End of Life Care in the Community

People's experience of end of life care and support in care homes, hospices and at home

October to December 2020

Your independent watchdog ensuring people's voices are at the heart of shaping health and care services in Leeds.

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Summary

Introduction

The further development of End-of-Life Care services for the people of Leeds is a key priority for the Leeds Health and Wellbeing Board and continues to be a key area of focus for the NHS, Care Homes and Social Care.

There is a recognition that more needs to be done to make sure that services can support people to die in their preferred setting including in their own home or community settings when they want to.

Our work focused on finding out about people’s experiences of end-of-life care and support in community settings, and to feed this into the future redesign of services.

We carried out online surveys and 31 people responded, telling us about their experiences of end of life care (for a loved one) in a care home, at home or in a hospice. We also carried out in-depth case studies with 15 people and this report has been shared with service providers and commissioners. This work took place in 2020 in the global Covid-19 pandemic and inevitably some people’s experiences were affected by restrictions needed in response to this. However, we know that in many cases, the restrictions highlighted issues already existing in the system.

The findings from the case studies have been shared with Leeds Palliative Care Network to feed this into the “Leeds Dying Well in the Community” project. We have worked with the project team to develop key findings and recommendations from both the survey responses described in this report and the case studies.

Key Findings

- There was an almost even split between people that had a good end of life care experience and those that reported a negative experience.
- There were large variations reported between the end-of-life care and support that people had received both at home and in a care home.

- Guidance and rules around Covid-19 and visiting further highlighted variations between care homes.

- People talked about the negative impact of the Covid-19 pandemic on both service provision and their experience, especially in terms of face-to-face interactions and pressure on services.

- Many people told us about positive interactions with staff, despite the services being stretched and the pressures that they were working under.

- Some families felt there was a need for better support or offers of support, especially in the months after their loved one died.

- Compassion, respect and communication were key factors, both when people had negative experiences and when respondents reported a positive end of life experience.

Key recommendations / messages

- Increased awareness of ways to offer outstanding end-of-life care for organisations and staff working in health and care services to ensure end of life support is delivered in a coordinated and consistent manner across all settings.

- Centralised and specialist support to be offered to care homes and other organisations caring for and supporting people at the end of life to highlight and share good practice.

- Training and support on end of life care to be provided for health and social care staff working with people at end of life to ensure all services are delivered in a compassionate and consistent manner. This training to include how to recognise that someone is approaching the end of their life, (or dying) and what to expect, but also how to have caring and compassionate conversations with the person who is dying and their loved ones.

- A central contact point to be available for families and carers supporting loved ones, where they can access information and be signposted to organisations that can offer support. This contact point should remain available both while people are caring for their loved one and after they have died and link to bereavement support services.

- Ensure that enough resource is made available so that people can receive the support they need at the end of life, and that this can be provided flexibly and in a timely manner.

Background

There are on average 6,800 deaths per year in Leeds, of which 75% are estimated to be able to benefit from Palliative and End of Life Care (P&EOLC)*. In Leeds, up to 1,700 additional patients per year will require P&EOLC, representing a rise in P&EOLC costs of up to 40%*.

Just under half (45.%, PHE EOLC profiles 2019) of all deaths occur in hospital but this is not the preferred place of death specified by the majority of people in Leeds who have taken part in advance care planning (EPaCCs and ReSPECT data). We need to make sure services can support people to have a good death at home, if this is what they want.

Significant work has taken place to improve service flexibility and this was hastened by increased demand due to Covid-19. Community services saw an increase of over 40% in people being supported to die in the community (with Leeds Community Healthcare data showing a 46% increase in people dying in place identified as "home" between April 2020 and March 2021).

The vision for Palliative and End of Life care in **Leeds' End of Life strategy** is:

"People will die well in their place of choice; carers and the bereaved will be well supported."

A piece of work has been initiated by Leeds Palliative Care Network called the "Leeds Dying Well in the Community" project. It has the aim of understanding and improving Palliative and End of life services available in the community. This is happening in two phases.

