

The Listening to Loss Project

September 2023 - February 2024

Creatively exploring experiences of
bereavement and grief in Sheffield

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Space to Breathe
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**Compassionate
Sheffield**

(space to
breathe)



DiverseCity
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Executive Summary

This report is a summary of findings and recommendations, following a collection of community engagement activities in Sheffield. The aim of this work was to provide compassionate and supportive spaces for people to reflect on their experiences of loss and to target our engagement work with traditionally underrepresented communities.

Through a creative approach we asked local people across the city to consider;

- What is loss to you?
- What challenges have you experienced?
- What helped you during your period of grief and loss?
- What do you wish was there, but wasn't?

Findings from these questions can be found on pages 7-12 of this report.

We have analysed the findings and seven recommendations have emerged which can be summarised as follows:

1. Support should be designed around cultural context
2. Emotional preparation for death should be considered
3. Review how people access 'services'
4. Do not forget where more deaths happened during COVID 19
5. Support key community figures
6. Consider that grief is often collective
7. Mind the gaps – support designed around the journey

More information about the recommendations can be found on pages 13 – 15.

Whilst the experience of death and loss is something we all have in common, the ways in which people access support has a cultural footprint. By investing some targeted time, energy and resource, we have an opportunity to address inequalities and the inequity of access to support, during this important part of life.

We hope the process of 'Listening to Loss' and this summary report act as a step in understanding cultural context, identifying existing assets and responding to the bereavement support needs of people in Sheffield.

The seven recommendations above emerged through findings from the community engagement process. The primary recommendation from the delivery partners of

this project is; **the conversation needs to continue**. Potential questions for framing future conversation can be found in the 'Reflective Questions' section of this report.

Reflective questions

In conducting this research and then preparing this report, we have been struck by a series of questions which prompt ourselves, and hopefully all of us to think collectively and in a spirit of partnership about the ways to support Sheffield's residents in death and bereavement.

We'd like to share these questions at the beginning of this report and to help frame the ways we might collectively work together to help local people.

- a) What is the everyday experience of bereavement and loss in the city? Are there 'Sheffield-specific' dynamics to loss and what more generic principles apply?
- b) What are the barriers that stop people from accessing services and support? Why and where do they exist?
- c) Considering the existing model of bereavement services; what are the strengths of existing services, and given the changes coming in local provision, how might we collectively maintain these strengths going forward?
- d) To what sense is it true that bereavement and loss is different depending on different faith, cultural and local community contexts? Are there similarities to build on and where differences exist, how do we adapt in support?
- e) We have discovered that key local figures and important local community/faith groups are central to the support people rely on. How can we work together across existing services to support these local figures and groups as they help others?

Project Report

Project Background

'Listening to Loss' is a collaborative project between Space to Breathe, Compassionate Sheffield and DiverseCity . We wanted to work together to establish the differences in approach, longings and experiences in the bereavement journeys of different individuals and communities across Sheffield.

The Sheffield Bereavement strategy emphasises "equity of access", yet during a discussion with a group of voluntary sector and statutory sector organisations, our collective experience suggested many communities' needs are not being recognised.

A sometimes "clinical" approach to bereavement means that practical concerns like funeral costs, housing, residency, repatriation or loneliness are not always factored in.

Compassionate Sheffield, Space to Breathe, and DiverseCity came together as three organisations that all felt this area was a priority for a listening exercise and all brought expertise and connections.

Compassionate Sheffield apply a community development and public health approach to death, dying loss and bereavement. Through their engagement work with individuals, communities and organisations, they bring a unique insight into experiences of bereavement and loss across the city. Compassionate Sheffield have funded this initial work.

DiverseCity have been working on the Hear to Hear project and in particular their "Café Sukoon" initiative, providing cross cultural listening spaces for people to come and talk. DiverseCity have a history of representing the needs of diverse communities across the city.

Space to Breathe are a wellbeing and mental health social enterprise in the city. They have used a creative arts-based research approach in projects with the NHS, People Keeping Well and Healthwatch UK to draw out emotive and responsive insights into challenges in the city alongside practical data. They also bring a wellbeing perspective, ensuring participants are looked after.

Project Approach

Using a mixture of face to face events, a virtual workshop and online surveys we aimed to both provide care and support to people's bereavement journeys and also ask for insight and comment on what would make things better.

We used the following methods:

- Between September and December 2023 we ran three face to face workshops called 'Listening to Loss' which created interactive stations and creative ideas to prompt reflections around bereavement (images of the stations in Appendix 1). These were hosted at:
 - Sheffield Hallam University
 - SACHMA
 - Firvale Community Hub.
- In February 2024, we designed, delivered and gathered insights during an online version of the Listening to Loss workshop.
- Throughout the project, we promoted an online questionnaire which gathered lighter touch feedback.
- During February and March 2024, we spoke to leaders of Voluntary Sector (VCS) organisations to discuss some of the initial ideas and findings.

The insights gathered through these methods, were designed to provide a safe and compassionate space for people to share their experiences and to reflect on these fundamental questions:

- What is loss to you?
- What challenges have you experienced?
- What helped you during your period of grief and loss?
- What do you wish was there, but wasn't?

The face to face and online workshops used William Worden's Four Tasks of Grief as a model for exploring bereavement. These tasks, which were outlined in Worden's book "Grief Counselling and Grief Therapy" (Brunner-Routledge; 3rd edition 2003.). The four tasks are:

1. Acknowledging: working through pain and grief
2. Accepting: accepting the reality of the loss
3. Adjusting: to adjust to an environment where the deceased is missing
4. Reinventing: to emotionally relocate the loss and move on with life

Worden suggests that these are four concurrent tasks that someone can consider who is facing loss or grief. Here, the process of mourning as an “adaption to loss¹” is set out in these four tasks that can be tackled concurrently or individually.

Feedback from the workshops suggests that structuring the engagement in this way was both therapeutic and help people navigate the complexities of times of grief. We used visual prompts and interactive activities to help generate reflections and capture content produced through this engagement work (images of the stations in Appendix 1).

Audience

The focus for the workshop was to engage with people from communities who are less connected to traditional bereavement support services. 21 people attended the face to face and online workshops.

- 6 males and 15 females
- 76% of attendees identified their ethnicity as other than White British – including Asian, Asian British, Black British, Roma and Mixed Race
- 18 of the 21 were aged 30 – 50 and 3 were under 30 years old

The online questionnaire was completed by 30 individuals. Below is a breakdown of the ethnicity recorded by participants.

Respondents to the questionnaire	
White British	15
Black/Black British	4
Asian/Asian British	4
Mixed race	2
Rather not say	5

Gender mix for participants was female 20 and male 10.

In terms of age, 3 participants were 30-39, and 9 people for each of the e remaining age brackets; 40-49, 50-59 and 60+.

Postcodes covered by the survey showed decent coverage with S1, S6, S35, S5, S10, S2, S17, S12, S11 and S13 represented.

Combing the demographic data of the workshops and online survey, the data suggests we have engaged with an ethnically diverse audience with only 20 of 51

¹ Worden 1983 pg.10

from a White British heritage. The data also suggests that delivering targeted workshops is a more effective way than online questionnaires, for engaging with people from traditionally underrepresented communities.

“This really helped and gave local people a space to share”
(Local host organisation)

Findings

Through the different formats we have highlighted these four areas of responses:

1. What is loss to you?
2. What challenges have you experienced?
3. What helped you during your period of grief and loss?
4. What do you wish was there but wasn't?

What is loss to you?

This question drew out one of the overarching ideas that because we speak infrequently about death, we have limited emotional literacy in how to navigate it. One respondent shared, “it’s really difficult to know what healthy grieving is and what it’s not.”

We began the process by asking people to express in their own words what loss meant. This word cloud demonstrates the breadth of responses.

The second category of responses were more positive. One participant at the Hallam event noted:

“A particular loss can’t be the end of the world. Hence, to accept it and move forward and explore the future with a positive mindset.”

Another noted the “life changing” nature of loss and how hard it is to navigate yet also suggested this was possible with help.

Most of all though, this first question highlighted the relational pain of bereavement. Words like loneliness and isolation were common. One called it “an assault on love.”

What challenges have you experienced?

In all the different settings we asked people what challenges they’d experienced. Through the online survey and in the workshops, there was consensus that the provision of support was a central issue.

The barrier to support fell into five main areas.

1. Support needs to be compassionately offered and timely

As one participant put it, she “always used to be independent and not need anyone so opening up and letting people in is my biggest barrier.” This person related how her nervousness in accessing support was misunderstood as a lack of commitment and she faced the potential of help being withdrawn. Any support needs to factor in the vulnerability of people involved and take time with them as they take time with their grief.

There is also a reality that grief happens differently for everyone and for some people they fall into a grey area. In those settings someone’s bereavement/grief may not be serious enough for formal counselling yet not insignificant enough to get no care at all.

2. Support means a long wait

There was general recognition that services have long wait lists and sometimes the need for help doesn’t coincide with the ability to book in. Many noted the conflict of the need to “sit with it first” – and many bereavement services suggest time before engaging – but then when ready they find there is a long waiting list.

3. There is a need for more general emotional preparation

In the online group, one person noted:

“Since the development of the NHS, death has moved from the home into institutions such as hospitals and hospices. We aren’t as familiar with death and dying and we aren’t exposed to it.”

Many noted the impact and help of Death Café’s and other such groups that get us used to talking about death. This is one element. But in our process we also noted that many struggled with the idea of “accepting” from Worden’s four tasks, by not accepting the loss we are not open to seeking or receiving support. One person said:

“Accepting was the hardest part, still feels unrealistic or a bad dream, but whenever I visit her grave I feel like this has happened and life is going on.”

4. Support needs to be flexible

As we chatted with people we noted that bereavement happens in different ways and often in unplanned or unexpected times. One person noted their grief journey began when “someone deteriorated quickly and I couldn’t respond.” Others noted the experience of grief during long illnesses like dementia and reflected on what is often termed “anticipatory grief.”

5. Impact of reduced access to support during Covid

Many people in our listening exercise noted the impact of COVID. One person noted:

“I think the impact of Covid - the fear, trauma and uncertainties - still have a massive psychological effect on us, even though, as a society, our day-to-day lives seem to have rattled on.”

It seemed clear at least amongst our audience, that COVID and lockdowns are still having an impact, both on having interrupted/abnormal grief processes that are impacting people now or in fears about loss/future.

One person experiencing loss talked about seeing the whole world act like nothing was wrong, yet to them they were still concerned about COVID, about infection and ultimately scared about what might happen.

During this engagement process, we noted that many communities we engaged with rely on key figures who offer support to families during times of crisis. This might be a figure at mosque/church, a community elder or just someone who is well connected and holds people/families together.

Some of these figures were present as we were hosted in different community groups across the city. We could see the reassuring presence of leaders of SACHMA and Firvale Community Hub as they supported local people.

However, many of these figures are doing this supportive role in their spare time, with little formal training but have accumulated knowledge through life experience. These individuals talked about how they don't have any formal structures or mechanisms in place around supporting people with loss. As these people are key pillars of how Sheffield communities grieve and navigate loss, perhaps we should ask ourselves how we can best support them.

Other supportive places in the local community emerged as:

- Funeral directors "who helped us understand the process."
- Registrars prepared to talk and explain what happens.
- Faith groups and Faith leaders
- Youth group leaders
- Coach at a boxing gym
- Hairdresser

Whilst preparing this report, a local VCSE organisation got in touch with us after experiencing two losses amongst its own staff. They asked whether the Listening to Loss experience could be something to help their own team. They noted that resources and support to help in collective spaces such as work seemed limited.

We heard from people that distracting, working hard or helping others to help normalise pain from loss was a common response. There may well be practical merits in this. However, providing space so people feel able to share when they are ready and providing tools and ways for people who experience collective loss to help each other seem important.

What do you wish was there, but wasn't?

We had a number of specific responses to this question, in this section we have tried to list as many as possible as they present tangible ideas for development and many have worked their way into the recommendations of this report.

A few people picked up that there seemed to be a gap between the funeral and times when some bereavement services encourage bereavement support. How do people navigate this time in a healthy way?

“There is an absence of care post-funeral. Most bereavement support services don’t kick in then, but after all the organising/planning of the funeral, people experience a real void.”

Many longed for support in local communities by local people where they felt like they belonged. Some noted that more informal support or support in free places such as libraries would help.

“I wish there was a family with me here, or environment where I feel like I am with my people.”

“Having a bereavement buddy, someone to help me understand why I am in so much pain.”

There was a desire for some information or shared knowledge that would help people navigate both the practicalities of managing a death and the emotional journey they might go on. It may be in the form of a grief support group where people could be orientated with models of loss.

We noted a general sense of confusion about registering a death and the different aspects of what is needed. Whilst we know resources exist to guide people at this time, so further education would be helpful.

“I wish I knew what to expect from death, from the funeral and advice about how I might feel after – a map of what might happen.”

Another person added their hope for “guidance on the bereavement journey and what is/isn’t healthy and normal. Some sort of check-in or support which isn’t condescending or impersonal.”

This person and others noted the earlier mentioned cultural barriers around grief, death and loss.

“I wish we had a better cultural perspective about death, grief and loss. I wish there was less of the ‘pull yourself together/just get on with it/it’s too hard, so I’ll minimise it’ kind of mindset.”

One participant shared, "I wish everyone could access therapy if they needed it. ' Whilst this person's desire for free therapy may not be practical, it was a recurring theme that there didn't seem to be a closely aligned link between mental health support offers and bereavement care, in both the health and voluntary sector.

The participants felt that bereavement care and mental health was treated as different entities, often with mental health support mechanisms not feeling confident in supporting people with bereavement. One person expressed it in this way – "Joining up with other support services - sometimes people can end up navigating multiple sources of 'support'.

Recommendations

The following recommendations are based on the findings of our project and focus on ways to promote healthier and more inclusive bereavement support going forward.

1. Support should be designed around cultural context

Throughout the report, the desire for support is a constant theme. The Sheffield Bereavement Strategy cites the need for "culturally competent bereavement counselling services citywide" and this certainly seems to be confirmed by this report. From our conversations, we would recommend a culturally competent approach would include:

- a) Flexibility – recognising the different ways we grieve
- b) Sensitivity – to emotions and to cultural needs
- c) Faith and spiritually aware – recognising the place of faith and spirituality in many people's bereavement journeys
- d) Practical as well as clinical – the impact of loss includes many practical elements such as pet care, visa implications and loneliness as well as the emotional and psychological impacts.

One area that we heard about was the distinctives of burial site needs for Muslim communities in the city. This is a crucial issue for this community and it would seem right that those with community connections, shared beliefs and experience be consulted with on issues such as these.

We would recommend a more varied and nuanced response to the area of bereavement care to meet these needs. We noted that the Faith and Voluntary Sector provide a stronger resource in this area, because they have flexibility and provide the practical support that is needed.

2. Emotional preparation for death should be considered

It is noted throughout the report that people find it hard to talk about death and wish they were better prepared before they have to face loss.

The task of orientating ourselves to the realities of death before we experience bereavement remains a priority. Respondents noted services like Death Cafés, Café Sukoon and community support provide key opportunities for this emotional preparation.

Other requests were for support in local and free to access settings and the question of a map to orientate ourselves to processes. Particular confusion arose around requirements for registering a death and getting information to people.

We would recommend a review of this area of preparation and consideration of a local map of services or supportive information, similar to the Sheffield Mental Health Guide where people can easily find support that helps them. We note that a mapping website like this exists in Manchester to good effect.

At the point of loss, people's regular refrain is "I've lost someone, what do I need to do?" Support in this area is crucial. Then after the loss, a person may process the emotional and psychological aspects of the loss but also may experience other practical challenges.

3. Review how people access 'services'

Everyone we spoke to was aware that there is a significant waiting list before accessing bereavement support. This often puts people off the process before they begin. People also noted that alternatives (e.g. therapy) cost money and again this can exclude people.

Whilst Waiting Lists are an increasing part of our society today, we would recommend the following ideas to help change this situation:

- That people can register for waiting lists after a death so that their wait time coincides with the recommended 6-9 months of "taking time" after a death before accessing support.

- That Voluntary Services, including those that support Mental Health be able to take some of the strain from these lists so that either supplementary support is received or at least that people are prepared to help whilst they wait.
- That more free to access groups and community connection points be promoted, so people can find their own context for support and avoid emotional isolation.

4. Do not forget where more deaths happened during COVID 19

COVID was a regular refrain in this project. It has affected people in terms of restricting/abnormal grief processes but also in terms of their own fears and anxieties.

We note that the Sheffield Bereavement Strategy notes that impact of COVID disproportionately on ethnic minority communities and on areas of high socio-economic deprivation.

In these areas, we would recommend priority be given to offering access to bereavement support but also consideration be given to the mental health impact of the pandemic and people's experiences. The disproportionate impact of the pandemic on certain communities must not be forgotten and the experiences of loss are a fundamental legacy of this inequality.

5. Support key community figures

We heard stories through this project of key community figures who make a big difference. In one setting we were told of an individual linked to a Mosque who supports families at times of loss and is spread incredibly thin.

These figures are often unpaid and untrained and we rely on their community-spirit and compassion for many of the unseen aspects of bereavement care in the city.

We would recommend consultations take place with community groups to help reach out to some of these individuals, to offer support and to acknowledge the value of their work.

6. Consider that grief is often collective

Grief and loss is not an individual act. Whether it be a local community grieving together or a workplace where colleagues have been lost – collective grief is an area where people seem unsure what, if any, help is available.

The existing offer of services is to provide support to individuals. There is an opportunity to consider the role of communities and organisations in supporting people with grief. We would recommend that expertise be shared with entities that provide support and enable collective grief. Whether that is the collective grief of an organisation for one of its employees, a school for one of its students, a member of a faith group.

These social events should be considered and services with expertise should consider how they could enable the collective grieving process.

7. Mind the gaps – support designed around the journey

This report has identified a number of gaps in support which we believe should be prioritised and considered. The existing offer of support is pieced together by lots of single providers, but we should consider the journey people go on and examine the gaps in support.

The gap between funeral and the (6-9 months) stage when bereavement is considered to set in. We note particularly the sense of isolation after a funeral when activity dies down and people often begin to feel alone.

We would recommend follow up visits, post-funeral and would suggest a process of liaison with faith communities to help bring this into actuality.

As a system, we should also consider people who exist in the gap – neither too serious for bereavement care intervention but, also not doing well enough to handle things on their own.

We'd recommend further group, drop-in services and supportive messaging be available for this context. We have to unlock the capacity of people they already trust and have contact with, reaching out to a service is often a barrier for people who fall into this gap.

People often need someone to help them navigate the practical realities of loss. We liked the suggestion of a 'bereavement buddy' and we'd recommend this concept be explored in Sheffield.

What next?

We hope the findings of this engagement project and this report are helpful and shine a light on the experiences of people in the city working their way through grief, bereavement and loss.

From here the next steps will be to:

1. Work between Space to Breathe, Compassionate Sheffield and Diversity to disseminate this report, its findings and recommendations.
2. Publish the report online and print to ensure people who've taken part know their feedback has been listened to and shared with decision makers.
3. Continue the conversation. Facilitated conversation with stakeholders due to take place, on June 14th 2024 – at Scotia Works Sheffield, 10:00 – 12:00.
4. Look to build on the recommendations of the report, trying to resource and deliver elements that will improve people's experience of loss.

Report compiled and written by Andy Freeman from Space to Breathe
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Appendix 1

Some photos of the stations the face to face workshops that were held events at Sheffield Hallam on 22nd November, SACHMA on 1st December and Firvale Community Hub on 20th February the events are below.



The venue at Hallam with stations across the room.



Netting was put up to let people peg the names of people they wanted to remember. Over 60 names were remembered through the events and online.



Art installations help prompt people's thinking about what loss means and how we find it to talk about loss and death



We used creative arts and imaginative ideas to prompt thinking.