



Leeds Palliative Care Network

Leeds Bereaved Carers Survey

2022- 23



Leeds Palliative
Care Network

Your
healthwatch
Leeds



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

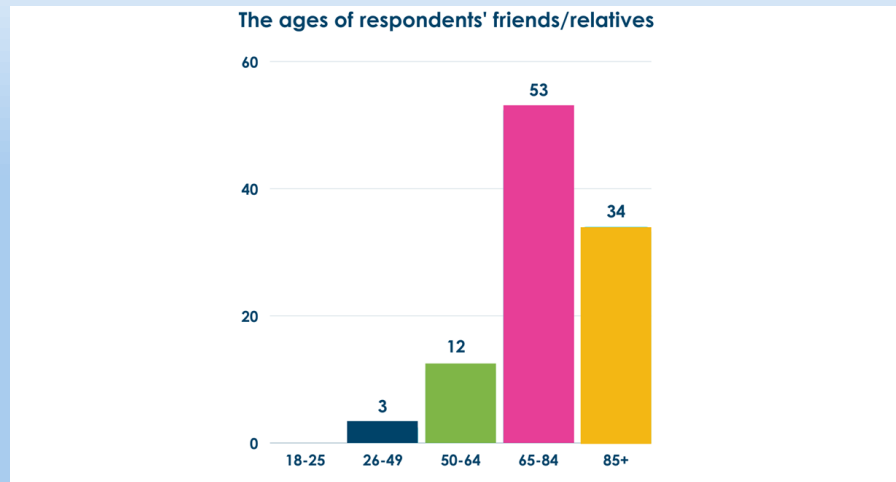
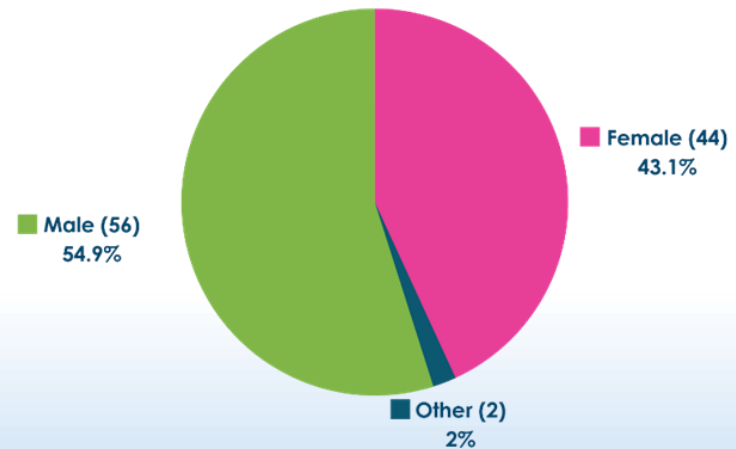
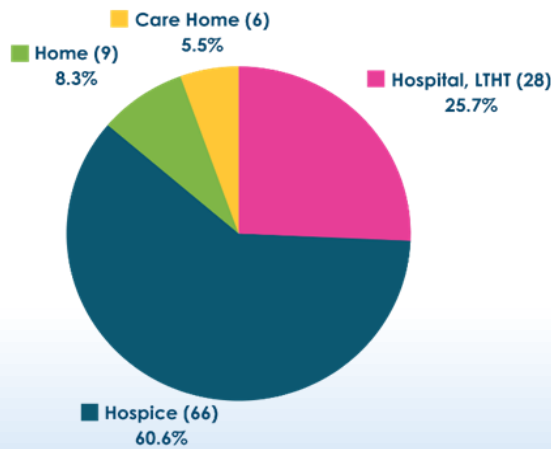
People's experience of end-of-life care and support
for their friend/relative in hospices, hospitals, in their
own homes and care homes

2022-2023

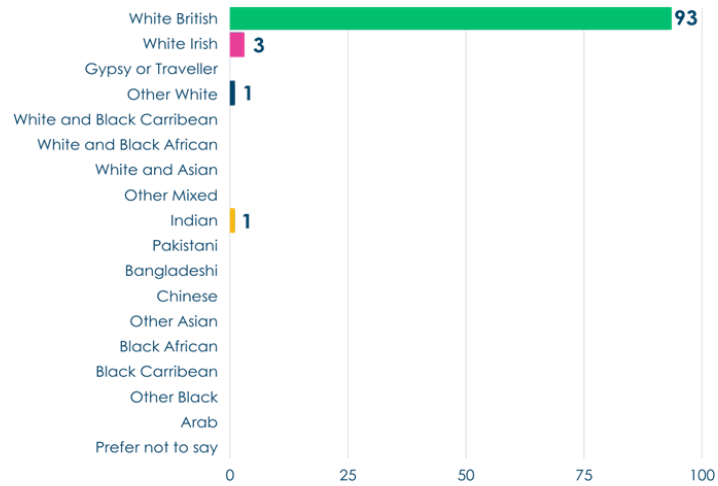
<https://www.leedspalliativecare.org.uk/seecmsfile/?id=440>

About the Respondents

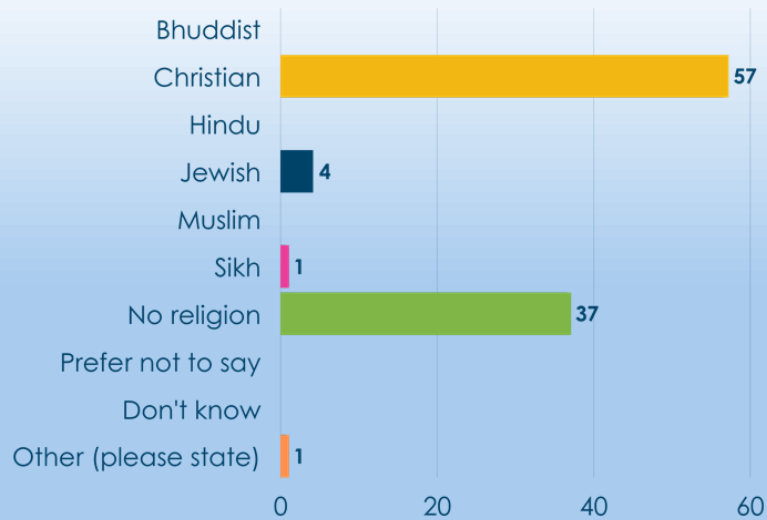
We received a total of 109 responses to our survey



The ethnicity of respondents' friends/relatives

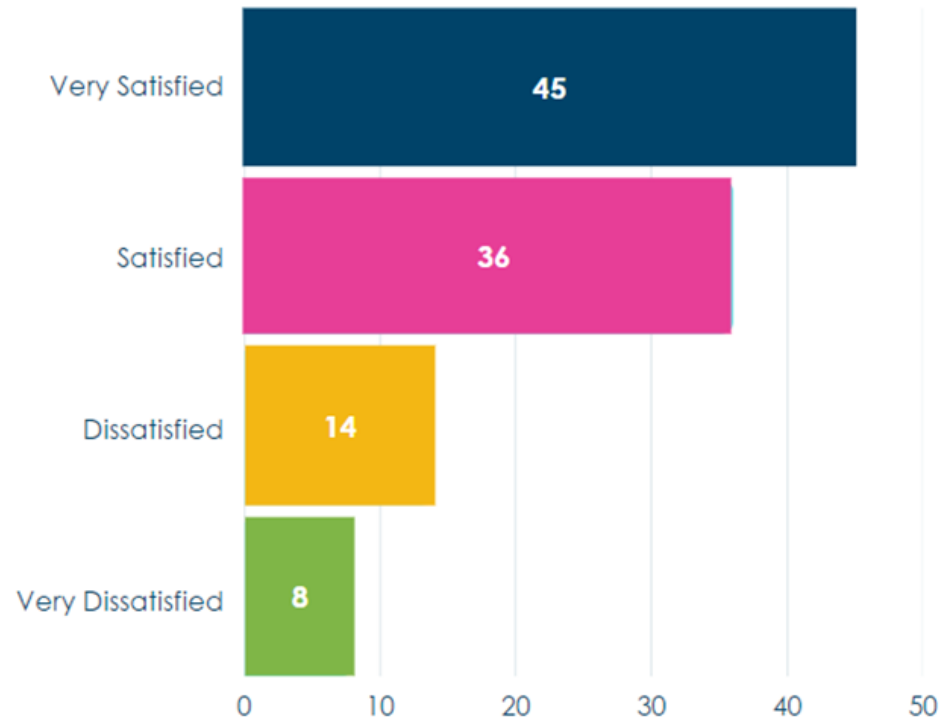


The religion of respondents' friends/relatives



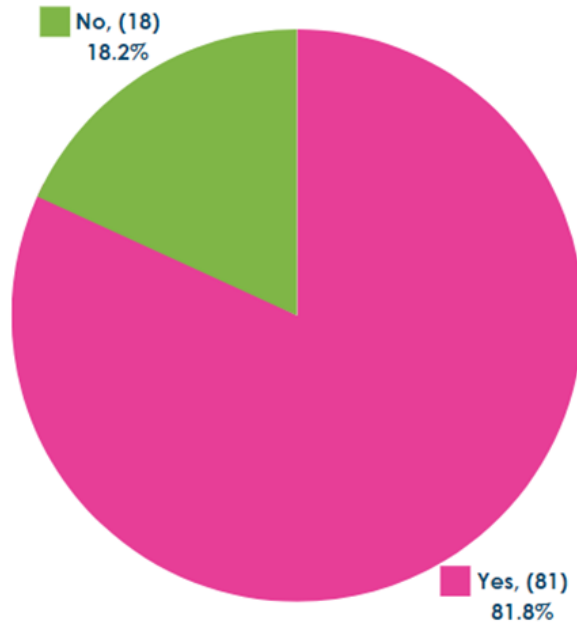
Working Together

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



Discuss Wishes

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



Summary of Findings

Hospices

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

Summary of Findings

Hospitals

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

Summary of Findings

Home

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

Summary of Findings

Care home

- We received 6 responses.
- 80% felt their loved one died in the right place.
- Respondents told us that dying at their care home had been their relative or friend's preference and were glad their wishes had been met.
- Respondents reported the distressing impact that the lack of coordination in care and management of end of life can have, suggesting the way in which services link and work together needs to be continually reviewed and improved.

Recommendations

Hospices

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

Recommendations

Hospitals

- Refresh awareness for all staff regarding the importance of utilising the SUPPORT Campaign for families / friends. This campaign is aimed at providing assistance and support to the families of patients who are nearing the end of their lives. This comprehensive initiative encompasses providing information about various provisions such as car parking permits, comforting care packs, access to toilet and shower facilities and designated family/prayer rooms. It also incorporates the importance of ensuring families receive regular updates and information regarding the provided care and visiting hours outside of regular working hours.
- Embed TALK campaign across clinical areas to ensure the communication needs for dying patients and their families are met in a compassionate way.
- Continue to raise the importance of aiming to minimise ward moves for patients at the end of life. Ensure any moves are communicated sensitively to patients and families.
- Ensure the results of this survey are reported through the Trusts end-of-life care governance structures.

Recommendations

At home

- Priority should continue to be given to enhancing communication regarding care plans, ensuring that all individuals involved are informed about the available support, what to expect, and how medications can help manage common symptoms at the end of life.
- Continue education programmes for community staff to ensure all are trained and competent with the end-of-life care processes and procedures.
- Promote the available information regarding post-death care, ensuring that individuals are well-informed about the necessary procedures and steps to take after the passing of a loved one.
- Share this report with Neighbourhood Services to highlight the impact of waiting times and the importance of communication with family members when there is a delay in visits at the end of life.

Recommendations

Care homes

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

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

Relief of pain & other symptoms

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

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

Thanks
Any Questions?