- Phase 1 is to understand what happens in Leeds for end-of-life care including the views of patients and carers (this report and the case studies).

- Phase 2 will be to ensure that services make best use of the resources available to deliver the most effective and compassionate care outside of hospital.

* *(Etkind et al, BMC Medicine, 2017)*

Why we did it

We were asked by Leeds Palliative Care Network to carry out a piece of work to find out about people's experience of end of life care in a community setting (care home, hospice, own home). This information would be a part of the project to look at the current system and feed into the future service redesign.

We were keen to use this opportunity to ensure that people's experiences and stories were heard and formed a key part of this piece of work. We wanted to ensure that these powerful personal experiences helped to inform and shape the service redesign, so things are better for people in the future.

What we did

We developed a survey to find out about people's experience of end-of-life care in a community setting. The survey was advertised widely through social media and organisations that work with and support people at the end of their lives. We contacted specific organisations through our **Weekly Check In** to promote the survey and the project.

We also offered people the opportunity to contact us and share their personal story, either through a Zoom interview, telephone call or by email. The aim of the stories was to provide a more detailed and personal account of people's experiences and share these with the service providers and commissioners.

We recognise that due to this work being carried out during the Covid-19 pandemic there were limitations and challenges in how we were able to engage with people. While we attempted to address some of these challenges, the lack of face-to-face interactions will have had some impact on who were able to engage with.

This report outlines the findings of the 31 survey responses.

What we found

We received 31 responses to the survey. 26 respondents (84%) stated their loved one had died, whilst five said that their loved one was currently receiving end-of-life care.

When asked where their relative/loved one died, or where they were currently receiving end of life care, 13 respondents (42%) told us in a care home and another 13 people (42%) said at home. Only five people were receiving or had received end-of-life care in a hospice setting.

Support

The vast majority of respondents (87%) said they had sought or tried to seek support to help either themselves or their loved one at the end of life. Four people said they had not. We received one answer that was unrelated to the question.

Out of the four respondents who did not seek support, three suggested this was because the care was dealt with by services already involved in their relative's care.

Those who did seek support were asked how easy or difficult it was to access. There were 27 responses to this question.

17 respondents told us it had been easy or not too difficult to access care and support. Many comments mentioned that they felt the care was handled well because they had services that were already engaged in their loved one's care, which resulted in a smooth transition to end-of-life care. However, others commented that while it had been quick to access, the care did not meet their needs.

"All supplied through the hospital without us having to ask. Care from hospice and nurses."

"Easy. She was already in the system, needed symptom management and got that."

"Easy to access but slow to react. I get the impression that GPs

are doing the least amount of home visits, no visits at all at the surgery and the nurses are consequently overrun with too many clients and not enough nurses."

Some responses highlighted disparities within and across different services. A common theme mentioned by respondents was the feeling that services were stretched and under pressure, which impacted the efficiency and quality of care.

"The cancer specialist and hospice support were easy to access, but community nursing seemed very stretched."

"Support from neighbourhood team was variable due to caseload demands on staff."

Five respondents specifically commented on the difficulty of accessing support. Issues included not receiving the correct information and difficulties getting support from a specific service.

"We do not know who to contact. The GP and care home have been poor in providing information and/or contact for our loved one."
"It was extremely difficult getting support from manager and staff at the care home."

Help and Advice

We received 30 responses to the question, 'Did you/do you know who to contact if you needed help or advice?'

24 respondents said they did (80%), compared to 6 (20%) who said they did not know who to contact.

Those who responded yes to this question were then asked who they approached, and what service they worked for. This revealed a wide range of services, and individuals within services, which people had used for help or advice.

The most common were GPs (5 respondents) and district nurses (5 respondents). Other places people told us they would contact for support included hospices, care home managers, nurses, pharmacists, home care providers, hospital doctors and Carers Leeds.

Experience of Services

Respondents were asked to tell us about their experience of any end-of-life health or care services that they or their loved one had accessed.

We received 26 responses to this question. 10 people told us where they had received support from but did not provide further information about whether this had been a positive or negative experience. Out of the remaining 16 respondents, just under half (7 responses) told us they had a positive experience, six said their experience had been negative and three talked about a mixed experience.

