

Appendix A:

Thirteen SWL Community Bereavement Gaps Workshops Reports 2024–25

South West London

Bereavement Services and Support:
Gaps Workshops Report (June 2025)



Contents

1. Gaps Workshops	2
2. Submitted Workshops Reports (2024-25)	3
2.1 Workshop Report: ASCA	3
2.2 Workshop Report: Centre of Change	9
2.3 Workshop Report: Cruse Bereavement Support	13
2.4 Workshop Report: Dignitate	22
2.5 Workshop Report: JFJ Foundation CIC	31
2.6 Workshop Report: Jigsaw	36
2.7 Workshop Report: Kingston and Richmond NHS Foundation Trust	41
2.8 Workshop Report: Mind in Kingston	47
2.9 Workshop Report: Rainbows Across Borders	50
2.10 Workshop Report: Seen	55
2.11 Workshop Report: St Raphael's Hospice	60
2.12 Workshop Report: Togetherness Community Centre	64
2.13 Workshop Report: Togetherness Community Centre	70

Appendix A: Thirteen SWL Community Bereavement Gaps Workshops Reports

South West London Bereavement Services and Support: Gaps Workshops Report (June 2025)

1. Gaps Workshops

There were 13 Gaps Initiative Workshop reports submitted to inform our Phase 2 community engagement for SWL Bereavement Services and Support. These are provided in this section for further information. Participating organisations and groups from across south west London were:

1. [ASCA – Addiction Support and Care Agency](#) (Richmond)
2. [Centre for Change](#) (Croydon) Provides counselling, coaching and mentoring to people affected by trauma, discrimination, unhealthy relationships, loss or grief.
3. [Cruse Bereavement Support](#) (Sutton)
4. [Dignitate](#) (Croydon) Dementia charity devoted to addressing dementia through a culturally sensitive and inclusive approach.
5. [JFJ Foundation](#) (Hackney – providing an outreach programme in Croydon) Educates young people on the dangers of knife crime and serious youth violence.
6. [Jigsaw4u](#) (Merton) Provides specialist wellbeing support services for children, young people and families across South West London.
7. [Kingston & Richmond NHS Foundation Trust – Early Pregnancy Unit](#) (Kingston)
8. [Mind in Croydon](#) (Croydon)
9. [Rainbows Across Borders](#) (Croydon) Voluntary self-help group for lesbian, gay, bisexual & transgender (LGBT) asylum seekers.
10. [SEEN](#) (Richmond) Support for people facing unplanned pregnancy and baby loss.
11. [St Raphael’s Hospice](#) (Merton and Sutton)
12. [Togetherness Community Centre](#) – Adults 60+ (Merton, Wandsworth, Sutton)
13. [Togetherness Community Centre](#) – Young People (Merton, Wandsworth, Sutton).

2. Submitted Workshops Reports (2024-25)

2.1 Workshop Report: ASCA ([ASCA – Addiction Support and Care Agency – Richmond](#))

- 12 people participated in focus groups held by ASCA on the 9th and 10th of December 2024.

ASCA clients and volunteers use “loss” and/or “bereft” rather than “bereavement.” The meaning of “loss” in our field of work does not always mean that a loved one has passed away.

Carers/family members: When someone who has had long-term alcohol or drug issues enters recovery, they begin to transform their lives. They become a different person, and their carers or family members no longer recognize this new version of them.

This is a “loss” – the carers or family members feel they have lost the person they married, their partner, and/or their father. The person they once loved is no longer the same.

Carers and family members feel at a loss because they no longer have someone to care for. Their loss includes:

- The loss of their loved one
- The loss of being a carer and no longer being needed

We had service users in the groups who had lost their loved ones due to:

- Suicide (including recent loss)
- Long-term addiction
- Recent widowhood
- Separation/divorce from a partner due to addiction
- Addiction and terminal cancer
- Miscarriage/loss of an unborn baby
- Premature death of babies
- Caring for someone with dementia and using alcohol, prescribed medication, or over-the-counter medication to cope with loneliness and isolation, experiencing the loss of the person they once knew and loved

- Adult children who lost a parent due to long-term alcohol use, discussing their experience of growing up in a family where a parent had an addiction and being a carer all their lives rather than being cared for

1. Focus Group Discussion Question

When experiencing "loss," what matters to you most?

- Loss of financial and physical help with child-rearing
- The feeling of no control
- *"I feel so lost, I don't know if I am coming or going"*
- *"To go somewhere where I will be met with warmth, understanding, knowledge, and kindness. I felt exhausted, frightened, and lost – unsure where to go for what – so confused."*
- Future
- Direction
- Self-love
- Hope
- Staying present
- One day at a time
- Light at the end of the tunnel
- Patience
- Time
- Being kind to myself
- Leaving the known for the unknown
- Prefer to stay in familiar situations where I feel safe and in control
- Hope
- Confidence
- Future
- Self-worth
- Self-esteem

- Direction
- Social life
- Future
- Anxiety
- Feeling connected to and grounded in my spiritual beliefs
- Feeling connected to my children
- Feeling looked after
- *"To feel connected to my son and have someone to speak to"*

2. Focus Group Discussion Question

What is the impact of your loss (e.g., physically, mentally, emotionally, social groups, employment, household income) and over what period of time?

- All of it
- Lonely – no one wants to know
- *"I am 90% parent to my two kids and 10% dad. I am overwhelmed with the lack of co-parenting and doing everything on my own. The lack of financial support from him—only a small contribution—leaves me struggling with day-to-day expenses."*
- *"I lost my husband, who was the breadwinner. He held everything together. He gave me confidence. It's all gone."*
- *"I'm going to have to sell the family home. My memories of him are in the house."*
- *"Feeling exhausted, alone, guilty, angry, resentful as left to sort out everything after putting up with his alcohol problem for all those years."*
- No energy, brain fog. Fear of the future and how I will manage financially. Fear of losing my job and having to take time off to arrange and organize things.
- Isolated
- Depressed
- Feeling like there's no hope for the future

- Massive emotional struggles
- Feeling alone/isolated
- Physical health deteriorated
- *"I lost my home, my family. I had nowhere to go. I had to restart my life on my own."*
- *"I feel unsettled and overwhelmed because I'm not used to dealing with change."*
- *"I feel lonely and trapped. Counselling helps me cope with the loneliness. Looking forward to the next day."*
- Anxious, lonely, no social life, affected my job
- *"I tended to isolate myself. My social life became more limited, and I felt desperate to talk to someone."*

3. Focus Group Discussion Question

For you, what does good loss/bereavement support/service look and feel like (from healthcare & bereavement services or from people, supportive networks, or organizations in your community)?

- Parent networking support group
- Having others that can help take the reins
- Counselling like the type ASCA provides. "I don't know of anywhere else I can get this type of counselling."
- "Friends support me; otherwise, I feel on my own."
- Counselling
- "Somewhere I can go to breathe and get support with emotional needs."
- "If I can stay well emotionally, I can put one foot in front of the other."
- "I need advice and support face-to-face."
- Warm, welcoming, kind, and understanding
- Friendly, welcoming place
- Supportive and reliable – "I get this from my counsellor at ASCA."

- "It is important to know that I am not alone and can ask for help when I need it. ASCA has given me this."
- A place where I can get support and feel heard. Talking and sharing.
- "A good service is local and easily available—a supportive place where I can get counselling weekly."
- "A good service is local, easy to get in touch with, and somewhere I can visit in person. I don't want to talk on the phone or online; I need human contact."
- GPs helping manage sleeping problems and loss of appetite
- People in my community (e.g., yoga group, social activities such as walking and talking)
- Support services to help me understand and find my identity in light of my loss
- A sense of community
- Peer support/advice on how to manage practical aspects of loss
- Specialist support for neurodivergent conditions

4. Focus Group Discussion Question

What do you think are the most important types of information and support that people need immediately after experiencing a loss/bereavement?

- "Where do I go to get help? I need information on where to find support resources."
- "I need a bereavement support group but have been told I can't have it because I am getting counselling. Why can't I have both?"
- "Initially, I needed human guidance, support, contact, and advice on next steps after my loss, plus information on any charities and resources in my local area."
- Someone to talk to who makes me feel understood and sees my pain
- Warm, kind, and welcoming local service
- Face-to-face counselling, not online, to feel less lonely

- "I think having someone listen and being heard makes a difference. It has helped me."
- Practical advice on managing funerals, benefits, etc.
- Information on how and where to access counselling services
- Local spiritual support
- Practical guidance on managing finances and social support
- *"Practical guidance on organising a funeral, claiming benefits I might be entitled to, and other financial support—what I need to do immediately and in the following months."*

2.2 Workshop Report: Centre of Change ([Centre of Change - Croydon](#))

- 14 people took part in the focus group.
- The discussion took place on Tuesday, January 21st, from 10 AM – 12 PM.
- The group was split as follows:
 - 2 men and 12 women
 - 71.5% BAME
 - 43% represented children and young people (25 years and under)
 - 21% represented people with social and/or emotional disabilities or SEN
 - 36% represented people with mental health challenges

1. About Bereavement

When grieving, what matters most?

We discussed this as a group and came up with some interesting points, some of which are quoted below:

- *"I think what matters most is going forward (moving on), especially if you have dependents and people relying on you. It is important not to give up."*
- *"Death is a taboo subject."*
- *"Death shouldn't be a taboo subject. I believe that birth, life, and death are a cycle that doesn't just end when you die, as we have a soul, which is an energy source. We should not fear death or separate it from life, and always try to remember in times of grief that we are all part of a journey that doesn't necessarily end."*
- *"Some religions celebrate death instead of feeling grief and a sense of loss, as it symbolizes the meaning of a new journey."*

Some members of the group shared their personal experiences with grief:

- *"I had a bad journey with bereavement. Losing your parents is probably the hardest path that most people in this room will take, as well as losing a child. The government is making cuts to support and bereavement*

services, which is why we need more services like Centre of Change, because people need comfort."

