely after** bereavement.

85% of men reported that they felt lonely.

“We had lost both our parents the year before my brother died and losing my brother so unexpectedly so shortly after their death was extremely tough for me.”

“I found it too overwhelming at times to even get out of bed and face the day and if I did I felt so alone, even if there were people with me offering support. I was sure I would never overcome the feeling of being alone.”

“She was my friend as well as my wife and it hurt knowing I would have to go on without her.”

“I feel loneliest at night, and I find it hard to switch off my mind and get to sleep. There was a period when I became dependent on using alcohol as a means to put me to sleep. I don't think unhealthy coping strategies are talked about enough with people who have been bereaved.”

68% of women said they'd felt lonely. Their comments around loneliness were equally as emotive as those made by men.

“Great sadness at the loss, difficulty eating and sleeping. Feelings of being unable to cope. This was the third close relative I had cared for during their last days and sat with as they had died, leaving me feeling bereft.”

“It really impacted me, as we were very close. I still find it difficult now. Crying, not sleeping, becoming insular, feeling very low.”

Finances

Slightly more women 26%, than men 22%, reported being affected financially by the death of their friend or relative. Women's comments were mainly about losing their spouse's salary or benefits. Just one man commented on a loss of income.

One person reported being financially impacted due to not being able to return to their place of work following the death.

“I was unable to go back to work as my employer was not supportive. Had to look for alternative employment.”

In addition to the specialist services that are available to support people with bereavement, people mentioned a few other places that showed empathy and compassion.



- Yorkshire Water **“They took care of practical things but it was obvious that the person I spoke to had bereavement training. Showed empathy and a slow pace. Gave me time to gather information together and phoned back when they said they would, ‘just made things easy’. Very kind and helpful.”**
- The Registrars’ Office at Huddersfield **“Very compassionate, warm, listened, gave eye contact, very soothing.”**
- Funeral services **“Co-op funeral care were very supportive towards the family, very helpful and went beyond what was expected.”**
- **“The first support we were offered was when we went to the funeral directors. The lady who saw us was really lovely.”**

KIRKLEES CARE CHARTER

I live in a community that is prepared to help
My community recognises that we all have a role to play in supporting each other in times of crisis and loss.



Conclusion

If someone's life ended at The Kirkwood, the feedback received was far more positive than for someone who died elsewhere. Overall, if the Palliative Care Team from The Kirkwood were involved in someone's care, the experience was better than those who didn't have involvement from this team. This applied to the bereaved person's perception of the care their friend or relative received and the support they received before and after the person died. If more people are identified as requiring an end-of-life or palliative care pathway, the support from the Palliative Care Team would naturally be more available to those needing it.

Where people died in hospital, the quality of care was variable, with some examples of care far below expectation and other comments highlighting good practice. People often indicated that they didn't want to die in hospital and, where feasible, people's preferred choice to die at home or at The Kirkwood was supported.

Many people whose friend or relative died at home reported feeling unsupported,. They often felt they were 'left to get on with it'. The quality of care from services such as district nurses was mostly good but people were concerned that such services were overstretched and this resulted in care not always being delivered in a timely way. For example, delays in administering pain-relieving medication.

It's reassuring to hear that most people felt that staff showed compassion and empathy. There were some lovely examples of these qualities being observed, often in the small things staff did for the person receiving EOLC like holding a hand and talking to them, even when they couldn't respond. People highlighted many services and individuals that they wanted to recognise and thank for the care and support they'd provided.

Most people understood the information provided to them at the time of diagnosis of a life-limiting condition and understood the care plan. Similarly, for sudden or unexpected deaths, most people understood the information given when they were told their friend or relative was going to die. However, some

people talked about vagueness in communication from staff and how they were sometimes left with questions they didn't feel able to ask.

Some people who had experienced more than one service providing care to their friend or relative reported that they'd encountered difficulties. This is mainly related to sudden or unexpected deaths. Comments for all deaths highlighted poor communication between services, lack of joined-up working, people having to repeat themselves to different services, and having to take on the coordination themselves. All these things often led to a difficult situation becoming increasingly stressful for friends and relatives and affected the time they had left with the person at the end of their life.

Bereavement support

We know that the impact of grief and loss can be significant and long-lasting.

Those who are bereaved, whether it was expected or not still have to go through a significant period of change and adaptation. Constructing a new identity and striving for independence in the face of changes to everyday activities and routines, loneliness, health concerns and changed relationships within the family and social network are essential features of older people's bereavement experience. It is, of course, not just the spouse or caregiver that experiences grief; the death of an adult or child affects many individuals in different ways. It may be that psychological support is the primary issue for some bereaved people. Often it is a mixture of psychological support, practical support and time/space to comprehend and digest the loss they have experienced. (Kirklees Joint Strategic Assessment)

The offer of and access to bereavement support in Kirklees is better for some than others. The proactive offer of bereavement support in Kirklees is almost always a result of someone already being known to The Kirkwood's Palliative Care Team. Those people told us they'd received a phone call and were provided with information about the bereavement support offered at The Kirkwood. Things are often different for those not known to the Palliative Care Team and for those who have experienced a sudden, unexpected death; in these instances, fewer people were provided with information about where and how to access bereavement support.

People with a learning disability were very clear that they want those around them to have more open and honest conversations around death. They also want to be asked about their feelings and to have the opportunity to talk things through with someone.

Advance care planning was mentioned as necessary to people with a learning disability. Therefore resources such as [Advance Care Planning and Bereavement Toolkit: West Yorkshire Health & Care Partnership \(wypartnership.co.uk\)](https://www.wypartnership.co.uk) may benefit from increased promotion.

We didn't engage with children and young people. However, some relatives of people who had died told us that they had struggled to access support for children and young people who had lost a parent. There is no local specialist bereavement support for children and young people. If a child is referred to the Emotional Health & Wellbeing Service, part of Thriving Kirklees, there is a long waiting list and not much available to support people in the meantime.

Most people look to their friends and family for support when experiencing a bereavement, slightly more so for women than men; whether this was through choice or necessity because there was no other support available is unclear.

Reflections on Kirklees Care Charter (appendix A)

Healthwatch were asked to comment on whether the content of the Care Charter reflects the things that are important to people receiving EOLC.

- It is felt there should be greater emphasis on support for people who are going on the journey with the person receiving EOLC; a commitment to listen to their voice, keep them informed, and involve them in decisions where possible.
- There is a sentence about choice: 'I can choose where to stay and avoid unnecessary trips to the hospital.' The stories we've heard reflect that choices can't always be met, so perhaps a caveat here to explain that choices will be respected where possible but will ultimately depend on clinical decisions and what's in the person's best interest.

The heading 'access to care' could be changed to 'the plan for my care is holistic', as the wording below this heading doesn't fit with 'access'.

Thank you

It has been a privilege to hear from so many people willing to share feedback with us on such a personal and often sensitive subject. It has been encouraging to read examples of compassionate care and to hear about professionals who have gone the extra mile to support a 'good death'. Providers and commissioners must reflect on and learn from the feedback we've heard, which highlights areas for improvement. 'Dying Well' and all that this encompasses, including bereavement support, must be a key priority for those who can make this a reality for people in Kirklees.



Recommendations

Recommendation	Who we are asking to lead on this	By when
'Dying Well' to be a priority in Kirklees Health and Wellbeing Strategy	Kirklees Council	End 2023
Use the findings from this engagement as a benchmark and repeat annually to track progress on quality of care, particularly where people die in hospitals or at home, and feedback relating to bereavement support.	Dying Well Board	May 2024
Plans in place to improve support for people who die at home and their carers	Dying Well Board in partnership with community based EOLC services	Oct 2024
Recognise and celebrate staff and services that demonstrate excellence in care, particularly examples of compassion and personalised care	Dying Well Board – annual celebration	October 2023 and annually thereafter
Information about bereavement support to be provided to anyone who registers a death in Kirklees. Registrars' Office websites to be updated with links to bereavement support.	Kirklees Council	Oct 2024
Loneliness Strategy in Kirklees to have a priority around supporting those who	Kirklees Council	Oct 2024

have been recently bereaved, particularly men.		
Information about and access to bereavement support for children and young people	Thriving Kirklees	Oct 2024
Most people turn to friends and/or family when they've been bereaved. Conversations around death and grief should be normalised so that more people can have supportive conversations with friends, family and colleagues. People should know where they can access additional information and support on these matters.	Dying Well Board & ICB	Ongoing activity
End of Life and bereavement training for staff working with people who have a learning disability and neurodiversity. This will equip staff to have more open and honest conversations with people who experience death.	Dying Well Board & ICB	Oct 2024

Appendices

Appendix 1 – Kirklees Care Charter

KIRKLEES CARE CHARTER

This charter was created by the Kirklees Palliative Care Partnership for people with a life limiting illness in Kirklees. We know the care system can be confusing and our aim is to ensure your care is focussed on what matters to you.

Our charter explains what you can expect from your care in Kirklees and sets out how organisations are working together to improve end of life care in Kirklees.

I am seen as me
I am informed as early as possible that I have a condition which is life limiting and will shorten my life, although I might continue to live an active life for some time. I, and the people important to me, get the opportunity to have honest, informed and timely conversations.

I have access to care
The people important to me are supported all the way through my journey. My care reflects my physical, social, psychological and spiritual needs.

I am supported by staff who are prepared to care
All the staff I come across, wherever I am, bring empathy, skills and expertise to give me care which is compassionate.

I am confident that my wellbeing and comfort come first
I can choose to stay where I prefer and avoid unnecessary visits to hospital. My care is regularly reviewed and my symptoms are managed as well as they can be.

I receive co-ordinated care
My needs and plans are known by everyone involved in my care and I am helped to achieve them. I know how to reach someone who will listen and respond at any time of the day and night.

I live in a community that is prepared to help
My community recognises that we all have a role to play in supporting each other in times of crisis and loss.

Fig 2: The Kirklees Care Charter

Sources of information

[Kirklees Joint Strategic Assessment: bereavement and end of life](#)

[National Survey of Bereaved People \(VOICES\) - Office for National Statistics \(ons.gov.uk\)](#)



healthwatch

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