Positive responses highlighted the efforts of staff in ensuring end-of-life care was of a high quality.

"All the staff at the care home loved her and were at pains to ensure that she, me and our sons were handled with love and care."

"The staff at St James hospital were fantastic; nurses, doctors, paramedics. Once home the district nurses were fantastic."

Mixed responses tended to highlight disparities amongst services and a lack of flexibility. Some responses reported a variation in attitudes of staff, with some showing kindness and compassion whilst others didn't.

"There was no respect, compassion or dignity shown by the management (of the care home) but the carers were brilliant."

People also talked about staff being kind, but feeling they were rushed and not always able to give the time and support needed.

"District nurses very kind but often in a hurry and we didn't want to keep them as [we] knew they had other patients as when phoned for help they weren't sure when they could come."

Negative responses stress the lack of dignity, compassion and poor communication experienced by both family carers and their loved ones.

"On the day my father died we accessed LCH community team, but unfortunately the experience was negative, the nurses who attended did not have any compassion, and communication and

reassurance was not there."

"They have received end of life care. It was communicated to us very insensitively by the care home and very matter-of-fact by the GP saying, 'They've seen it all before' and that our loved one had days to live."

A common theme throughout all answers was the need for good care, compassion and kindness as well as clear communication at end of life.

Digital

When respondents were asked if they accessed digital appointments, 27 people responded. The majority of respondents (78%) said they did not.

The majority of respondents did not leave further comments about this. However, 3 people did comment about their digital access with the GP and felt this had been ok.

"Sort of ok talking to GP but would have preferred to see them."

"I emailed the GP surgery and got timely responses."

Out of the 21 respondents that did not access services digitally, some gave further detail about this. 12 said that they had not needed to access anything digitally or had face to face contact instead.

"We didn't need to access anything as it was all done through the hospital"

"The GP came out to visit mum."

Four respondents commented that they did not know it was offered by the service and were not made aware of it.

"I'm unsure whether this was available"

What worked well/what could be better

Respondents were asked if there was anything else they wanted to tell us. Out of the 22 people that left further comments, 9 (41%) were positive, 7 (32%) were negative and 6 (27%) were mixed.

Answers that were positive tended to focus around smooth processes with end-of-life care, and referred to particular services and individuals that had made sure care was provided well. Themes of care, compassion, respect and dignity came up a lot.

“Excellent care from the care home. Treated all family and mother with care and respect in difficult circumstances.”

“We felt that my Mother and family were well supported throughout the process and my Mother passed away with dignity and respect in a calm environment in her own home.”

Where responses were mixed these centred around poor communication and variations between different services and staff with some providing excellent care and others not so much. Another theme was about the constraints on staff due to high demand and the apparent lack of capacity. However, people also talked about the positive support from many of the staff when they were available.

“All the nursing staff were wonderful when they were here and the many different nurses who came to attend to mum were both professional and very caring. But they seem to have too much work for not enough staff.”

“The nurses both in the hospital and hospice were excellent and so supportive. I was referred to the bereavement support after my mum died but I didn't hear from the service. I would have liked some support from them.”

Where people said things could have been better, many talked about a lack of compassion and dignity at the end of life. Others talked about poor communication between services and with them as families, leading to additional stress at a very difficult time. Some mentioned a lack of support for them as a family.

“If the nursing staff would have more compassion and keep us informed of the care each step of the way, we would have felt more reassured.”

“Communication is very poor. Medical staff and Care Home staff seem very matter-of-fact and forget that although they may see

this every day, families do not. I think they forget that this person is loved, unable to see their family and is not kept informed"

Covid-19 and the impact of the pandemic was mentioned by four respondents. This impact was seen in regard to visiting relatives in care homes and stretched services. As a result, processes seemed slower and there were fewer staff to deal with issues and poor communication.

"I understand the problems caused by Covid-19 but there is no excuse for lack of care and support at end of life."