- *"I felt numb, not sure what to do, but I needed someone to acknowledge my pain and try to understand me."*

We also discussed the importance of having pets and children to go home to in times of grief:

- *"I think it's important to have people understand what you're going through. For me, having my own space with my pets and children helps keep me going and feeling alive."*

2. Impact of Bereavement

What is the impact of bereavement (e.g., physically, mentally, emotionally, social groups, employment, household income) and over what period of time?

- *"Bereavement impacts people's finances quite drastically. It might affect their property too, and all of these things have to be taken care of while you're juggling everyday life—it's really difficult."*

A shared personal experience:

- *"When my parents passed, my brother tried to take over sorting everything out, but as I was the oldest, I was the next of kin. It was up to me to take care of everything and divide it among the six of us. It was hard to divide everything fairly, and my sister ended up taking all the jewelry, which upset me and my brothers. I just wanted to respect my parents' wishes and the will."*

In response to this experience:

- *"It's easier for families to argue over material things rather than address the grief and pain of losing their loved one. There are so many emotions happening at the same time, and I don't believe you can put a time limit on grief, as everyone processes things differently and in their own time."*

3. About Bereavement Support

What does good bereavement support/service look like (from healthcare & bereavement services or from people, supportive networks, and organizations in your community)?

- *"People who actually respond and don't just leave you on a waiting list. It is important that when you seek help, someone is there to listen. If the response time is too long, you may shy away from getting the help and support you need."*
- *"Making sure that the person isn't feeling judged in any way."*
- *"I believe all schools should have pastoral care."*

We also discussed the flip side—what we felt 'not-so-good' bereavement support looked like:

- *"There are time limits on support (e.g., services only last for six weeks), but there is no time limit on grief. It might make people feel like there's no point in seeking support if they feel they need at least 12 months of services. The beginning sessions of counselling, for example, are spent getting comfortable with the person, and before you know it, your sessions are over, and you haven't even fully opened up yet."*
- *"It's hard to get an appointment with a GP for support now—there's no accessibility."*

However, this statement was not universal, as some members stated they were always able to get GP appointments when needed.

4. About Immediate Information and Support from Healthcare Providers

What do you think are the most important types of information and support that people need immediately after experiencing bereavement?

- *"Knowing that someone is there to listen when you're ready to talk."*
- *"Support should be made clearer, as sometimes people are unaware of what support is available. For example, I did not know St. Christopher's could support my family while we were losing my dad, as I believed it was only for end-of-life care and cancer patients. Especially if you do not have family support, it is important to have more awareness of what is available."*

5. About Other Bereavement Support and Services

Tell us about the bereavement support services in the borough that you know about.

- Centre of Change

- St. Christopher's
- Macmillan
- Mind
- Social Services
- Cancer Help (Tesco – Purley)
- Woodside Bereavement
- CUH Chaplaincy Services

6. Getting Information About Bereavement Support and Services

What do you think are important sources of information about bereavement support and services?

- GP
- Croydon Council
- Supermarket boards
- Online (social media)
- Television
- Places of worship
- Pharmacy
- Word of mouth
- Support groups
- Coffee mornings

2.3 Workshop Report: Cruse Bereavement Support ([Cruse Bereavement Support - Croydon, Sutton and Merton](#))

South West London Bereavement Support Focus Group Engagement
Sutton Cruse Report – 11th January 2025

Time and Place:

- Carshalton Beeches Baptist Church on 11th January 2025 at 12:30 PM.

Participants: Total – 16

- Sex: 14 females, 2 males
- Ages:
 - Females: 33, 38, 42, 44, 46, 48, 50, 53, 54, 55, 56, 65, 66, 70
 - Males: 54, 65
- Ethnicity:
 - White British × 14
 - Black British × 1
 - Pakistani × 1
- Religion:
 - Christian × 6
 - Hindu × 1
 - No religion × 9
- Special Needs: None
- Bereavements:
 - Sudden and difficult × 10
 - Expected × 5
 - One participant had no bereavement experience
- Who Died:
 - Parent × 8
 - Partner × 3

- Sibling × 2
- Child × 1
- Friend × 1

Additional Information:

- Bereavement clients × 8
- Cruse volunteers × 2
- 1 facilitator
- 1 note taker
- Bereavement counsellors × 2
- Funeral care worker × 1
- Trustee of a bereavement charity × 1

(Additional information below provided after KVA prompt)

- Survivors of bereavement by suicide – Yes, one woman’s niece took her own life.
- People with learning disabilities – Not in this group, but we do support people with learning disabilities, though not often. We use *Books Beyond Words*, and about five volunteers have received training.
- Special educational needs and disabilities (SEND) – See above. We can accommodate wheelchairs, but no one in this group required it.
- Neurodivergent people (such as autism and ADHD) – We support neurodivergent individuals and have volunteers with experience in this area, but there were no neurodivergent participants in this group.
- Domiciliary (home care), care, and nursing home workforce – We provide support in care homes and private homes when required. One attendee’s sister had died in a care home.

- Hospice and other palliative care-focused teams – We have links with St Raphael's, which provides bereavement support for those who die in the hospice.
- Residents in care and nursing homes – See above.
- Recently widowed individuals, including those from the Afro-Caribbean community – One participant in the group was a widowed Hindu.
- Refugees, asylum seekers, and people from migrant communities – In this group, just the participant mentioned above. However, we support anyone who is referred.
- People from LGBTQ+ communities – *"As a gay man, whose older partner had died, I was very isolated."*
- People living with frailty and/or dementia – We support individuals in this group, but there were no such participants in this session. One attendee's mother had died with dementia.
- People experiencing loss through pregnancy and/or fertility issues – We provide support in this area, but no one in this group had this experience.
- Death of a child – Yes, one mother lost her 17-year-old son to Sudden Adult Death Syndrome.

1. Focus Group Discussion Question – When grieving, what matters most?

- Finding someone to talk to outside the family
- Being listened to and heard
- Speaking to someone I trust who won't judge me
- Early information about what to expect
- Time to process the shock
- Talking to someone who can explain my emotions and reassure me that I'm grieving correctly

- Practical matters like funeral arrangements, travel, and how to inform others
- A hug
- Support in adjusting to life without my loved one and managing additional responsibilities
- Managing conflicted relationships, which can make grief more difficult
- A safe space to meet others in a similar situation
- Support to express my feelings with others who understand
- Information—Cruse's *Understanding Bereavement* session helped me feel normal

2. Focus Group Discussion Question – What is the impact of bereavement?

- Physical impact: Participants agreed that this is not well understood or discussed. Many noted that GPs might prescribe medication when grief support is needed instead. Common physical effects include shock, real pain, panic attacks, brain fog, exhaustion, weight gain, poor sleep, constant crying, withdrawal, and nausea.
- Mental impact: The need for understanding and being allowed to feel low without pretending to be okay. Grief can be frightening and exhausting. Some people turn to alcohol or drugs as coping mechanisms.
- Emotional impact: Many did not understand the shock of grief and how it affects them. Accepting the loss happens gradually. Feelings of isolation, social withdrawal, and difficulty enjoying life were common.
- Social impact: Grief often leads to withdrawal from social life and a loss of interest in activities.
- Employment impact: Many participants raised concerns about work-related challenges, including:
 - Lack of bereavement leave, particularly for those on zero-hour contracts
 - Being forced to use annual leave for a funeral
 - “Sick leave policies do not consider grief as a valid reason.”

- *“Employers vary in their support—some are compassionate, others expect employees back after a week, even after the death of a child.”*
- Some people needing extended time off work due to grief
- The need for formal policies regarding bereavement-related absences
- Household income: Financial strain is particularly severe when the deceased was the primary earner. Some participants needed referrals to food banks and Citizens Advice Bureau (CAB). Financial hardship can significantly impact the grieving process.
- Time frame: *“There is no set time for grief. It can last for years, with triggers such as a second death or life event reigniting emotions.”*
- Additional thoughts:
 - *“Bereavement due to murder or suicide is particularly difficult, especially when the press is involved.”*
 - *“Death of a child is exceptionally hard.”*
 - *“Inquests delay and extend the grieving process.”*
- Discussion outcome:
 - *“There is a need for better general information on death and grief, particularly for employers and healthcare professionals.”*
 - Many disadvantaged groups, including prisoners and addicts, are significantly impacted by grief and require extra bereavement support services.
 - While most bereaved individuals receive support from family and friends, 10-15% need additional help. Funding bereavement support services is essential to prevent long-term health, social, and economic problems.

3. Focus Group Discussion Question – What does good bereavement support/service look like?

- Healthcare:
 - Early, accessible, timely, and informed support

- Reducing long wait times, which harm well-being
- Improved knowledge of grief among healthcare professionals
- Greater awareness in education and healthcare providers to support bereaved children
- Ending inappropriate referrals—many bereaved individuals are sent to talking therapies, wait for an assessment, and are then told they are in the wrong place. This negatively impacts mental health.
- Bereavement services:
 - Funded, timely, and available support and information
 - Group meetings to talk and process emotions
 - *Understanding Bereavement* sessions (Cruse) found to be very helpful
 - Seamless transition to counselling if needed
 - Coping strategies provided early in the grieving process
 - *“Hospice support only available if the person dies in the hospice, leaving gaps in support for others.”*
- Society and media:
 - A culture shift to normalize death and grief as part of life
 - Better media coverage to educate the public about grief
- Employers:
 - *“There is a need for improved bereavement leave policies, especially for suicide, sudden deaths, and child loss.”*
 - Greater awareness and education for employers to help grieving employees
- Community support:
 - Local bereavement networks and organizations need funding to continue providing vital support

4. Focus Group Discussion Question – What are the most important types of information and support needed immediately after bereavement?

- Clear, accessible information about available bereavement support
- Financial assistance for those struggling due to the loss
- Lists of charities offering specialized bereavement support
- Helplines and contact information
- Guidance on what to expect during the grief journey, including physical and mental health impacts
- Advice on communicating bereavement needs to employers
- Many participants felt rejected by services and struggled to find support
- *“Hospitals provide some good information, but better community links with chaplains and bereavement officers would help.”*
- Staff should receive training in *Understanding Grief*
- Information about inquests
- GPs need clearer guidelines on:
 - What talking therapies do
 - What bereaved individuals need
 - Available bereavement services in the community
 - Support for those experiencing traumatic or sudden deaths
- Overprescription of medication for grief should be challenged
- *“Hospices should refer clients to community bereavement services when they cannot provide direct support”*

5. Focus Group Discussion Question – Bereavement and support services known in the borough

Croydon:

- Woodside Bereavement Services
- Rowland Brothers Foundation (9-5, funded by Rowland Funeral Directors)

- Compassionate Friends
- SLOW (Sibling and Child Bereavement Support)
- St. Christopher's Hospice
- Jigsaw4U (Bereavement Support for Children)
- Cruse (closed due to lack of funding)
- Survivors of Suicide

Sutton (all services are free):

- Cruse (closed due to lack of funding; reopened with restricted support due to financial issues)
- St. Raphael's (only for those who die in the hospice)
- Jigsaw4U (Bereavement Support for Children)
- Compassionate Friends
- Sutton Women's Centre (offers counselling but not specific bereavement support)
- Talking Therapies (does not cover bereavement; complex grief occasionally supported)

Merton (service not free):

- Wimbledon Guild (recently opened, covers bereavement support)

6. Focus Group Discussion Question – Key sources of bereavement support information

- GP
- Funeral directors
- Google/internet
- Cruse
- Good Grief Trust
- Hospitals
- Hospices

- Schools/universities (ELSA for primary children, counselling for older students)
- Employers (some have employee programs, but they are often too short)

Summary

- Participants found the session useful.
- Greater funding for bereavement charities is essential, particularly for Cruse, which provides free tailored support.
- Most referrals to Cruse come from individuals aged 25–55, who often need evening and weekend support—services currently unavailable elsewhere.
- Early intervention is crucial to preventing health, social, and economic problems, including suicide.
- A centralised local resource for bereavement information would be beneficial.

2.4 Workshop Report: Dignitate ([Dignitate](#) – Croydon)

Introduction

On Wednesday, 18th December 2024, a Cultural Bereavement Session was conducted as part of the South West London Bereavement Support and Services initiative. The session aimed to explore the unique needs and experiences of individuals from diverse cultural backgrounds as they navigate grief.

Organised by Dignitate, a community-driven dementia charity, the session focused on empowering caregivers, particularly within culturally diverse communities. Dignitate bridges the gap in culturally competent support after a dementia diagnosis, providing:

- Holistic care and education to reduce stigma.
- Support networks to assist carers.
- Preventative interventions to reduce crisis situations that lead to hospitalisation.

With a focus on the ‘invisible patient’—the carer, the charity fosters resilience through peer-led networks, events, and practical resources, enabling families to navigate dementia with dignity and confidence. Recognising both anticipatory grief in dementia care and the grief that follows the loss of a loved one, Dignitate facilitates bereavement groups, offering culturally safe spaces for carers to process their emotions and heal collectively.

The session brought together a range of participants, including community leaders, volunteers, and individuals with personal bereavement experiences. This report provides an overview of the session, detailed insights from the discussion, and actionable recommendations for enhancing bereavement support services.

Participant Demographics

The session was attended by 10 participants from diverse cultural backgrounds, reflecting a range of life experiences and perspectives. This diversity provided an in-depth exploration of bereavement, particularly anticipatory grief and the challenges faced by carers of people with dementia.

The group included:

- Four participants from Caribbean backgrounds (one man and three women, aged between 55 and 70).
- One woman from Sierra Leone, approximately 72 years old.
- Two participants of Southeast Asian heritage (one man and one woman, aged between 38 and 42).
- One woman of West Indian descent, aged 36.
- Two women from Jamaica, a mother and daughter, aged 68 and 32, respectively.

This diverse composition provided culturally rich insights into the grieving process, highlighting the impact of anticipatory grief during dementia caregiving and the profound emotional, social, and cultural challenges of bereavement.

Younger participants shared intergenerational perspectives on grief, while community leaders and faith-based representatives discussed systemic and cultural influences on bereavement experiences. The range of ages, cultural backgrounds, and caregiving roles contributed to a holistic understanding of grief and the opportunities to develop culturally competent bereavement support.

The session illuminated the distinct needs of different demographics, fostering an awareness of how tailored support can better address the unique aspects of grief across communities.

Session Highlights

The session explored key themes from the funder's discussion guide, supplemented by powerful personal anecdotes and cultural insights.

1. What Matters Most During Grieving?

Participants highlighted several key factors that shaped their grieving process, blending emotional, practical, and cultural priorities.

Connection to the Deceased

- Participants emphasised the importance of preserving memories through stories, photographs, and rituals.
- Many found comfort in remembering positive moments with loved ones:

"When grief comes, I try to think of the good times I spent with the individual because your mind often focuses on the negatives."

- Cultural practices supported this connection. For example:
 - Jamaican 'Nine Nights' allows families to share grief through storytelling and music.
 - Southeast Asian ceremonies involve honouring the deceased with offerings (e.g., in some traditions, the immediate family does not cook for 10 days while the community provides food).
- Participants also engaged in personal rituals to maintain a connection to their loved ones:

"Wearing a piece of their jewellery helps me feel close to them."

- Continuing bonds theory suggests that grieving involves modifying, rather than relinquishing, the relationship with the deceased. Participants described how they:
 - Kept their loved one's belongings.
 - Maintained shared traditions.
 - Visited places that held sentimental value.

Cultural and Religious Mourning Practices

- Religious and community-driven ceremonies helped participants navigate grief collectively.
- However, diaspora communities often face logistical and financial challenges in continuing these traditions.
- Some participants shared that faith-based rituals provided initial comfort but lacked long-term emotional support.

"Our traditions give us strength, but when they end, it can feel like you are left alone to navigate the emptiness."

Community and Family Support

- The presence of a supportive community was identified as a cornerstone of the grieving process:

"We celebrate life, even as we mourn. It's not just about tears—it's about connection."

Space for Open Expression

- Many participants discussed how cultural norms suppress open grieving, particularly for children and young adults.

"As a child, you couldn't express yourself—you were just dragged along. The saying was 'Children should be seen, not heard'—that silence stayed with me for years."

- Delays in accessing professional bereavement support were another challenge. Many faced:
 - Waiting lists of three to six months before receiving counselling.
 - A sense of abandonment once cultural mourning traditions ended.

"After 'Nine Nights', everything goes quiet. That's when it gets really hard."

2. The Impact of Bereavement

Participants described bereavement as a deeply layered experience, affecting emotional, physical, social, and economic well-being.

A. Emotional and Psychological Impact

- Attendees recounted feelings of despair, anger, and confusion, often occurring in waves, triggered by:
 - Significant dates (e.g., anniversaries, birthdays).
 - Memories of the deceased.
 - Unresolved family conflicts.
- One participant described the compounding nature of grief after losing multiple family members:

"It feels like just as you're trying to process one loss, another hits, and you never get a chance to catch your breath."

- Some individuals reflected on childhood grief and how cultural norms discouraged open emotional expression:

"I'm still stuck in that place. When you're silenced as a child, it's very difficult to break free from that as an adult."

- Guilt was another recurring theme, particularly when family tensions complicated the grieving process:

"I kept thinking about the arguments we had or the things I didn't do for them when they were alive—it's hard to forgive yourself."

- Participants stressed the need for open conversations about grief to normalise its psychological impact and reduce stigma around seeking professional support.

"Just being able to talk about it with others who understand has helped me more than I can express."

B. Physical and Health Consequences

Grief frequently manifested in physical symptoms, including:

- Sleep disturbances (insomnia or oversleeping).
- Changes in appetite (weight gain or loss).
- Chronic fatigue and exhaustion.
- Increased stress-related illnesses (e.g., high blood pressure, migraines, digestive issues).

"Internalising grief doesn't just affect your mind—it starts impacting your body, too. It becomes an illness."

Several participants reported that unresolved grief worsened pre-existing health conditions, such as:

- Diabetes
- Cardiovascular disease
- Arthritis

One participant shared their experience as a caregiver:

"When I was looking after my dad with dementia, the stress made my own health decline. My blood pressure shot up after he passed."

Participants from Black, Asian, and other ethnic minority communities highlighted how cultural stigma around grief often led to psychosomatic symptoms:

"In my culture, you're expected to keep it together, to show strength. But holding it in made my migraines unbearable, and I couldn't sleep."

The group advocated for holistic approaches to bereavement support, such as:

- Incorporating culturally sensitive practices (e.g., meditation, yoga, spiritual guidance).
- Collaboration between bereavement services and healthcare providers to monitor the physical health of grieving individuals.

C. Social and Familial Strain

- Family conflicts over inheritance, estate management, and caregiving responsibilities often intensified grief.

"I'm still trying to grieve, but I can't because everything has been pushed onto me."

- Many described isolation after the formal mourning period ended:

"Once the ceremonies are over, you're left alone. It's like the world expects you to just carry on."

D. Employment and Economic Impact

- Returning to work shortly after bereavement was a major challenge.
- Many participants found that workplace bereavement leave was insufficient, particularly when grieving a traumatic or unexpected loss.

"You're expected to grieve in silence while showing up to work and performing like nothing happened."

- The financial strain of funerals and estate management was particularly difficult for participants from cultures where elaborate ceremonies are customary.

- In Caribbean traditions, for example, 'Nine Nights' involves nightly gatherings, food, music, and community engagement, creating financial and emotional burdens.

3. Barriers to Bereavement Support

A. Cultural and Systemic Barriers

1. Stigma Around Seeking Help

- Many communities discourage openly discussing grief or seeking professional support.

"In our community, you're supposed to fast and pray. But sometimes, fasting and praying isn't enough."

- Some participants felt uncomfortable speaking with counsellors from their own cultural backgrounds, fearing judgment or breaches of confidentiality:

"I felt like I couldn't open up to them because they might judge me or spread my story within our circles."

2. Limited Access to Immediate Support

- Long waiting lists (3–6 months) for counselling left many individuals struggling without structured support.

"After 'Nine Nights', everything goes quiet. That's when it gets really hard."

- Hospices only provided bereavement support to those who had lost a loved one within their facilities, leaving out many families in need.

4. What Does Good Bereavement Support Look Like?

A. Culturally Competent Services

- Bereavement support should integrate cultural mourning traditions, such as:
 - Jamaican 'Nine Nights'
 - Southeast Asian prayer rituals
 - Faith-based grieving spaces

"If they don't understand our traditions, it's hard to trust them with something as personal as grief."

B. Peer-Led and Community-Based Initiatives

- Faith leaders, community ambassadors, and peer networks should be involved in bereavement support.
- Peer-led groups create safe spaces for grief expression.

"You don't feel like you have to explain yourself—they just get it."

C. Immediate and Practical Support

- Guidance on financial and legal matters, including:
 - Funeral arrangements.
 - Estate disputes.
 - Benefits and support options.
- Participants praised initiatives like the Croydon Death Literacy Project, which helped reshape community perceptions of hospices as places of care and support.

"The project has helped us see hospices not as places of fear but as hubs of care and connection."

5. Recommendations

1. Strengthen Collaboration

- Build partnerships between healthcare providers, community leaders, and bereavement organisations.
- Train GPs and hospice staff to identify and support anticipatory grief.

2. Expand Peer-Led Support Groups

- Fund culturally specific bereavement circles for caregivers and diverse communities.
- Include dedicated groups for dementia caregivers.

3. Increase Public Awareness

- Outreach campaigns through churches, mosques, temples, and cultural events.
- Community radio and social media to provide bereavement resources in multiple languages.

4. Advocate for Workplace Bereavement Policies

- Flexible leave policies and mental health support for grieving employees.
- Recognition of the unique grief of dementia caregivers.

"Grief doesn't just affect your heart—it affects your whole life. Support needs to reflect that."

6. Conclusion

This session reinforced the urgent need for culturally competent bereavement support, particularly for dementia caregivers.

By fostering inclusive bereavement support networks, ensuring timely access to resources, and addressing cultural barriers to grief expression, we can create a more resilient, compassionate, and equitable bereavement care model.

2.5 Workshop Report: JFJ Foundation CIC ([JFJ Foundation CIC - Hackney](#))

Focus Group Details

Date: 21st December 2024

Time: 10:00 AM – 1:30 PM

Participants: 10

Age Range: 17 – 35

Backgrounds: Afro-Caribbean, African, and White British

Neurodivergence: 2 participants with ADHD, 1 with Autism

Bereavement Types:

- By suicide: 2 participants
- By homicide: 5 participants
- By natural causes: 3 participants

Overview

Introduction

This focus group report examines bereavement services, exploring participants' experiences, challenges, and recommendations regarding support following the loss of a loved one. The findings highlight key aspects such as accessibility, cultural influences, financial impacts, and the scope of available services, offering actionable insights for improving bereavement support.

Key Themes

What Matters Most When Grieving?

Participants identified several crucial factors that influence the grieving process:

1. **Support System:** A strong network of family, friends, or community members was deemed essential for both emotional and practical support.
2. **Validation of Emotions:** Participants emphasised the importance of being heard and understood without judgment, particularly in cases of homicide or suicide.

3. **Time and Space:** Many expressed the need for adequate time and mental space to grieve without external pressures.
4. **Access to Resources:** The availability of counselling, support groups, and educational materials was a recurring concern.
5. **Self-Care:** Grief took a toll on participants' physical and emotional well-being, highlighting the importance of self-care practices and external support for those struggling to recognise their declining well-being.
6. **Cultural and Spiritual Practices:** Many found comfort in rituals and traditions aligned with their beliefs.

Impact of Bereavement

Discussions revealed the multifaceted effects of bereavement, including:

1. **Emotional Impact:** Participants reported waves of sadness, anger, guilt, and anxiety, with emotions fluctuating over time.
2. **Physical Health:** Many experienced fatigue, sleep disturbances, and stress-related physical issues.
3. **Cognitive Effects:** Common challenges included difficulty concentrating, forgetfulness, and insomnia.
4. **Social Isolation:** Some withdrew from social interactions, intensifying feelings of loneliness. Participants particularly noted a lack of understanding when dealing with traumatic loss, such as homicide or suicide.
5. **Work and Productivity:** The grieving process disrupted focus and performance, leading some to take extended leave.
6. **Spiritual Reflection:** Loss often prompted deep spiritual exploration or questioning among participants.

Scope of Bereavement Services

Participants outlined the services they wished to have more access to:

1. **Counselling and Therapy:** One-on-one sessions were highly valued for personalised support.

2. **Support Groups:** Group discussions provided solidarity and comfort.
3. **Educational Resources:** Materials explaining grief stages, coping mechanisms, and practical guidance on what to do immediately following a loss.
4. **Practical Assistance:** Support for legal, financial, and administrative matters was frequently needed.

Accessibility of Services

Participants highlighted barriers to accessing bereavement support:

- **Geographical Availability:** Those in rural areas had limited access to services.
- **Affordability:** The cost of private counselling was a significant barrier, as was the cost of travel to support services.
- **Cultural Sensitivity:** Services often lacked respect for diverse cultural and religious practices.
- **Awareness:** Many participants were unaware of available services.
- **Specialised Services:** Tailored support for children, young people, and those experiencing traumatic grief (e.g., witnessing a murder or suicide) was limited.

Cultural and Financial Aspects of Bereavement

1. Cultural Influences

- **Rituals and Practices:** Cultural mourning rituals provided structure and meaning in the grieving process.
- **Community Roles:** Some cultures emphasised collective grieving and support, which participants found valuable.
- **Stigma and Expression:** Cultural attitudes influenced how openly participants expressed emotions or sought help.

2. Financial Impacts

- **Funeral Costs:** Participants or their families struggled with the financial burden of funerals.
- **Lost Income:** Time off work due to grief created financial strain for many.
- **Access to Services:** Financial constraints limited participants' ability to access counselling and bereavement programs.
- **Support Programs:** Financial assistance programs were seen as crucial for mitigating these challenges.

Sources of Bereavement Support

Participants identified key sources of information and support:

1. **Healthcare Providers:** Trusted professionals, such as GPs, provided referrals to bereavement services.
2. **Community Organisations:** Faith-based groups and charities played a crucial role in offering support.
3. **Online Directories:** Many relied on platforms such as Google to locate support services.
4. **Books and Publications:** Self-help books and guides helped participants understand grief.
5. **Hotlines and Helplines:** Immediate support via helplines was considered invaluable.
6. **Peers and Support Networks:** Word-of-mouth recommendations often led to effective resources.

Challenges Identified

1. **Stigma Around Grief:** A societal reluctance to discuss grief openly made it harder for individuals to seek support.
2. **Underfunding:** Many bereavement services faced resource limitations, affecting their availability.
3. **Staffing Issues:** A shortage of trained professionals hindered service delivery.

4. Tailored Support: Groups with specific needs (e.g., children or those experiencing traumatic loss) were underserved.

Recommendations

1. Increase Funding: Allocate resources to expand bereavement services.
2. Training Programs: Enhance training for professionals to address diverse grief-related needs.
3. Raise Awareness: Conduct public campaigns to promote bereavement support beyond GP referrals.
4. Expand Access: Introduce telehealth and virtual support services for those in remote areas.
5. Culturally Appropriate Services: Develop programs that accommodate diverse practices and religious beliefs.
6. Research and Evaluation: Invest in studies to assess the effectiveness of bereavement support interventions.

Summary

The focus group discussions underscored the importance of comprehensive bereavement services in helping individuals navigate loss. Addressing accessibility, funding, and cultural sensitivity will significantly enhance the effectiveness of bereavement support services. Collaborative efforts between government, healthcare providers, and community organisations are crucial to ensuring equitable bereavement support for people of all ages and backgrounds.

2.6 Workshop Report: Jigsaw ([Jigsaw4u](#) – Merton)

January 2025

Jigsaw4u delivered two focus groups, each consisting of 11 participants. Group 1 included children and young people (aged 11 to 18) who had accessed our Bereavement Service, while Group 2 comprised their parents/carers. The focus groups were conducted at the Wilson Wellbeing Centre in East Merton.

The families who participated were specifically selected to represent a range of communities, including survivors of bereavement by suicide; people with learning disabilities, special educational needs and disabilities (SEND), and neurodivergent individuals (such as those with autism and ADHD); people from the Afro-Caribbean community; refugees, asylum seekers, and other migrant communities; and individuals from LGBTQ+ communities. All the families reside in the South West London boroughs of Croydon, Merton, and Sutton.

Each session lasted three hours, with a 30-minute refreshment break halfway through. Group 1 also took additional short breaks as needed by the children and young people. The discussions explored various themes related to the Community Engagement Gaps criteria, including awareness, access, quality, and support.

Key Themes from the Discussion

How did you first hear about bereavement support?

- Referred by school
- Referred by a social worker
- Found you online
- You helped our friends when their dad died

Was it easy for you to access?

- Yes, you called us right away
- The school organised everything
- The waiting time was too long

Were there any challenges when accessing bereavement support?

- It would be better if it started sooner
- Sometimes you want to talk, but when the time comes, you don't feel like it—so it was good that you were patient and waited for me to be ready
- I was worried about my son understanding everything, but you made him a social story, which I thought was amazing

Was the support culturally sensitive and responsive to your specific needs?

- You asked when you weren't sure, which was important
- I hadn't thought about it until now, but yes, it was
- I don't think it needs to be—death is death
- I felt my beliefs were included in what we did, and I liked that

How do you think bereavement services can better reach underserved communities?

- By advertising in places of worship
- By being in community spaces like this (Wilson Wellbeing Centre)
- Jigsaw4u represents everyone—it feels like we are all the same with you
- Schools share a lot of information, so working with schools is important
- Posters in doctors' surgeries

Were there any language or communication barriers that made it difficult for you to fully access support?

- It's great that you work with autistic people—social stories help them understand, as they think in pictures
- Everything was at my own pace, so no
- The worksheets helped me understand what happened in each session
- You always checked—I could have said if there was a problem, but there wasn't

What would make you feel more at ease when approaching the service?

- Nothing—the flyer explained everything

- Having people who look and sound like me providing support

How can the specific needs of your community be supported?

- If the autistic person is non-verbal, they will need PECS (Picture Exchange Communication System) to understand things
- Some people are spiritual rather than religious—considering them would be helpful
- Everyone is individual
- Translators should be available for those who do not speak English
- Having staff who speak different languages
- Being able to choose whether to speak with a man or a woman

What worked well, and what didn't?

What worked well:

- Being listened to
- Building a memory box to keep forever
- Having a space to talk about grief
- Professional support from specialists in this area
- Understanding that how I feel is normal
- Additional support with the food bank, fun days, and Christmas presents, which we couldn't afford
- Helping the school understand my situation
- Not feeling alone
- Being made to feel special

What didn't work well:

- No major concerns were raised

Have any community groups helped you?

- No, nothing
- Nobody knew what to say

- Everyone at my church was amazing

Is there stigma around seeking bereavement support in your community?

- I think people just don't know what to say
- Everyone has their own stresses and no time for yours
- No stigma—it's no one's fault
- There is some suspicion around outsiders—not you specifically, but some may have ulterior motives
- I didn't tell everyone—I didn't want people feeling sorry for me

Was it important for you to connect with others who had experienced a similar loss?

- No, it is a personal experience
- Yes, it helped me realise I was not alone
- I made friends there
- It was nice being around others whose lives were not perfect

How can individuals going through bereavement be better supported?

- Financial help—we were in a financial crisis when my husband died
- It's nice that we can stay in touch with you after the counselling sessions
- Just having someone there for support
- Encouraging people not to give up and to keep going
- By having more services like yours

What kind of long-term support would you find helpful?

- To be able to return in the future if needed
- Telephone check-ins to see how we're doing

Conclusion

The focus groups provided valuable insights into the experiences of bereaved families, particularly children and young people. Key themes highlighted the importance of timely access to bereavement support, cultural sensitivity,

financial assistance, and long-term engagement. Participants expressed appreciation for Jigsaw4u's patient, inclusive, and community-driven approach, as well as the additional practical support offered alongside bereavement counselling.

Moving forward, improvements can be made by increasing outreach in underserved communities, providing more culturally specific support options, addressing financial barriers, and ensuring long-term follow-up services. By continuing to listen to the needs of bereaved families and refining service delivery, organisations can create more accessible and supportive bereavement care in South West London.

2.7 Workshop Report: Kingston and Richmond NHS Foundation Trust ([Kingston and Richmond NHS Foundation Trust - Kingston](#))

January 2025

Early Pregnancy Unit

Kingston and Richmond NHS Foundation Trust
Kingston Hospital KT2 7QB

Focus Group Report

Authors:

Miss Meena Shankar – Consultant Gynaecologist
Clare Livermore – Matron, Women's Health

Summary of the Project

Following a successful application to the SWL Bereavement Community Engagement Gap Grant – Kingston Voluntary Action, the Early Pregnancy Unit at Kingston Hospital conducted a focus group discussion to better understand the needs of individuals affected by early pregnancy loss.

This report summarizes key insights from a patient forum focused on bereavement and loss support. Participants shared personal experiences and provided valuable feedback on improving healthcare services, bereavement support, and community resources.

Project Members

- Miss Meena Shankar (Project Lead and Consultant Gynaecologist)
- Elana Dellal (Facilitator and Chaplain)
- Clare Livermore (Matron, Women's Health)

Background

Healthwatch Kingston (HWK) and Kingston Voluntary Action (KVA) were commissioned by NHS South West London to undertake a community engagement pilot project in 2022, exploring people's experiences of bereavement and support services. The report from this pilot identified gaps, leading to the commissioning of a Phase 2 project aimed at engaging groups not included in the initial pilot.

One such group comprised individuals who had experienced pregnancy loss and/or fertility-related loss. The Early Pregnancy Unit at Kingston Hospital was keen to ensure that women and their partners who had suffered early pregnancy loss were included in this project. As a result, a grant was successfully secured to run a focus group.

Purpose

A woman’s experience of miscarriage, as well as that of her partner, is influenced by various factors, including the circumstances of the loss, the pregnancy, and previous experiences. It is normal to experience a range of emotions. Research indicates that good support following pregnancy loss can have a positive impact on long-term well-being.

This focus group discussion aimed to understand the needs and experiences of women and their partners navigating pregnancy loss, infertility, and related challenges.

Details

- Date: Friday, 17th January 2025
- Time: 12:30 PM – 2:00 PM (1.5 hours)
- Venue: DoubleTree by Hilton, Kingston Upon Thames (1 Skerne Road, Kingston Upon Thames, KT2 5FJ)
- Participants: Eight individuals

Participant Demographics

The focus group comprised eight participants—seven women and one man—all of whom had been cared for at the Early Pregnancy Unit at Kingston Hospital and had experienced one or more miscarriages.

Table 1: Participant Demographics

Participant Ethnic Background (Sex) Age Number of Early Pregnancy Losses			
1	Asian (Indian) (F)	37	1
2	White Other (F)	42	6
3	Asian (Indian) (F)	38	1

Participant Ethnic Background (Sex) Age Number of Early Pregnancy Losses

4	White British (F)	35	3
5	White British (F)	46	4
6	White Other (F)	34	1
7	White British (F)	41	5
8	White British (M)	N/A	5

Focus Group Discussion Topics

Topic 1: About Bereavement

Bereavement is a deeply personal and sensitive experience. The type of support required varies between individuals based on faith, beliefs, life philosophies, culture, social circumstances, and generational differences.

Question: When you experienced your loss, what mattered most to you? What type of support was most important?

Key Themes:

- Talking: All participants emphasized the importance of talking about their loss with family and friends.
 - *“Talking about it when I was ready with family and friends—it doesn’t go away... I’m still talking about it.”*
 - *“Talking helped because when you open up, others open up too. I found out my brother’s wife had four miscarriages—I didn’t know until I shared my own experience.”*
- Sharing: Discussing their loss with others helped participants feel less isolated.
 - *“It takes a weight off your shoulders when you share something.”*
- Challenging the 12-week pregnancy announcement rule: Some participants expressed a desire to break the stigma surrounding early pregnancy loss by openly sharing news of pregnancy earlier, allowing them to receive support if a miscarriage occurred.

Healthcare Interactions:

- Participants sought empathy and understanding from healthcare professionals.
- Positive interactions were valued:
 - *“A doctor who acknowledged the loss and said, ‘It’s so awful, I’m sorry you are here,’ made a difference.”*
- Negative interactions left a lasting impact:
 - *“Being handed a leaflet made me feel like just another administrative process.”*

Validation of Loss:

- Small gestures such as mementos, keychains, and remembrance tokens were meaningful to some.
- Online support forums were helpful, though not all participants were aware of them.

Topic 2: The Impact of Bereavement

Key Themes:

- Physical: Participants described a *“dual nature”* of symptoms—initial excitement followed by grief.
- Emotional: Anxiety about fertility and the impact of miscarriage on future pregnancies was common.
- Relationships: Many partners coped differently:
 - *“My partner shut down and wouldn’t come to appointments—he thought it was bad luck.”*
- Employment: Some participants returned to work immediately as a coping mechanism. However, workplace comments about their absence were unhelpful.
- Financial Strain: IVF treatments, fertility tests, and private healthcare placed financial burdens on participants.

Topic 3: Immediate Bereavement Support

Key Needs:

- A private, compassionate environment: Participants highlighted distress at having to wait in the same areas as pregnant women.
- Follow-up check-in calls: *“A call a week later to check in would have been really helpful.”*
- Better communication between GPs and hospitals: Many felt lost between services, with GPs unaware of their hospital experiences.
- Access to clear, patient-friendly resources: A simple guide written by someone who had been through a miscarriage would have been useful.

Topic 4: Long-Term Bereavement Support

Key Suggestions:

- Structured Information: A timeline explaining NHS and private testing options.
- Support Groups: Dedicated bereavement groups for men and women.
- Online Hubs: A centralized platform listing available services and resources.

Recommendations

1. Immediate Improvements

- Implement a check-in call one-week post-miscarriage.
- Designate private waiting areas for pregnancy loss patients.
- Train staff on empathetic communication strategies.

2. Medium-Term Goals

- Develop an online resource hub for bereavement support.
- Provide bereavement counselling referrals at the point of loss.
- Offer tailored support groups for men and women.

3. Long-Term Vision

- Improve record-keeping between hospitals and GPs.
- Reduce waiting times for recurrent miscarriage clinics.
- Partner with local organizations to offer remembrance tokens.

Conclusion

The forum provided invaluable insights into the emotional, physical, and financial challenges of early pregnancy loss. Addressing these gaps through empathetic care, structured resources, and improved communication will significantly enhance bereavement support for individuals and families.

By implementing the recommended actions, Kingston Hospital and its community partners can create a more compassionate, inclusive, and effective bereavement care system.

2.8 Workshop Report: Mind in Kingston ([Mind in Croydon](#) - Croydon)

21st and 23rd of February 2025

South West London Bereavement Support Engagement – Mind in Croydon

Following the delivery of the bereavement support groups, please see below a summary outlining the sessions and the feedback received. A PowerPoint presentation was created using the guidance and initial information provided. The aim was to discuss bereavement, provide education and awareness, offer support, and facilitate discussions around the topic. This included:

- The cultural impact of bereavement
- Emotional expectations
- Bereavement models
- The practical challenges faced by those who are grieving
- Available support services

Sessions and Attendance

We delivered two support groups, consisting of 14 applicants, with 2 individuals unable to attend. The groups were held on the 21st and 23rd of February 2025, from 10AM to 1 PM.

Diversity and Group Participation

We were pleased to have a diverse range of attendees, including individuals who are:

- Neurodivergent
- Individuals with learning difficulties
- People experiencing extreme anxiety
- Participants from different ethnic and cultural backgrounds, including Asian, Afro-Caribbean, and European communities

Part of the presentation focused on the impact of cultural and religious influences on grieving. The diversity of attendees led to rich discussions, allowing

participants to learn from one another and understand the varied perspectives on bereavement and funeral practices across different cultures.

For instance, participants from European backgrounds highlighted how their approach to grieving, planning, and organizing funerals differed significantly from those of attendees from the Caribbean and South Asia.

Neurodivergent attendees shared their unique challenges in processing grief. Some found it difficult to accept their loss, while others, although able to acknowledge it, struggled with the practical aspects of bereavement, such as:

- Paying bills on time
- Understanding wills and legal processes
- Managing emotional regulation

Within the groups, participants shared their personal losses, which varied not only in cause but also in the range of emotions they experienced. While some felt deep sadness, others described feeling confusion or anger, often influenced by the nature of their relationships with the deceased.

Attendees who had lost loved ones to suicide expressed common emotions of guilt, bargaining, and self-questioning ("What if?"). Some had complex relationships with the deceased, making it difficult for them to process the loss.

Feedback from the Groups

The feedback from the support groups was overwhelmingly positive.

- Many participants were initially anxious about attending, fearing vulnerability. However, they found the sessions beneficial and appreciated the opportunity to talk openly about grief.
- The most significant takeaway was that what they were feeling was normal. Although grief is painful, attendees found comfort in knowing that others shared similar emotions.
- The cultural discussions were particularly valuable, as they ensured no one felt alienated. Everyone felt comfortable sharing their cultural or faith-based funeral practices, and some attendees found the discussions eye-opening.

- Participants expressed that being in a group setting and discussing grief collectively was particularly helpful, especially for those on waiting lists for bereavement counselling, where appointments could take a long time.
- While not a substitute for one-on-one therapy, the group sessions provided a valuable space for connection and mutual support among those experiencing grief.

Future Considerations

There was significant interest in whether similar support groups would continue in the future.

- Attendees expressed a need for ongoing bereavement support, not just for educational purposes but also as a way to connect with others and support one another through grief.
- The concept was compared to other support groups (e.g., for addiction or mental health challenges), reinforcing the idea that bereavement support groups should be more widely available.
- Neurodivergent attendees highlighted the unique difficulties they face when processing grief, particularly in navigating the legal and practical aspects following a loss. While the sessions discussed available support, their experiences reinforced the need for greater awareness and tailored assistance.

Conclusion

Overall, there is a clear demand for long-term bereavement support. While these short-term sessions were beneficial, participants emphasized the need for a more structured and ongoing approach to bereavement care.

Being involved in delivering these sessions has been a valuable experience, and it is evident that expanding these services on a more regular basis would provide meaningful support to those navigating grief and loss.

2.9 Workshop Report: Rainbows Across Borders ([Rainbows Across Borders](#) – Croydon)

Rainbows Across Borders (LGBT asylum seekers and refugees)

21st December 2024 (Focus Group 1 – 10 participants) Time: 17:00 – 21:00

27th December 2024 (Focus Group 2 – 7 participants) Time: 17:00 – 20:00

Question 1: What Matters Most When Bereaved?

Participant A:

"My dad committed suicide in March 2019. I feel an overwhelming sense of guilt for not being able to keep him alive, even though we lived in the same house. On the day he took his life, he told me, 'I want to kill myself,' but I went to work. When I returned, I found that he had hanged himself. I sometimes feel like I'm living in a bubble, feeling lost, believing I could have done something differently. Yet, I try to live a normal life by keeping busy with my job."

"I sought bereavement counselling, which cost £50 an hour, but it was a complete waste of time."

"It matters to me that I have held onto a few of my father's belongings. I sometimes leave them in the same place for years to feel his presence in the house. I kept his shoes and a voicemail on my phone, but when I upgraded my phone, the voicemail disappeared." (Participants expressed sympathy: "Auh")

"My brother has kept a profile picture of our father on his phone to preserve his memory. A few weeks after my father passed, a friend walked me around the house. Now, when I feel sad or intoxicated, I go to my father's room and talk to the empty space, feeling as if his presence remains."

Participant L:

"For me, it's about putting God first and knowing that I will meet my loved ones again. Being part of a religious community, singing hymns, and believing that their souls will go to heaven brings me comfort."

Participant G:

"I feel guilty, wishing I had done or said something different before they passed. Cultural traditions matter a lot to me, as different communities grieve in different ways. I prefer to be left alone with my immediate family initially, to allow us to process the loss together."

"In Muslim communities, people are buried the same day. In Seventh-day Adventist and Baptist traditions, they do not grieve openly. When I visited a Seventh-day Adventist relative after a loss, I was full of grief, but it felt like I was an outcast. In some Baptist communities, grief is almost dismissed, as if they are erasing the presence of the deceased, which can feel like a form of denial."

"It is also difficult when people die without writing a will, as family members often end up in conflict. For me, it is important that proper arrangements are made in advance so that survivors are not left with the burden of legal disputes."

Participant H:

"I need people around me to empathise with me. Losing a loved one is a pain that cannot be duplicated."

Participant E:

"My friend passed away and left children behind. The children said they couldn't understand why their mother died, and no one could truly understand how they felt. It is important to have support for those left behind, especially children, as their emotions and needs can be difficult to navigate."

Question 2: The Impact of Bereavement

Participant A:

"I had a mental breakdown. Six months after my father's passing, my aunt demanded a substantial sum of money that he had borrowed from her in the 1990s."

Participant M:

"I had an emotional breakdown. I used to talk to my mother every day, and losing that daily source of comfort led to deep emotional distress."

Participant J:

"I witnessed my Ugandan cousins transition from excellent to poor schools after their father—who was the primary provider—passed away. Their well-off friends distanced themselves, leaving them even more isolated."

Participant R:

"When someone passes away, they often take important family details, documents, or history with them—especially in communities where record-keeping is rare. Death is considered a taboo topic, so no one talks about preparations, leaving survivors struggling to piece together information."

Participant A:

"Family conflicts and breakups are common after a death. When my grandparents died, it caused major disagreements over assets and money."

Participant G:

"The loss of a loved one can lead to further tragedies. A friend lost two children within a month, and the grief affected their mother so badly that she collapsed and died."

Participant A:

"I struggled with suicidal thoughts after my father's death. On one of my darkest nights, I drank an entire bottle of whiskey. I could have lost my life that night too."

Participant A:

"We often forget about the emotional impact on younger children. They, too, need support. Creating a memory box with letters and sentimental items can help them preserve the memory of their loved ones."

Participant A:

"When my sister passed away, she left behind three children. They couldn't cope with staying in the same house and had to change schools and move to a different area."

Question 3: What Does Good Bereavement Support Look Like?

Participant R:

- Physical support: Having people visit and spend time with the bereaved during the first few weeks or months.

Participant G:

- Financial support: Contributing money or food in the initial weeks of bereavement. *"In Africa, mourners often bring items to the deceased's home, and the community collectively bears the financial burden".*

- Emotional support: Providing a longer period of presence for the bereaved. In some cultures, relatives stay for over a month, which contrasts with the UK, where hosting guests for extended periods can be financially and logistically challenging.
- Bereavement fund: Setting up financial support for the deceased's family.
- Safe spaces: Creating community centres or hiring spaces where bereaved families can gather and grieve together.

Question 4: Experiences with Bereavement in Hospitals

- Paperwork challenges: The bureaucratic process of obtaining the green form and death certificate from the coroner often causes delays in funeral arrangements.
- Cultural differences in handling the deceased: In many African cultures, the deceased remains in the family home until burial, while in the UK, the body is moved to a mortuary immediately. One participant noted that after losing their uncle, they didn't see the body for a month until the church service before repatriation to Kenya.

Question 5: Most Important Sources of Bereavement Information

- Bereavement support service telephone numbers
- Cause of death – death certificate
- The will
- Funeral arrangements and services
- Counselling services for family members
- Places of worship

Question 6: Awareness of Bereavement Services in the Borough

- Croydon Bereavement Services (Civic Centre) – free of charge
- Hospitals

- Prayer rooms
- Churches
- GPs
- Local councils
- Friends and family networks
- Funeral services (e.g., RAP & Sons, though not Croydon-based, serve all of London)

Note:

Most participants were unaware of bereavement services in Croydon. The group was composed of LGBT asylum seekers and refugees, highlighting the need for greater outreach and culturally specific support services.

Conclusion

The focus groups revealed diverse perspectives on grief, with cultural, financial, and emotional factors significantly influencing the bereavement experience. Participants highlighted the lack of awareness of available bereavement services and the need for greater support in navigating grief, paperwork, and family disputes. Community-based bereavement initiatives and more accessible information on support services were identified as critical areas for improvement.

2.10 Workshop Report: Seen ([SEEN](#) – Richmond)

SEEN provides a safe space to support individuals facing unplanned pregnancy and baby loss. We also deliver healthy relationship and sex education to empower and nurture our community.

Established for 25 years, we recently rebranded as SEEN to reflect our evolving services, where we Support, Empower, Educate, and Nurture through our work.

SEEN is a small, local charity based in Twickenham, with a team of eight part-time staff, 15 volunteers, and five trustees.

Baby Loss–Specific Responses

1. About Bereavement

Bereavement is a deeply personal and sensitive experience. The support individuals need varies depending on their faith, beliefs, life philosophies, culture, social circumstances, and generational differences.

Focus Group Discussion Question:

When grieving, what matters most?

Answers:

- *"Unexpected"* by Rachel Lewis (a book on baby loss and miscarriage) was found to be extremely helpful.

2. The Impact of Bereavement

Focus Group Discussion Question:

What is the impact of bereavement (e.g., physically, mentally, emotionally, socially, on employment, household income) and over what period of time?

Answers:

- After experiencing a second or third miscarriage, participants described feeling as though a physical barrier had been placed in front of them, making it impossible to move forward: *"If you are hit in one leg, you limp on. If you are then hit in the other leg, you are forced to stop!"*
- *"I have dual trauma—from experiencing both loss and surgery."*

- “I carried my trauma into my next pregnancy.”
- “My anxiety persisted throughout subsequent pregnancies.”
- “I became emotionally exhausted due to numerous clinical appointments and scans, which often felt unhelpful in moving forward.”
- “I relived the loss at future scans and doctor’s appointments.”
- Feeling emotionally disconnected from their body.
- Over-exercising as a means of regaining control over their body.
- Unexpected grief intensity, comparable to losing a parent.
- “I panic when entering settings with children or seeing an empty nursery in the home.”
- Reluctance to exercise or regain pre-pregnancy body shape, as the belly represented the last connection to the baby.
- A complex love/hate relationship with their body after miscarriage.

3. About Bereavement Support

Many bereaved individuals receive the support they need from family, friends, and their community, such as social clubs, networks, spiritual leaders, or places of worship. However, others require additional support from healthcare providers, GPs, and bereavement services.

Focus Group Discussion Question:

What does good bereavement support/service look like (from healthcare services, bereavement services, or community-based networks)?

Answers:

- Uncertainty about next steps: *“Do you try again, or do you do things differently (e.g., go private next time)?”*
- Home visits from a midwife for six weeks in a subsequent pregnancy were immensely helpful.
- “A&E medical pathway was inadequate—staff did not read patient notes or understand their history.”

- “A plan was created for my next pregnancy, but not all clinical staff followed it, forcing me to relive the trauma by repeating my story.”
- SEEN and hospital support were invaluable—described as “incredibly positive experiences.”
- SEEN’s support for couples was unique and highly valued, as it recognized the impact on partners.
- Many wished SEEN could be replicated nationwide.
- Being placed in a waiting room with other pregnant women after learning about a miscarriage was described as “*torture*.” A complaint to PALS resulted in the creation of a separate waiting area.
- The layout at Kingston Hospital was problematic—“*The neonatal department and EPU are positioned too close together*.”
- Recommended resources:
 - *Listening to podcasts by The Worst Girl Gang Ever*
 - *Reading the book Conversations on Love*
- “Being reassured that my mental well-being was a priority was motivating and aided my healing.”
- Being signposted to SEEN made a significant impact—“*I don’t know where I would be today without SEEN*.”
- Baby Loss Awareness Week—some participants found social media overwhelming and chose to avoid it.
- Discrepancies in mental health care:
 - One specialist reassured a participant that mental health medication was safe, despite a GP and hospital midwife repeatedly advising against it.

4. Immediate Information and Support from Healthcare Providers

Focus Group Discussion Question:

What are the most important types of information and support that people need immediately after experiencing bereavement?

Answers:

- Access to viability scans.
- Compassionate and patient care from hospital nurses following the loss.
- Clear explanations about why a miscarriage may have occurred, if requested by the patient.
- Encouragement to conduct more research on miscarriage.
- Standardized bereavement leave at work (minimum of two weeks).
- GP follow-ups focusing on mental health and therapy options.
- Earlier access to medical testing—currently only available after three miscarriages.
- Availability of the new "Baby Loss Certificate" via the NHS, which should be offered promptly and optionally.

5. Awareness of Bereavement Support and Services

Focus Group Discussion Question:

What bereavement support services are you aware of in the borough?

Answers:

- Tommy's
- Mariposa Trust
- Sands

6. Accessing Bereavement Support Information

Focus Group Discussion Question:

What are the most important sources of information about bereavement support and services?

Answer:

- SEEN was described as "*pure support for us.*"

Conclusion

The focus group discussions highlighted emotional, physical, and logistical challenges following pregnancy loss. Participants emphasized gaps in bereavement care, particularly in:

- Healthcare communication—ensuring medical professionals read patient notes and follow care plans.
- Hospital environments—ensuring sensitive physical layouts and separate waiting areas for grieving parents.
- Mental health support—providing clarity on safe treatments and ensuring follow-ups by GPs.
- Bereavement leave—standardizing workplace policies to allow for emotional recovery.
- Early medical testing—offering testing and support before three miscarriages occur.
- Continuing SEEN’s work—expanding the model to more locations to provide accessible and inclusive support.

By implementing these improvements, bereavement support for individuals experiencing pregnancy loss can become more effective, compassionate, and widely available.

2.11 Workshop Report: St Raphael's Hospice ([St Raphael's Hospice – Merton and Sutton](#))

On Monday, 16th December 2024, we held a Bereavement Focus Group at St Raphael's Hospice.

The group consisted of 12 participants who had received bereavement support from St Raphael's Hospice in the past year. All participants were elderly (aged 70 and above), with the oldest participants nearing 100 years old. Each had experienced the loss of a life partner. The group was made up of 10 women and 2 men.

1. About Bereavement: What Matters Most When Grieving?

- Participants emphasized that talking about their bereavement experience was the most important factor, particularly expressing personal feelings and emotions.
- They agreed on the importance of self-compassion, noting that there is no right or wrong way to grieve.
- Finding support was vital, though some found it challenging.
- Many spoke about dealing with guilt following their loss and found that emotional support was helpful in managing these feelings.
- The greatest challenge was learning to live without their partner. They all agreed that community support, such as bereavement support groups, helped in this transition.

2. The Impact of Bereavement: How Does Bereavement Affect People Over Time?

- Participants described physical, mental, and emotional impacts that, while they may lessen, never fully go away.
- The early stages of grief were described as a "terrible mental pain" felt physically in the heart and stomach, particularly in the mornings.
- Social losses were significant—many felt they received fewer invitations, lost connections, and became more isolated over time.

- Loneliness increased during Christmas. Some shared that they felt especially sad when going to bed, leading them to stay up later, which resulted in fatigue the next day.
- Family dynamics changed in complex ways, which was difficult to navigate.
- Some participants who had experienced sudden or traumatic losses were diagnosed with PTSD. They found that having a diagnosis helped them understand their emotions and move forward.
- Bereavement support groups were particularly beneficial, as meeting others with similar experiences helped reduce feelings of isolation.

3. About Bereavement Support: What Does Good Bereavement Support Look Like?

- Participants felt a good bereavement service should provide a safe space to talk about things they might not feel comfortable discussing with family or friends.
- Support needed to be actively offered and encouraged—many had ignored bereavement support letters but responded to phone calls from St Raphael's.
- *"My GP service was unhelpful; I wasn't offered practical support."*
- One participant shared that they were turned away from an Age UK bereavement service because it was only available for those under 75, which all participants agreed was unacceptable.
- The approach of St Raphael's staff was praised as gentle, compassionate, and persuasive.
- Support groups helped participants form new friendships and connect with others in their community.
- Light-heartedness was important—one participant emphasized that being "allowed to feel happy" was incredibly valuable.
- Participants agreed that a good bereavement support group should allow them "to be themselves, to laugh, to cry."
- Many felt bereavement groups served as a gateway to other services, such as St Raphael's Wellbeing Services.

- One participant described their bereavement group at St Raphael's as "a lifesaver."

4. Immediate Support and Information After Bereavement

- The most urgent need after bereavement was practical guidance on what needs to be done next.
 - Financial advice and legal guidance were seen as crucial.
 - Clear, simple information on bereavement support services was essential, as many felt too overwhelmed to seek help on their own.
 - Any barriers to accessing support should be minimized to ensure those in grief can easily reach the services they need.
-

5. Awareness of Bereavement Support Services in the Borough

- Most participants were unaware of other bereavement support services in their area.
- One participant was aware of a bereavement group at a local hospital but had no further details.
- Another participant knew of a church-based bereavement group.
- Overall, there was a general lack of awareness about bereavement services outside of St Raphael's.

6. Getting Information About Bereavement Support and Services

- Hand-delivered information was seen as the most effective way to inform participants about bereavement support.
- Many first received information at the hospice when their loved one was in care.
- Receiving information in person was significantly more impactful than receiving a letter, as many participants were less likely to search for services online.

- Participants agreed that face-to-face communication played a vital role in encouraging them to engage with bereavement support services.

Conclusion

The focus group highlighted several key themes in bereavement experiences:

1. The need for social connection—participants found bereavement support groups vital in reducing isolation.
2. The lasting impact of bereavement—grief may ease over time but never fully disappears.
3. Challenges in accessing bereavement support—most participants had little awareness of available services, apart from those at St Raphael’s.
4. The importance of active outreach—bereavement support should be offered proactively, as many participants ignored written invitations but responded to personal phone calls.
5. Practical guidance is essential—many needed clear, simple information on legal, financial, and administrative aspects of bereavement.
6. Barriers to bereavement care for older adults—age restrictions on services were seen as unfair and highlighted gaps in support for those over 75.

Participants praised St Raphael’s for its approach, describing the hospice’s bereavement support as compassionate, community-driven, and life-changing. They emphasized the need for ongoing support, particularly for elderly individuals facing bereavement and social isolation.

By addressing barriers to bereavement care, increasing outreach, and expanding accessible support services, St Raphael’s and other bereavement organizations can further enhance the well-being and resilience of those experiencing loss.

2.12 Workshop Report: Togetherness Community Centre (Togetherness Community Centre Adults (60+) Report - Merton, Wandsworth and Sutton)

Togetherness Community Centre (Merton) – Adult (60+) Bereavement Workshop

Monday, 6th January 2025, 1:00 PM – 3:30 PM

- Sessions attended by 1 male, 9 females (aged 60 and over)
- Ethnicity: African-Caribbean
- Participants: Some had physical disabilities
- Boroughs represented: Merton, Wandsworth, Lambeth, Sutton
- Bereavement experiences:
 - 6 participants had experienced a recent loss
 - 4 participants had recently lost a family member or friend
 - 3 participants were experiencing grief related to the anniversary of a loss

I. About Bereavement

Discussion Question: *When grieving, what matters most?*

Participants highlighted that grief is not solely related to the death of a loved one but can also stem from various life changes, including:

- Loss of homeland
- Redundancy (job loss)
- End of a relationship
- Child taken into care
- Imprisonment of a loved one
- Illness / hospitalisation
- Dementia

- Loss of mobility/independence
- Loss of a pet
- Bankruptcy
- Divorce / Relationship breakdown
- Loss or damage of something meaningful

Participants expressed that the most important aspects of bereavement support are:

- Comfort and companionship (not being alone)
- Having someone to talk to
- Prayers, hugs, and physical touch
- Support with self-care
- Patience in explaining events and working through next steps
- Time to process the loss—"It takes time for reality to register and sink in."

2. The Impact of Bereavement

Discussion Question: *What are the impacts of bereavement (physical, mental, emotional, social, financial), and how long do they last?*

Participants acknowledged that the impact of grief varies greatly depending on individual circumstances, cultural background, and social norms, which are often not considered by professionals or services.

Identified impacts included:

- Emotional & Psychological Effects:
 - Sadness
 - Tearfulness
 - Guilt
 - Anger / Resentment
 - Personality changes
 - Overexcitement

- Violence / Self-harm
 - Substance misuse (alcohol, drugs)
 - Physical & Behavioural Effects:
 - Loss of appetite / Overeating
 - Over- or lack of personal care
 - Playing loud music to cope
 - Sleep disturbances
 - Social Effects:
 - Family or friendship breakdowns
 - Feelings of blame
 - Cultural taboos surrounding grief
-

3. About Bereavement Support

Discussion Question: *What does good bereavement support look like?*

Participants emphasized that bereavement support should be available 24/7, as grief does not occur within set timeframes. They noted that the quality of support depends on the person delivering it.

Key recommendations for a good bereavement service:

- Multiple access points – GP surgeries, online bereavement support
- Face-to-face support options
- A "one-stop" online service for accessible resources
- Stronger connections with places of worship
- Bereavement training for religious, faith, and community leaders
- Facilitated "family meetings" for emotional and practical support
- Proactive contact with the bereaved rather than waiting for them to seek help
- Signposting to relevant services

- Support to help people prepare for bereavement in advance
- Normalizing conversations about grief and loss
- Access to culturally competent bereavement guidance
- A structured, staged bereavement response (immediate, medium-term, and long-term support)

4. Immediate Information and Support from Healthcare Providers

Discussion Question: *What information and support are needed immediately after a bereavement?*

Participants stressed the importance of a rapid response from professionals and publicly available bereavement information.

Recommendations included:

- Posters in high-visibility areas (bus stops, libraries, supermarkets, gyms, community centers, public spaces)
- Workplace bereavement conversations – designated bereavement leads in schools, colleges, and universities
- Reframing bereavement as a normal part of life, rather than treating it solely as a crisis event
- Better response from social services – "Unless someone dies in a hospice, compassion is often lacking."
- Greater opportunities for people to grieve at home

5. Awareness of Bereavement Support Services

Discussion Question: *What bereavement services are available in your borough?*

Participants had very limited awareness of bereavement services in their boroughs. Many only became aware of services after experiencing a bereavement, but even then, knowledge remained unclear or incomplete.

The few services mentioned included:

- Samaritans

- Macmillan Cancer Support – but only accessed in the context of bereavement
- Age Concern (Age UK) and Citizens Advice Bureau (CAB) – unclear about bereavement-related services
- Department for Work and Pensions (DWP) – mentioned, but participants were unsure what support was available

6. Accessing Bereavement Support Information

Discussion Question: *What are the most important sources of information about bereavement support?*

Key recommendations for better information-sharing:

- Immediate response from professionals
- Face-to-face support opportunities
- Direct connections with key people and organizations
- Easy access to printed leaflets
- Social media platforms (though most participants lacked confidence in using smartphones)
- Age-appropriate information – structured guidance for all ages, including children (from age 5 upwards)

Additional Insights

Follow-up Sessions & Demand for More Support

- Four follow-up sessions were held on Thursday, 9th January, leading to further in-depth discussions.
- Adults requested more bereavement-focused sessions, each covering different aspects of grief.
- Young people declined one-to-one support but requested facilitated group discussions.

- The final session (planned for Monday, 13th January) was postponed due to a participant collapsing and being taken to the hospital. It was rescheduled for Thursday, 15th January 2025.

Closing Statement

The bereavement workshops confirmed that community members are eager to explore emotional and physical well-being topics related to grief.

- Previous workshops at the Togetherness Community Centre have covered early cancer detection, wills and estate planning, and Lasting Power of Attorney (LPA).
- Bereavement discussions have sparked further interest, with members wanting to engage their families in these conversations.
- Word-of-mouth has led new community members to inquire about future bereavement support workshops.

It is hoped that further workshops will be provided more widely, ensuring accessible, culturally competent, and community-led bereavement support.

2.13 Workshop Report: Togetherness Community Centre

([Togetherness Community Centre Young People – Merton, Wandsworth and Sutton](#))

Togetherness Community Centre (Merton) – (Young People) Bereavement Workshop

Sunday, 5th January 2025 – 2:30 PM – 4:30 PM

- Sessions attended by 9 young people (aged 12–17)
- Ethnicity: African-Caribbean, African, European, Black British
- Boroughs represented: Merton, Wandsworth, Sutton, Croydon, and Lambeth
- School attendance: Most participants attended schools in Merton.
- Bereavement experiences:
 - 7 participants had experienced the recent death of a family member or someone they knew.
 - 7 participants had suffered other types of bereavement.

1. About Bereavement

Focus Group Discussion Question: *When grieving, what matters most?*

Participants noted that bereavement is not only related to the death of a loved one but can also result from other forms of loss. They identified the following:

- Loss of family members or friends
- Loss of freedom (e.g., imprisonment, displacement)
- Loss of privileges or opportunities
- Parental separation
- Leaving school or changing schools
- Asylum-seeking experiences
- Siblings moving away

- Relocation to a different area or country

2. The Impact of Bereavement

Focus Group Discussion Question: *What are the emotional, mental, social, and physical effects of bereavement?*

Participants agreed that the impact of grief varies greatly between individuals and that people often do not consider bereavement until they are personally affected.

Identified impacts included:

Emotional & Psychological Effects:

- Hiding feelings / Suppressing emotions
- Using entertainment as a distraction
- Avoiding difficult conversations / Deflecting questions
- Anxiety, fear, and disappointment
- Frustration and isolation
- Self-harm and substance misuse

Behavioural & Social Effects:

- Withdrawing from friends and family
- Stopping social media activity or messaging
- Neglecting personal appearance and self-care
- Becoming vulnerable to online predators

3. Bereavement Support Needs

Focus Group Discussion Question: *What does good bereavement support look like?*

Participants felt that bereavement support should be widely available and accessible before a loss occurs rather than only after an individual experiences' bereavement.

Key recommendations for improving bereavement support:

- More advocacy and awareness-raising
- Increased advertising of services to young people
- Use of social media, including TikTok surveys, to engage youth
- Child-friendly bereavement resources
- "Grief has no structure, so why should bereavement information be structured?"
- Training for faith and community leaders to share bereavement information
- More bereavement workshops in schools
- Cultural perspectives on grief should be included in discussions
- Discussions on the impact of celebrity deaths on young people
- Long-term bereavement support, not just immediate interventions

4. Immediate Bereavement Information & Support

Focus Group Discussion Question: *What information and support are needed immediately after a bereavement?*

Participants raised concerns that young people are often excluded from bereavement discussions because adults assume the information is too distressing.

Key recommendations for immediate bereavement support:

- Parental and adult acknowledgment that children and young people grieve differently from adults
- Youth clubs, community centres, GPs, and churches should provide bereavement support
- One-to-one and family group discussions should be available
- The internet should be a key resource for young people, providing age-appropriate bereavement support

- Support should be available across boroughs, not restricted to where a young person lives
- "Unless you experience bereavement, you are not included, and information is not shared with you."
- "Not knowing the truth can be worse than hearing difficult news."

5. Awareness of Bereavement Support Services

Focus Group Discussion Question: *What bereavement services are available in your borough?*

Most participants were unaware of bereavement services. Even when deaths occurred in their schools, assemblies were held, but no direct support was provided.

Sources of support identified by participants:

- Family & friends
- Social media
- Childline
- School mentors and pastoral care teams
- Churches and youth groups
- GPs
- "Random people" and strangers offering support

6. Accessing Bereavement Support Information

Focus Group Discussion Question: *How should information about bereavement services be shared with young people?*

Participants strongly felt that bereavement conversations should be normalized at all ages to build resilience.

Key recommendations:

- Leaflets in public places
- Bereavement promotions on TikTok and social media

- TED Talks about bereavement, led by young people for young people
- PHSE (Personal, Social, Health & Economic Education) lessons on grief in schools

Closing Summary & Next Steps

Participants were highly engaged and expressed strong interest in further bereavement discussions.

- One young person planned to speak to their school council about introducing structured bereavement discussions.
- The Holiday & Food Programme (HAF) is considering adding bereavement discussions to their summer and Easter holiday activities.
- Plans are in place to engage faith leaders in the community to encourage more open conversations about bereavement within families and religious settings.

The workshop confirmed that young people want more structured, open conversations about grief and need better access to bereavement information. Future workshops will be designed to ensure young people receive the support they need in a way that feels accessible and inclusive.



Healthwatch Kingston is an independent statutory service (not part of the NHS nor Kingston Council). You can find out more about us on the [Healthwatch Kingston website](#).

Healthwatch Kingston was set up by the [Health and Social Care Act of 2012](#) to be the independent champion for local NHS and social care.

We seek the views of patients, service users, carers and the public to help services work better for the people who use them. We play an important role bringing communities and services together. Everything we say and do is informed by what local people tell us.

As well as encouraging those who run local services to act on what matters to people, we also share local views and experiences with [Healthwatch England](#) and the [Care Quality Commission](#) who make sure that the government put people at the heart of care nationally.

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Kingston Voluntary Action is an infrastructure organisation that provides a wide range of support to the voluntary sector. We support local charities and community groups at all stages of their development.

Our Vision: Communities and people that KVA works with are empowered to drive social change towards a fairer, more inclusive, healthier and happier society.

Our Mission: Meeting the needs of community organisations and individuals by equipping them with relevant tools, skills, knowledge, confidence and voice to drive positive change.

Our Values: We are Collaborative, Resilient and Creative.

Our Strategy: [2025-2028: Stronger Organisations, Healthier Communities](#)

Our Role: KVA is part of a national network of over 250 local infrastructure bodies, known as Councils for Voluntary Service (CVS).

We believe that infrastructure has a crucial role in helping to build strong, connected communities.

We see infrastructure as based on three complementary and intertwined strands: capacity building, connecting and representation.

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