

Insight Report: Bereavement Services

Understanding the experiences, needs and preferences of people who use bereavement services in Leeds.

October 2024, V2.0

1. What is the purpose of this report?

This paper summarises what we know about bereavement services in Leeds. This includes the experiences, needs and preferences of:

- People (adults) who use bereavement services.

Specifically, this report:

- Sets out sources of insight that relates to this population.
- Summarises the key experience themes for this population.
- Outline the experiences of people in the population who have a protected characteristic.
- Outlines next steps.

This report is written by the [Leeds Health and Care Partnership](#) with the support of the [Leeds People's Voices Partnership](#). We have worked together (co-produced) with the key partners outlined in [Appendix A](#). It is intended to support organisations in Leeds to put people's voices at the heart of decision-making. It is a public document that will be of interest to third sector organisations, care services and people with experience bereavement services. The paper is a review of existing insight and is not an academic research study.

2. What do we mean by bereavement services?

Bereavement services means emotional, psychosocial, and spiritual supports services provided to the family/friends before and after the death of a patient to assist them in coping with issues related to grief, loss, and adjustment.

3. What are the key themes identified by the report?

The insight review highlights a number of key themes:

- Long waits to start bereavement counselling.
- Communication about wait could be better for both patients and professionals.
- Generally, people tended to rely on family and friends for support as they feel uncomfortable talking about this topic.
- Once people access bereavement counselling the feedback is good and they found it valuable.
- Offer of bereavement counselling is not consistent. More likely to be offered if a loved one dies in a hospice.
- People find it helpful to have space to talk.
- Choice of accessing counselling is important - phone, one to one, face to face or group.
- Timeliness of support is important.
- Bereavement counselling is distinct from other forms of counselling.
- The helpfulness of meeting with other people who are grieving and who understand.

This insight should be considered alongside city-wide cross-cutting themes available on the Leeds Health and Care Partnership website. It is important to note that the quality of the insight in Leeds is variable. While we work as a city to address this variation, we will include relevant national and international data on people's experience of bereavement counselling.

4. Insight review

We are committed to starting with what we already know about people’s experience, needs and preferences. This section of the report outlines insight work undertaken over the last four years and highlights key themes as identified in [Appendix C](#).

Source	Publication	No of participants and demographics	Date	Key themes and quotes relating to bereavement support
St Gemma’s Hospice	<p>One-to-one bereavement counselling evaluation</p> <p>Not available online</p>	77 responses	May – July 2024	<p>St. Gemma’s ran an evaluation survey.</p> <ul style="list-style-type: none"> • Person-centred service • Timeliness of support • Good relationship with the counsellor • Value the support in processing emotions of grief • Value of developing practical coping strategies and understanding of grief; ability to resume activities of life, for example work. • Life enhancing nature bereavement support; importance of having a space outside of the family. • Bereavement counselling is distinct from other forms of counselling; grief and the process bereavement support as a gateway to accessing other form of support.
St Gemma’s Hospice	<p>Bereavement Café Feedback</p> <p>Not available online</p>		May – July 2024	<p>Two in-person bereavement cafes running on the first and third Friday morning of the month.</p> <ul style="list-style-type: none"> • The helpfulness of meeting with other people who are grieving and who understand. • Opportunity to learn from other people’s experiences of the grief journey and in turn, share with others. • The Bereavement Café as a springboard for friendship.