"Covid restrictions meant no one could visit Mum in the care home from early March until her death at the end of June. Her Alzheimer's means she wouldn't understand why neither of her children or her husband were visiting her anymore."

Our messages / recommendations

This report highlights some of the key issues around end-of-life care in the community. While some of the issues raised were impacted by the Covid-19 pandemic, and the huge pressures that it put on the care system both locally and nationally, it is important to note that this alone cannot account for the inconsistencies in end-of-life care and support reported by the participants.

The findings of the report demonstrate some good practice, with staff often showing kindness and compassion and providing invaluable support for families during a difficult time. Here, staff show how it is possible to apply flexibility around the rules and guidance, allowing a much better experience for people and their loved ones at the end of life.

However, there are also examples of end-of-life care and support being negatively impacted by insufficient communication (between services and with loved ones), and a rigid interpretation of Covid-19 rules and guidelines as well as the pressures on services and staff.

Based on what people have told us about their experiences both in the 31 surveys and in the 15 case studies we have worked with the team from the "Leeds Dying Well in the Community" project and developed the following recommendations to address some of the issues:

- Increased awareness of ways to offer outstanding end-of-life care for organisations and staff working in health and care services to ensure end of life support is delivered in a coordinated and consistent manner across all settings.

- Centralised and specialist support to be offered to care homes and other organisations caring for and supporting people at the end of life to highlight and share good practice.

- Training and support on end of life care to be provided for health and social care staff working with people at end of life to ensure all services are delivered in a compassionate and consistent manner. This training to include how to identify end of life and what to expect, but also how to have caring and compassionate conversations with the person who is dying and their loved ones.

- A central contact point to be available for families and carers supporting loved ones, where they can access information and be signposted to organisations that can offer support. This contact point should remain available both while people are caring for their loved one and after they have died and link to bereavement support services.

- Ensure that enough resource is made available so that people can receive the support they need at the end of life, and that this can be provided flexibly and in a timely manner.

Next Steps

The report will be shared with Leeds Palliative Care Network. The work on the case studies has already been shared with key people in the “Leeds Dying Well in the Community” project.

We will agree with them the next steps to be taken in response to the recommendations and work with them to ensure any agreed actions are followed through and implemented. We will undertake any follow up work required to ensure there are real changes made to the service so that it is a good experience for everyone.

The report will also be published on the Healthwatch Leeds website.

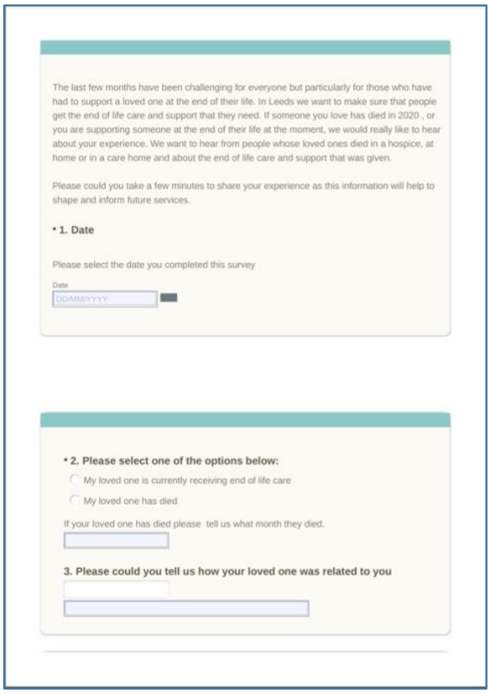
Thank you

This report has been written by Sharanjit Boughan, Community Project Worker at Healthwatch Leeds, in collaboration with Phoebe Collis, Volunteer at Healthwatch Leeds.

We would like to thank all those that took the time to complete the online surveys and share their very personal experiences with us.
A very special thank you goes out to all those that shared their very personal and sometimes difficult and painful stories with us through the case studies. We hope that we have done your stories justice and they will help show what works well and where things need to be better.

Appendices

Appendix 1 - Survey



The last few months have been challenging for everyone but particularly for those who have had to support a loved one at the end of their life. In Leeds we want to make sure that people get the end of life care and support that they need. If someone you love has died in 2020 , or you are supporting someone at the end of their life at the moment, we would really like to hear about your experience. We want to hear from people whose loved ones died in a hospice, at home or in a care home and about the end of life care and support that was given.

Please could you take a few minutes to share your experience as this information will help to shape and inform future services.

• 1. Date

Please select the date you completed this survey

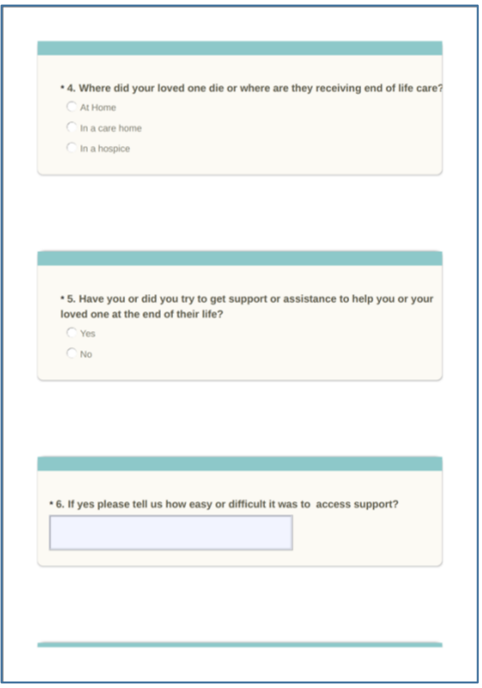
Date
DD/MM/YYYY

• 2. Please select one of the options below:

○ My loved one is currently receiving end of life care
○ My loved one has died

If your loved one has died please tell us what month they died.

3. Please could you tell us how your loved one was related to you



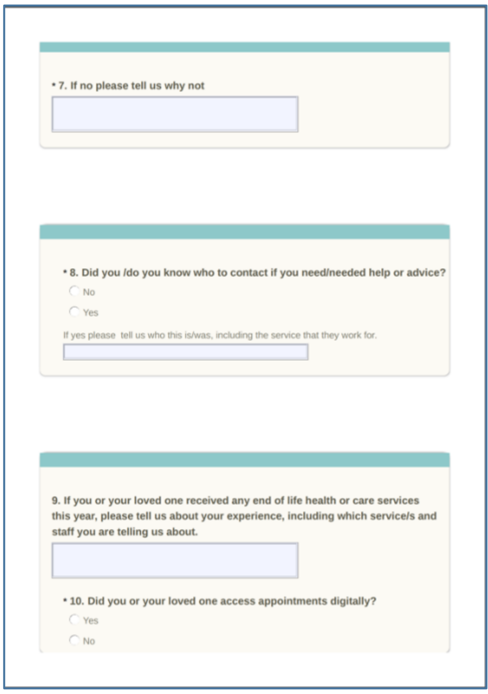
• 4. Where did your loved one die or where are they receiving end of life care?

○ At Home
○ In a care home
○ In a hospice

• 5. Have you or did you try to get support or assistance to help you or your loved one at the end of their life?

○ Yes
○ No

• 6. If yes please tell us how easy or difficult it was to access support?



• 7. If no please tell us why not

• 8. Did you /do you know who to contact if you need/needed help or advice?

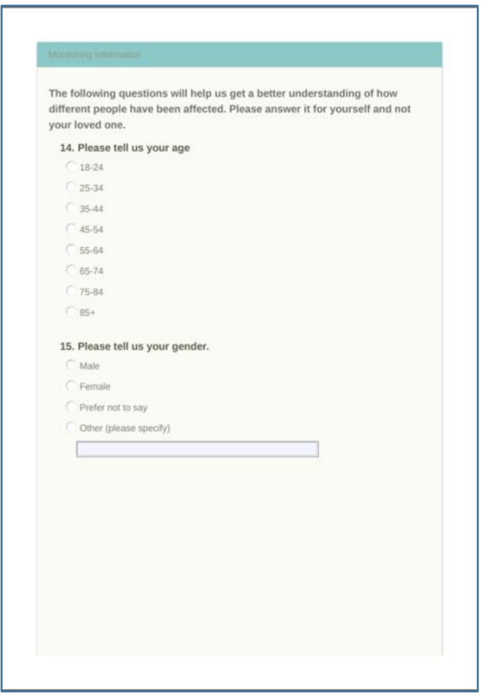
○ No
○ Yes

If yes please tell us who this is/was, including the service that they work for.