Source	Publication	No of participants and demographics	Date	Key themes and quotes relating to bereavement support
St Gemma's Hospice	Growing around Grief Group Feedback Not available online		May – July 2024	<p>Six-week structured group looking at models / theories of grief, art and metaphor, memories, hope and self-care. Runs three times a year .</p> <ul style="list-style-type: none"> • Normalisation of the grief process • The helpfulness of meeting others in a similar situation close bond formed throughout the group. • Increased knowledge of strategies/resources, a deeper self-understanding • A safe space to learn how to talk about the deceased person; the provision of a structure and purpose to the week; increased confidence, increased ability to ask for help.
Carers Leeds	Bereavement Group Evaluation Not available online	12	2024	<p>Two groups: Bereaved carers support Group and Cross Gates bereavement support.</p> <ul style="list-style-type: none"> • Meeting others who have been bereaved is helpful. • Support from the group co-ordinator. • Information and support • Attending the bereaved carers support group has helped with wellbeing. • Support from other carers has enabled me to feel less isolated. • It helps to talk about loss in a safe environment.
West Yorkshire Healthwatch	People's experiences of end-of-life care in West Yorkshire https://nds.healthwatch.co.uk/sites/default/files/rep		2024	<ul style="list-style-type: none"> • Most people told us they were not receiving bereavement counselling or support. People largely looked to family or to friends for emotional support with dying and bereavement, but there was widespread acknowledgement that many people are uncomfortable with talking about these issues.

Source	Publication	No of participants and demographics	Date	Key themes and quotes relating to bereavement support
	orts_library/20240301%20Wakefield%20Peoples-experiences-of-end-of-life-care-in-West-Yorkshire.pdf			<ul style="list-style-type: none"> • The provision of bereavement support for unpaid carers who have cared for a dying loved one was very uneven; only when a person had received hospice care or when a parent had lost a child did, we regularly hear that bereavement support was offered. • Very few people had accessed bereavement support or counselling. One woman told us she felt it was her role to be strong and supportive to others, which made it harder for her to reach out when she needed help. • Another said that she felt services expected their users to fit around them, whereas it would be better if services came to people. (Feelgood factor Leeds) • Many of the bereaved people we spoke to as part of this project told they were talking to someone about their experience for the very first time • Most people saw family and friends as the first contacts they would turn to for support through dying and bereavement, with very few saying they saw this as the responsibility of a wider community. • Not everyone received the support through caring for a dying loved one from family and friends. Sometimes, the individuals we spoke with felt that others weren't equipped to have conversations about death with them: their families and friends didn't know what to say and tended to avoid the subject
Leeds Teaching Hospital NHS Trust (LTHT)	Summary of Maternity Bereavement Experience Measure Not available online		2023 / 2024	Feedback from Bereaved Families at LTHT: <ul style="list-style-type: none"> • Families felt that aftercare from staff was supportive and that they had memory making opportunities and were involved in their care. • There was feedback about difficulties with GP and outpatient services. • Families expressed importance of having ease of parking facilities.

Source	Publication	No of participants and demographics	Date	Key themes and quotes relating to bereavement support
				<ul style="list-style-type: none"> • Families also discussed the importance of a dedicated space to discuss results of their pregnancy or baby loss investigations. • Delay in induction was also reported by some families. • Information sharing was helpful before attending hospital.
<p>NHS West Yorkshire ICB in Leeds</p>	<p>Cruse Leeds Bereavement Quality and Equality Impact Assessment (QEIA)</p> <p>https://www.healthandcareleeds.org/wp-content/uploads/2024/10/0028_Cruse_QEIA_Bereavement_Services_V4.0_Final_Accessible_v2.7.pdf</p>		2024	<p>Feedback from Leeds Cruse bereavement service</p> <ul style="list-style-type: none"> • “I found the helpline and the understand your bereavement online session very helpful. I also found the bereavement sessions one to one very helpful. I would like to say that the wait for a volunteer was long, and I had to chase it up. Also, I think maybe 8-10 sessions would be more helpful. 6 weeks fine but I would have appreciated a few more. Also, info about bereavement groups”. • “I was very down and depressed following the death of my husband last year. I didn't let my feelings out to family, and I wasn't going out. Upon starting my zoom meetings with Elvira, I felt as though she understood me immediately and she has helped me so much”. • “I have been very happy with my support & the volunteer was excellent”. • “All the Staff were very helpful. Understanding and caring helped me a great deal”. • “I have found it helpful to have space to talk”. • “Thank you to everyone involved but especially to the volunteer I can now see a future”. • “I enjoyed the one group meeting that I had but that wasn't enough. Twice when I first rang Cruse, I was told that they were very busy and had a waiting list. Later when I rang, I spoke to a caring man who was very helpful”.

Source	Publication	No of participants and demographics	Date	Key themes and quotes relating to bereavement support
				<ul style="list-style-type: none"> • “I would advise anyone in the same position to please get in touch like I did”. • “Feel so much better after our chats. Was easier to talk on the phone to someone I don't know, rather I was able to open with her encouragement, about my loss, my future without him. The volunteer was very compassionate and with her help I started to focus on the time we had together and the good times we had rather than the time we won't have together. Even though I am now going through a difficult time with my health, I feel more able to cope that I would have without her help to cope with my grief”.

5. Additional Reading

- Engagement summary August 2023 from Carers Leeds:
 - A man lost his wife due to suicide and was shocked at how little support he was offered - contact hbutters@nhs.leeds for the report
- Central North Leeds PCN – Two social prescribers - General feedback about the Cruse service 2024:
 - Long waiting lists for clients accessing Cruse service.
 - Communication with professional referrers is not good.
 - Telephone calls for counselling may not be always the right method for people who are grieving.

7. Inequalities Review

We are committed to tackling health inequalities in Leeds. Understanding the experiences, needs and preferences of people with protected characteristics is essential in our work. This section of the report outlines our understanding of how end of life care is experienced by people with protected characteristics (as outlined in the Equality Act 2010 – [Appendix D](#)).

Please note that we are aware that the terminology used in relation to the recognition of a person's identity may depend on the context of its use. Some people may define some terms differently to us. We have tried to use terminology that is generally accepted. Please do get in touch if you would like to discuss this further.

Protected Characteristic	Insight
Age	At present, we have been unable to source any local evidence relating to age.
Disability	At present, we have been unable to source any local evidence relating to disability.
Gender (sex)	At present, we have been unable to source any local evidence relating to gender (sex).
Gender reassignment	At present, we have been unable to source any local evidence relating to gender reassignment.
Marriage and civil partnership	At present, we have been unable to source any local evidence relating to marriage and civil partnerships.
Pregnancy and maternity	<ul style="list-style-type: none"> • Families felt that aftercare from staff was supportive and that they had memory making opportunities and were involved in their care. • There was feedback about difficulties with GP and outpatient services. • Families expressed importance of having ease of parking facilities. • Families also discussed the importance of a dedicated space to discuss results of their pregnancy or baby loss investigations. • Delay in induction was also reported by some families. <p>Information sharing was helpful before attending hospital.</p>
Race	At present, we have been unable to source any local evidence relating to race.
Religion or belief	At present, we have been unable to source any local evidence relating to religion or belief.
Sexual orientation	At present, we have been unable to source any local evidence relating to sexual orientation.
Homelessness	At present, we have been unable to source any local evidence relating to homelessness.
Deprivation	At present, we have been unable to source any local evidence relating to deprivation.

Carers	At present, we have been unable to source any local evidence relating to carers.
Access to digital	At present, we have been unable to source any local evidence relating to access to digital.
Served in the forces	At present, we have been unable to source any local evidence relating to serving in the forces.

8. Gaps and considerations – are there any gaps in our evidence or things we need to consider?

- Undertaking this insight report highlighted the lack of patient / public feedback available from people experiencing bereavement services. We are unaware of whether provider organisations are not collecting service experience or whether the information is being sent to the ICB but not getting to the relevant departments.
- Any future commissioning of bereavement services needs to have a robust patient experience element within the contract and feedback loop back into the ICB.

9. Next steps – What happens next?

This insight report will be used to improve bereavement services in Leeds.

We will add the report to our website and use this platform to demonstrate how we are responding to the findings in the report.