9. If you or your loved one received any end of life health or care services this year, please tell us about your experience, including which service/s and staff you are telling us about.

• 10. Did you or your loved one access appointments digitally?

○ Yes
○ No



Monitoring Information

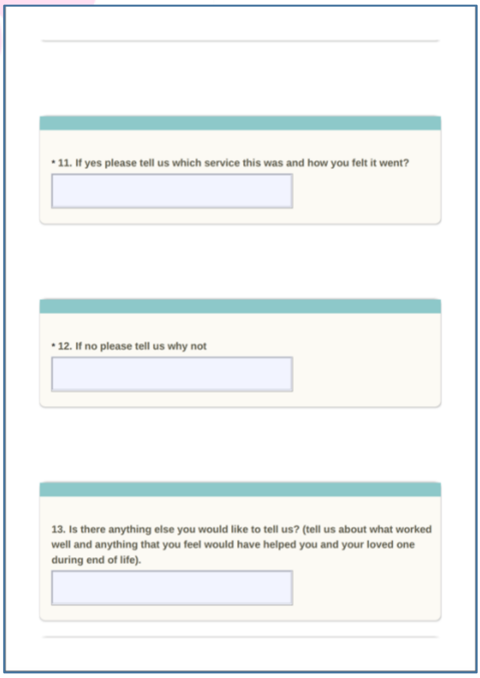
The following questions will help us get a better understanding of how different people have been affected. Please answer it for yourself and not your loved one.

14. Please tell us your age

○ 18-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64
○ 65-74
○ 75-84
○ 85+

15. Please tell us your gender.

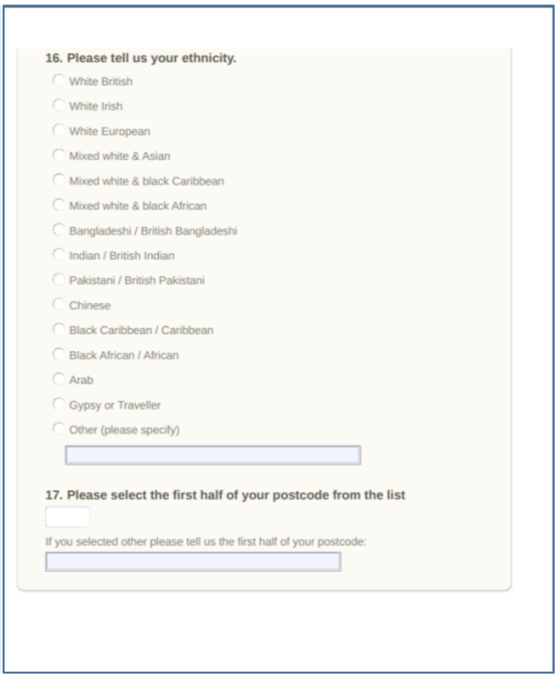
○ Male
○ Female
○ Prefer not to say
○ Other (please specify)



* 11. If yes please tell us which service this was and how you felt it went?

* 12. If no please tell us why not

13. Is there anything else you would like to tell us? (tell us about what worked well and anything that you feel would have helped you and your loved one during end of life).



16. Please tell us your ethnicity.

○ White British
○ White Irish
○ White European
○ Mixed white & Asian
○ Mixed white & black Caribbean
○ Mixed white & black African
○ Bangladeshi / British Bangladeshi
○ Indian / British Indian
○ Pakistani / British Pakistani
○ Chinese
○ Black Caribbean / Caribbean
○ Black African / African
○ Arab
○ Gypsy or Traveller
○ Other (please specify)

17. Please select the first half of your postcode from the list

If you selected other please tell us the first half of your postcode: