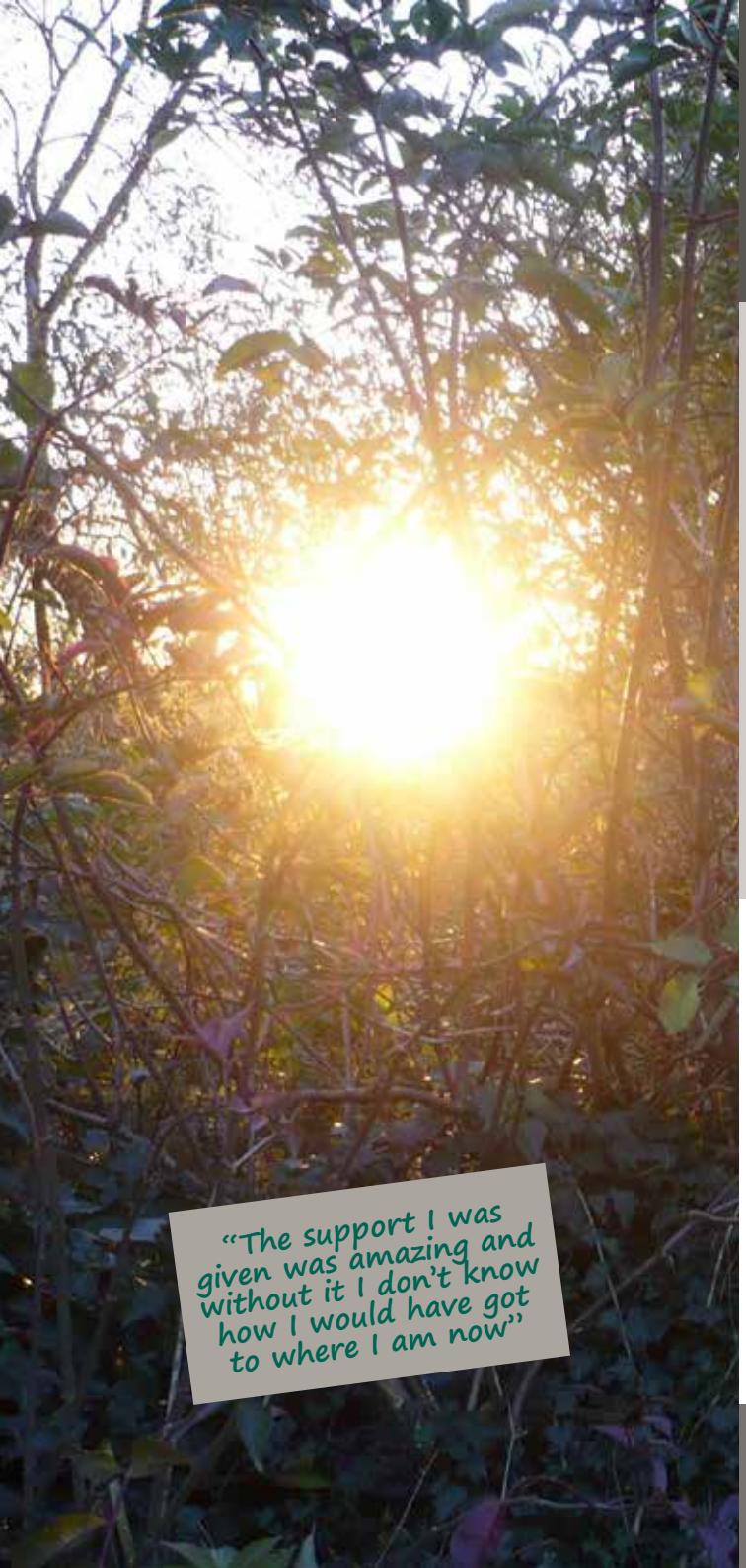


"Openly, honestly & authentically without the masks":

An independent evaluation of the

High Peak CVS

Bereavement Support Service

High Peak CVS
BEREAVEMENT SUPPORT GROUPS

COMMUNITY FUND

Kerrie Fletcher

April 2022

Contents

Executive Summary

At a time when people across the whole world are experiencing loss and grief on a scale not seen in living memory, High Peak CVS has piloted an innovative approach to supporting people struggling with bereavement, and learned lessons relevant to communities everywhere.

This report set out to evaluate this new approach and found it to be highly successful, effective and offering valuable learning to others looking to support bereaved people.

It has delivered a successful community-based bereavement support service, which, as the survey findings show, makes a tangible positive difference to the wellbeing, social connection and self-care of those who use the service, supporting them in both grief work and transition to the next phase of their lives.

It offers a safe space where those struggling with bereavement can express their loss, gain insight into their grieving and find fellowship and support from their peers.

The recent *Report of the Lancet Commission on the Value of Death: bringing death back into life*, called for a whole-system Compassionate Communities approach, within which death, dying and bereavement are understood and valued as normal life experiences, and where support is provided within and with communities. The High Peak service aligns closely with this vision.

The Covid-19 pandemic has brought a scale of loss unprecedented in living memory and a legacy of disruptive - sometimes traumatic - bereavement experience for those who lost loved ones during the pandemic. Existing social and medical care services remain under pressure. Even in more normal times, they often lack the capacity or expertise to provide effective support to those who are grieving. In this context such a service has never been needed more.

The High Peak Bereavement Support Service offers a proven and cost-effective way to address the pressures and challenges of bereavement.

"I cannot think of another arena where I can express my vulnerable self. I have found my voice and others in the group have either had similar experiences or validated my need to grieve in my own way. Openly, honestly and authentically – without the 'masks', without the pretence + without all the effort of other relationships."

"The support I was given was amazing and without it I don't know how I would have got to where I am now"

"The group provided just the kind of support I needed – enough to make me feel able to cope without it. "

Background

The High Peak CVS Bereavement Support Service was established in 2018 to meet an identified gap in local support for people who had experienced bereavement. In 2019 the service received a 3 year grant from the National Lottery Community Fund.

This report is an evaluation of the service, based on a review of project documentation and monitoring reports, a survey of individuals who have used the service, interviews with staff, partners and service users, and observation visits to 3 support groups.

Activity

The service provides facilitated Bereavement Support Groups which meet fortnightly in community settings. These provide a safe space, enabling bereaved individuals to share their experiences and support each other, and to better understand and cope with their grief.

At the time the evaluation was carried out (November 2021 - January 2022), there were 4 Bereavement Support Groups in Buxton, Chapel-en-le-Frith (2 groups, daytime and evening) and Glossop. A fifth was due to start early in 2022, with further groups planned to complete coverage of the district.

From 1 January 2019 to 31 December 2021:

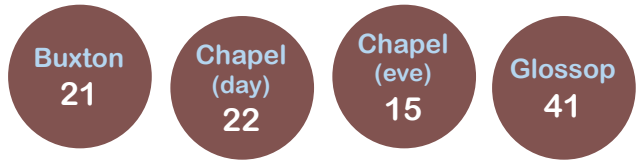
101 total number of Bereavement Support Group sessions

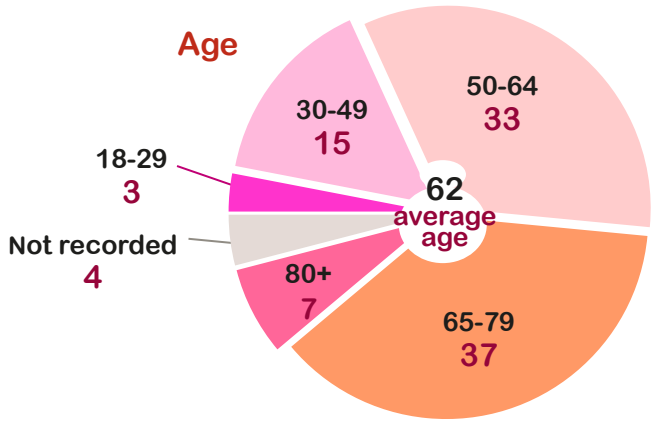
99 people had attended a group

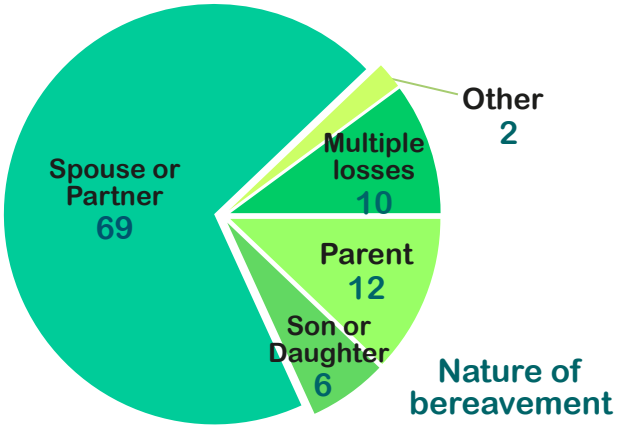
56 women **43** men

Average cost **£1,096** per person supported by the service

Location







Was it effective? Survey findings

The aims of the project, for bereaved people, were to:

- Reduce feelings of desperation and fear after bereavement;
- Improve mental health;
- Improve self-care;
- Increase self-confidence;
- Re-engage past interests, hobbies, and in community support networks and activities.

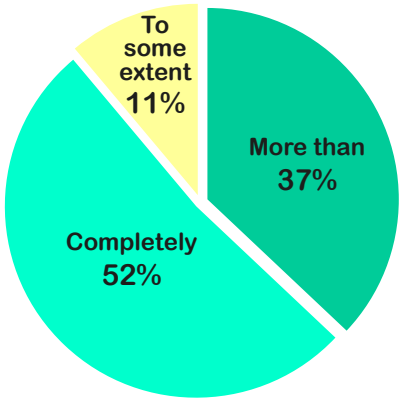
Expectations

Respondents spoke of seeking comfort, understanding, help, support, connection and a safe space in which to express and deal with their grief:

Time out from the everyday to express self in relation to the bereavement... to meet others experiencing major loss and find ways of coping. To be supported and understood by others experiencing such loss and to have a safe space to express self.

Did the group meet those expectations?

89% of service users who responded said that **the service had** either **completely met** or **exceeded their expectations**. None said it had completely failed to meet them.



Outcomes: Summary

Health, wellbeing and self-care

- It had a positive impact on my **mental wellbeing** (97%)
- It helped me look after my own **physical and mental health** (86%)

A number of service users commented on how the groups encouraged and reinforced the importance of self-care, both psychological and physical.

> *The group helps greatly with mental health issues, relating to dealing with simple every day life to dealing with such abject thoughts of taking ones own life.*

Reduced feelings of fear and desperation: Increased confidence - 'grief work'

- It **helped me with my grief** (93%)
- It **increased my self-acceptance** while grieving (93%)
- I could **discuss the really difficult stuff** (96%)
- I felt able to **talk honestly** about my feelings and experience in a **safe space** (100%)

Service users reported how hearing the stories of others - and the insights offered by the facilitator - had helped them better understand their grief journey and weather its ups and downs.

> *I can now deal with the triggers which once reduced me to tears. I no longer feel self pity. I am more stable.*

> *I look forward to the support and chance to share. I feel better, if exhausted, afterwards. It's reinforced that there is no right way, no time limit etc & that the path forward is not straightforward or easy.*

Reduced feelings of fear and desperation: Connecting, caring and fellowship

- I felt **less isolated / less alone** (96%)
- I felt **included** (100%)
- I felt **heard, understood and accepted** (100%).
- I grew to **care about the others** in the group (100%)
- I felt **cared for by the others** in the group (100%)

Another common theme was the importance of the fellowship of others with similar experiences. The group values of inclusion, respect and acceptance were powerful in reducing the sense of emotional isolation that many individuals felt. They could also explore difficulties in their relationships with others.

> *I have felt reassured that I am not alone in the emotions and experiences I have faced. Others too are going through the maelstrom.*

Restoration and re-engagement

- I felt **more confident to re-engage** with wider social activities, when I was ready to do so (89%)

The groups are naturally focussed more on loss than restoration, as the purpose of the group is to engage in 'grief work'. However the groups encourage and enable more positive engagement in restoration work outside the group, tackling difficulties and celebrating successes.

> *I can now cope better with being a lone widower and with living with the memories of over 50 years. I am more positive and can take on new ventures. I have learned to manage expectations. I can now present my identity as a person in my own right - rather than as widower.*

Experience of the group

- The groups are **well structured and well run** (100%)
- There is **a safe and accepting atmosphere** within the group (100%)
- I feel **confident in the staff member** facilitating the group (100%)
- I would **recommend the Support Groups** to someone else who had experienced a bereavement (100%)

Beneficiaries spoke highly of the supportive environment and values of the group, as a place where they could express themselves authentically, discuss difficult feelings, and feel confident that it was a safe place to do so.

> *I cannot think of another arena where I can express my vulnerable self. I have found my voice and others in the group have either had similar experiences or validated my need to grieve in my own way. Openly, honestly and authentically - without the 'masks', without the pretence + without all the effort of other relationships.*

There were also many positive comments about the facilitators. All respondents would recommend the groups to others and many expressed their wish that a similar service be made available to all bereaved people everywhere.

> *People need help and support kindness and understanding. When they lose someone this isn't always forthcoming from friends and family for various reasons. This service is needed and does serve its purpose.*

Defining features: Why it works

The High Peak Bereavement Support Group model has 5 key features which are important to its effectiveness:

Purpose and focus

The focus of the groups remains firmly and explicitly on bereavement, the experiences of loss and grief, and the tasks of grieving and mourning. Other models of bereavement support tend to limit attendance for a fixed period or work to a set programme, or else drift over time into becoming social groups. The High Peak groups maintain a clear focus on the work of grieving, allowing people to move on when they decide they are ready – which also creates space for new members to join.

Bounded space

There is a predictable framework for each session. Groups start and end promptly at a predefined time. There is a simple structure for each group session with all those present encouraged to contribute at each stage: Initial 'check in' and sharing; discussion or exploration of particular experiences/issues/topics; a closing round, sharing a success and/or one way in which each person will look after themselves after the group. However, what is explored in the group flows from the experiences and feelings shared by those present; there is no predefined programme.

Rites of passage: Entering and leaving the group

There are referral and assessment processes to ensure clear understanding and expectations. Those leaving are encouraged to come and say their farewells and celebrate this point of transition. To date no-one has ever asked to return to a group once they have left. These rites of passage into and out of the group help maintain its clarity of purpose and boundaries.

Finding fellowship in grief

Telling their stories and hearing those of others on a similar journey – with theoretical insight offered by the facilitator where appropriate – leads to both mutual support and increased 'grief literacy', helping people to feel less alone. The group size is relatively small and membership is fairly stable over time so powerful relationships of sharing, support and fellowship develop where people can share: "*Openly, honestly and authentically – without the masks*"

Holding the group

While sharing of lived experience is a key element, however the service is not simply a peer support group. It might be better described as facilitated therapeutic group support. Experienced, qualified and skilled professional facilitator(s) coordinate the groups, maintain their boundaries and rites of passage, 'hold' the session as a safe space, invite contributions and ensure everyone has the chance to speak, reflect and sum up, offer potential insights and maintain a culture of respect, empathy, non-judgement and confidentiality. They also follow up any concerns about individuals outside the session.

This holding and supporting function allows individuals who participate to focus on themselves, their grief work, and each other. The contribution and value of the facilitator was explicitly acknowledged by many survey respondents, as well as by those interviewed.

"I learned that to feel sad, angry and insecure was all part of the grieving process. I felt better in myself being able to talk freely about how I was feeling."

Recommendations

High Peak CVS is recommended to:

1. **Stabilise and embed** the learning to date: Following the disruption of Covid, the service needs a period of time to consolidate: To build a robust staff and volunteer team, to establish the planned new groups, to reflect on the experience to date, and to inform decisions about the future.
2. Carefully **explore options for future growth.** High Peak CVS should consider its role in this. Rapid expansion, or supporting others to replicate the model elsewhere, both risk drawing capacity away from local frontline delivery. An independent analysis of options would be a worthwhile investment.
3. For continuity and quality of service delivery, in a challenging economic environment and competitive jobs market, **review remuneration of service staff** to ensure that suitably qualified and experienced staff can be recruited to and retained in key posts,
4. To ensure the widest possible benefit, the service should **increase the visibility of its offer**, both by developing professional referral pathways and by marketing and promotion to wider and more diverse audiences.
5. Explore potential to **improve bereavement awareness and grief literacy.** A recurring theme is the extent to which people and services struggle to providde appropriate support, to people who are bereaved and grieving. The service should consider whether it could explicitly address this in communities, drawing on the experiences of service users with lived experience. For example, using a 'social action movement' approach similar to that of the Alzheimer's Society's Dementia Friends programme.

1. Introduction

In a well-known Buddhist story a young woman, Kisa Gotami, experiences the death of her infant son.

Frantic with grief, unable to process the loss, she wanders around the village carrying his dead body, asking everyone she meets if they have any medicine that will make him better. Whether she meets with sympathetic, bemused or scornful responses, she is unable to hear the truth that her child is beyond help.

Finally, a kindly villager tells her to go and see the Buddha – he will be able to give her the medicine she seeks.

The Buddha agrees to help her – if she will just fetch him a pinch of mustard seed. But the mustard seed must come from a household which has never experienced a death.

With renewed hope Kisa Gotami goes from house to house. Many householders are able and willing to give her mustard seed, but when she asks whether anyone has ever died there, they always answer: Yes, of course.

Only when she has visited every house in the village does the truth dawn on her – the dead far outnumber the living and every single household has its own story of loss.

She returns to the Buddha, who gently reaffirms what she has discovered for herself. Only now is she able to accept the reality that her son is dead, and give his body up for cremation.

The story illustrates a number of themes that are relevant to this evaluation:

- The paradox that while bereavement and loss are human universals, and grief is a normal part of life, the individual experience can feel overwhelming and lonely;
- Fellowship with others who have experienced similar loss, hearing their stories and telling your own, can bring relief on the journey, helping a person to understand their grief and find their own way to grieve;
- Each experience is unique and each person has to do their own 'grief work'. However if someone is struggling, the support of a third party (in the story, the Buddha) exercising skilful means, can help them with the process – nudging them towards greater insight rather than telling them what they should do, think or feel;
- A fourth point: The person struggling needs to have this support accessible to them in their community. They also need to know, or be told, how and where to find it.

"Listening to the experiences of others I realised not only that grief was acceptable but that others too were in the same situation. I was not alone."

2. Origins and history of the High Peak Bereavement Support Service

High Peak CVS (registered charity number 1096462) is a small/medium sized charity[1] based and working in the High Peak District of Derbyshire. Its most recent published accounts (for the year ending 31 March 2021) show an income of just over £334k and a staff team of 14.[2] The charity's primary focus is building the capacity of local voluntary and community organisations to make a positive difference to their communities, as well as supporting the development of new groups and services to meet identified community needs.

The origins of the Bereavement Support Service lie in a 2017 Nesta '100 Day Challenge' initiative which brought together local multi-disciplinary teams from across health, social care, the voluntary sector (including High Peak CVS) and people with lived experience. These groups set out to explore new ways of working to improve care and outcomes for local people. The Glossop team focussed on end of life care. One gap identified was support for bereavement.

As the local voluntary and community sector development agency, High Peak CVS then organised an initial scoping meeting (Jan 2018) bringing together partners with a professional interest, (hospice, district nurses, hospital chaplain, counselling services, funeral homes), and bereaved people themselves.

Based on ideas shared at this meeting and very honest input from bereaved people about their needs, a pilot Bereavement Support Group in the Glossopdale area was set up by HPCVS. This initial pilot was funded by NHS Tameside & Glossop CCG for 12 months to November 2019. Based on the experience and learning from the pilot a bid to extend and develop the work was submitted to the National Lottery Community Fund.

In October 2019 a 3 year National Lottery Community Fund grant of £123,933 was secured. Subsequent additional funding of £51,706 over 2 years was awarded in March 2021 to help the project deal with the impact and legacy of the Covid 19 pandemic. This funding will run out at the end of 2022. At the end of its second year of Lottery funding the service had supported 99 individuals at a cost of approximately £1,096 per beneficiary.[3]

High Peak CVS has worked closely throughout with local partners, including, in the initial pilot, Co-op Funeral Home and staff from Tameside & Glossop Health Care Trust; and since March 2020, with Blythe House Hospice who currently co-facilitate and host the two Chapel-en-le-Frith Support Groups.

"I look forward to the support and chance to share. I feel better, if exhausted, afterwards. It's reinforced that there is no right way, no time limit etc & that the path forward is not straightforward or easy."

3. The evaluation

Evidence gathering for the evaluation took place between November 2021 and January 2022. The final report is based on assessment of the following material:

- A review of documentary evidence provided by the service, including data on service beneficiaries, funding bids and monitoring reports, supporting documents such as role descriptions, service guidance/policies, marketing materials and transcriptions of exit interviews.
- 3 interviews with the Service Coordinator/ Facilitator who was responsible for developing, delivering and supporting the High Peak Bereavement Support Groups, from the initial pilot to the present day;
- Interviews with a volunteer who supports the Buxton group and with two Blythe House Hospice staff who support and co-facilitate the two Chapel-en-le-Frith groups (which take place at the Hospice)

"Thank you so much for the support. Thank you for the encouragement and sensitive, but clear, leadership of the counsellors. They are excellent. Thank you for the mutual support of the group. Thank you for being able to express my gratitude."

"I was given the time and space to articulate my feelings. I needed to work through my emotions and was able to shed tears. Before I held back my emotions and thoughts and this built up stress within me. Everyone was patient with me and with one another – leaders and group alike."

Gathering evidence from **those who had used the services** was particularly important, and their experiences were captured via:

- A survey, which all service beneficiaries (past and present) were invited to complete either on paper or online, asking about their experience of the service and the difference it made. 29 people completed some or all of the survey – a response rate of 29% (of 99 all-time beneficiaries);
- Semi-structured discussions with service users themselves, either 1:1 or in small groups. In all, I spoke directly to 16 service users (2 former and 14 current attendees – one of whom was attending for the first time, and one for whom this was their final session);
- Direct observation of 3 group sessions, 1 in each location (Buxton, Chapel-en-le-Frith and Glossop) attended by 20 service users in total.

Unless otherwise stated, all *text in italics* and in quotes are the words of service users themselves, either from their written survey responses, exit interview transcripts, or direct quotes from what they said to me in 1:1 or small group discussions.

Sincere thanks to all of those who gave up their time to contribute to the evaluation, and particularly those service users who completed the survey, shared their experiences in person and/or allowed me to attend and witness their support groups in session.

4. High Peak Bereavement Support Service: A Theory of Change

5. Vision and Purpose

Underpinning the service, as staff and partners responsible for its delivery articulated it to me, is a belief that bereavement is a normal (if painful) life experience, which most people will and should negotiate without needing professional intervention. Those experiencing the grief of bereavement are best supported by and within their family, friends and community. For those struggling with grief, the most powerful remedy is sharing their stories with, and learning from, those with lived experience.

The model aligns with the long-term vision articulated in the recent *Report of The Lancet Commission on the Value of Death: bringing death back into life*[4] as **Compassionate Communities**: A society where death, dying, bereavement and grief are widely understood and accepted as a normal part of the life cycle, as physiological, relational and spiritual experiences; and where communities normally provide the support that people need through these experiences.

The report notes that death has become increasingly medicalised and removed from communities and individual life experience. The focus is on preventing death and extending life, rather than ensuring dying people and their families are supported through the experience of death and bereavement, as normal life processes. During the Covid pandemic particularly:

> "People have died the ultimate medicalised deaths, often alone but for masked staff in hospitals and intensive care units, unable to communicate with family except electronically."[5]

All of this impacts on people's understanding of death and bereavement, and their confidence both in navigating these experiences themselves and supporting others through them. This is as true of medical professionals and support providers as it is of the family, friends and acquaintances of bereaved people. Even bereavement itself is can be medicalised in the absence of other support mechanisms: Medication or psychiatric treatments being offered as first port of call for bereaved people struggling to cope with their grief.

The Lancet report sets out five principles for a "whole death system" These five principles are:

(1) The social determinants of death, dying, and grieving are tackled;

(2) Dying is understood to be a relational and spiritual process rather than simply a physiological event;

(3) Networks of care lead support for people dying, caring, and grieving;

(4) Conversations and stories about everyday death, dying, and grief become common;

(5) Death is recognised as having value.[6]

As one of the authors of the Lancet report has reflected, there are two broad Compassionate Communities approaches (with some communities combining both):

- Those which **increase literacy and awareness of death, dying, grief and loss** (for example, through events, awards, campaigns, death cafés or arts activities); and
- Those which **create social support** for those coping with the experience.[7]

6. Assumptions

6.1 Bereavement and the work of grieving

Bereavement is the loss of a significant relationship as a result of death.

Grief is the lived response to that – the emotional and physical reaction experienced by a person as a result of bereavement.

We can helpfully distinguish this from **grieving,** the process of adapting and changing over time to adjust to the loss.

As Dr Mary-Frances O'Connor (a neuroscientist specialising in the effects of grief) points out:

> "grief never ends, and it is a natural response to loss. You will experience pangs of loss over this specific person forever...But...your grieving, your adaptation, changes the experience over time" [8]

Another factor is **mourning,** the outward/public face of grief, the actions and manner of expressing grief – usually within culturally defined perimeters of what is normal, expected or acceptable.

There is no cure for bereavement. It is a fact of life and a normal part of our life experience. Grief is painful and grieving is hard work; however most people will cope with the support of family, friends and time. Others will need additional support to help them find their way through the experience.

Each person's experience of loss and grief is different and unique. However, the psychologist William J. Worden has suggested that the grieving process generally involves a set of tasks. These are not consecutive stages that must be completed in a predefined way, nor are they phases passively experienced. Rather, they are tasks that each individual will engage with in their own way:

- To accept the reality of the loss, and the new reality of our changed world;
- To process the pain of grief – but also take time off from experiencing this pain;
- To adjust to a world without the deceased and master the changed world we find ourselves in;
- To find a way to remember the deceased, to honour our relationship and ongoing connection with them;
- To embark on the rest of one's journey through life, developing new roles, identities, and relationships.[9]

In engaging with these tasks, individuals will naturally oscillate between the processes of:

- **Loss** (the emotional work of grief and processing the experience of bereavement); and
- **Restoration** (dealing with the demands of the current reality, and looking forward).[10]

It is not possible to do both at once, and individuals will take a break from one to deal with the other (taking time out of day to day life in order to experience and process grief; taking time out from grief work to do something here and now, or plan for the future).

6.2 Who needs support and why?

As noted above, most people will get the support they need from those around them, to help them cope with grief and negotiate the grieving process.

However some individuals will have a more complicated experience and, as a consequence, seek support from beyond their normal support relationships: Grief that feels intense, overwhelming or frightening; which is persistent, disruptive or prolonged; and/or which does not resolve over time.

This can be for all kinds of reasons, including any or all of the following factors:

- The nature of the loss – for example, a sudden, unexpected, untimely or traumatic death:

  I was relatively young to lose my husband and none of my friends were in this position

- The relationship with the deceased – the role they played in a person's life and the quality of the relationship;
- Previous experiences and memories of loss, which have a cumulative effect, or which trigger a more intense response to the current experience;
- Other life experiences which make a person potentially vulnerable, such as physical or mental ill-health, social isolation, poverty or having been a long-term carer;

  I have experienced a challenging, dysfunctional birth family, bereavement has added another layer to this. The group has been available to express this in order for me to find a way through.

- The ability of family or friends to provide support. Some bereaved people simply do not have people they are close to nearby or available; or are afraid to burden others with difficult emotions; or find that those they are close to cannot offer support (for example, because they are themselves grieving):

  The group is the only setting where others are grieving & bereaved. With my family + relationship/friendships I can feel isolated/ alone + a pressure to 'get on with it'

  I have lots of [other] people I can talk to, but for example my sons, they are also experiencing [their own] loss [of their mother].

Linked to point four is a wider issue, that as communities and individuals, we may lack understanding of bereavement and grief, and may not feel confident in how to respond. This will be as true of professionals and service providers that a bereaved person encounters, as it will be of their personal support circle. Those experiencing bereavement may be surrounded by people who genuinely care, and who want to be helpful and supportive, but simply don't know how to go about it.

Culturally acceptable expectations of mourning behaviour can also enable or inhibit a person's ability to experience and/or express their grief:

There's no platform for this anywhere else, it's not broached in our society.

Social pressures and expectations of what is 'normal' or 'acceptable' mourning can impact on a person's ability to experience and express grief in the way that meets their emotional needs:

I realised that what I was feeling was normal.

6.3 How is it best provided?

Sometimes the only remedy offered to those struggling with grief is medical (medication, psychological therapies or psychiatric treatment), which come at a high cost both to health and care systems and the individual (for whom they may not be appropriate or effective, and for whom they pathologise the normal grief process):

I was offered counselling [by my GP] – but that wasn't what I need, I'm not ill, I'm just grieving.

However, absence of appropriate bereavement support can result in social isolation or poor self-care, which impact negatively on mental and physical health, ultimately leading to a higher likelihood that medical intervention will be needed.

The Bereavement Support Groups offer a middle way, between the absence of external support and medicalised intervention. However this is provided within and from the community in which they live, enabling people with lived experience to connect with, care for and support each other. It is the kind of intervention that the Lancet report advocates for, "cutting across the usual dividing lines of lay or professional care," and with relationships between professional staff and those receiving support "based on connection and compassion" rather than transactional in nature.[11]

It indirectly helps the NHS & other services possibly emergency services by supporting people some of whom are in the most vulnerable time of their lives and are in great need of help & support.

6.4 The High Peak model

The delivery model developed by High Peak CVS:

- Creates **social support** for those living with bereavement and loss, by providing a safe space, within which people who are grieving can come together to support and learn from each other:

  It helped enormously to have the space to fully express my grief - something which I could never fully do with family and friends.

- Increases **literacy and awareness of grief and loss,** by helping participants increase their awareness of the process and tasks of grieving, as well as enabling the sharing of stories:

  I have learned from the group that grief is not linear + progressive, I have been stuck and avoided grief by activity & distraction. It helped me to find my own way to grieve, celebrate my father's life + the impact he has had + continues to have in how I live life moving forward.

7. Activity

7.1 What does the service offer?

The High Peak Bereavement Support Service provides facilitated, fortnightly **Bereavement Support Groups**, within community settings, where people who are struggling with bereavement can:

- **Tell (and retell) their stories** and be heard;
- **Articulate honestly** whatever they are feeling and experiencing, in a **safe space**;
- **Connect with, share and learn** from others experiencing similar loss;
- Better **understand** their experience and the process of grieving;
- Develop **coping strategies** to deal with difficult situations, 'triggers' and flashbacks, and with emotional responses that can feel overwhelming or disturbing - including anger, guilt, confusion, longing, despair, suicidal thoughts, low confidence, feeling stuck.
- Feel supported in their grieving, as they take steps toward the **next phase of their life**, when they are ready to do so.

From 1 Jan 2019 - 31 Dec 2021

99 people attended one of the **4 groups** established across High Peak District:

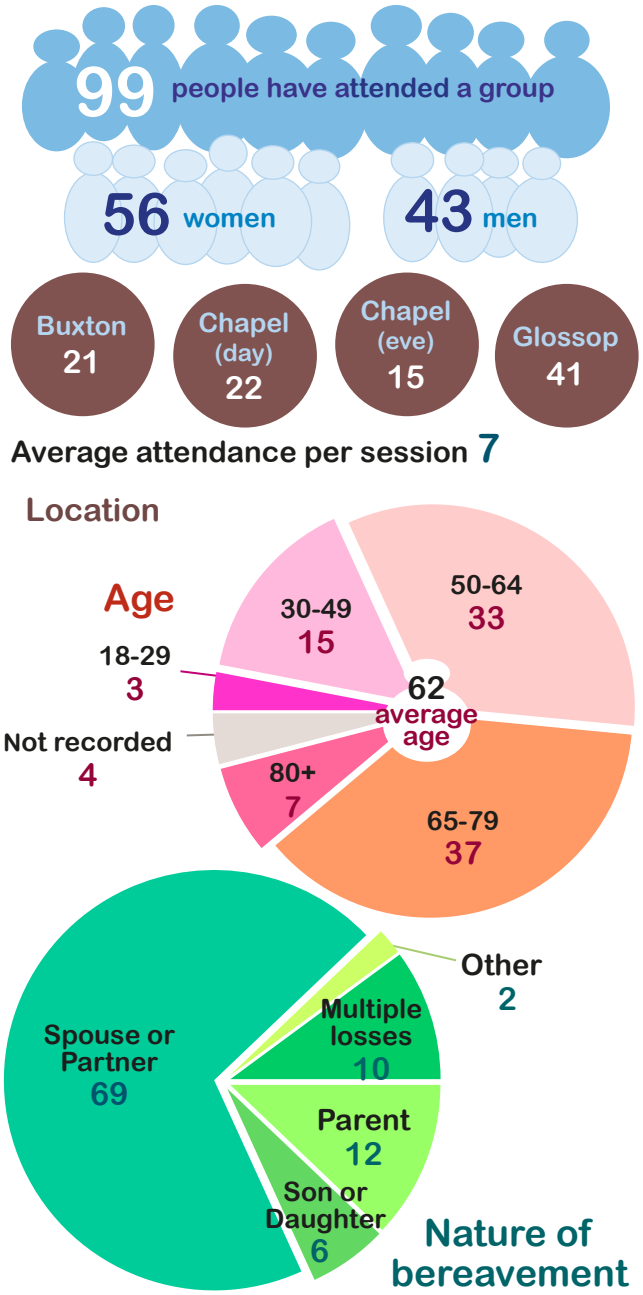
- One in **Glossop** (daytime)
- One in **Buxton** (daytime)
- Two in **Chapel-en-le-Frith**, at Blythe House Hospice (1 daytime and 1 evening)

101 total number of Bereavement Support Group sessions

99 beneficiaries

Average cost **£1,096** per person supported by the service[3]

7.2 Who has used the service?



7.3 How are the groups structured?

Individuals can self-refer to the service, or be referred by professionals or other services. Following a referral the service Coordinator will have an initial, 1:1 conversation or conversations with the individual, to explain the purpose of the Support Groups and assess whether they will meet that person's needs (see section 10.3 on p17 for more about the assessment criteria and process).

If appropriate, the person is then assigned to a local group. If there is a waiting list for a place, or they are not yet ready to attend, the Coordinator maintains contact with that individual in the interim.

The groups meet fortnightly. Each session lasts 90 minutes and follows the same structure, which is:

- The session opens promptly with a welcome from the facilitator; each attendee is invited in turn to 'check in' – to share what has happened for them since the last session, how they are feeling and anything that is particularly 'live' for them;
- The facilitator then sums up and draws out themes that have arisen in the check in;
- There is open discussion around themes from the check in, with attendees encouraged to share their feelings and experiences;
- There are also regular facilitated exercises or explorations on a grief theory or around a particular issue that has been prevalent in recent sessions, for example 'anger in grief' or 'memory sharing.' (I did not directly observe this, as it was not a feature of any of the sessions in the 3 observation visits).
- The session ends on a positive with another round – each attendee is invited to share one thing that has gone well for them since the last session, and/or one way they are going to take care of themselves after the session.

The focus of the sessions throughout is explicitly on bereavement and the personal experience of grief and grieving.

A paid member of staff organises the venue and dates for the groups and acts as facilitator to the sessions - opening and closing the sessions, inviting contributions, reflecting back contributions and themes, maintaining focus and inviting contributions.

They also follow up any concerns about the wellbeing of an individual, arising either from what they have expressed in a group, or, in the case of unexpected non-attendance, checking in on their welfare. Where appropriate, individuals are referred to other sources of support. In addition to the support provided by the groups, staff made **252 one-to-one support calls** (including when the groups were paused during the Covid pandemic lockdown).

Two of the groups (Buxton and Glossop) are facilitated solely by a High Peak CVS staff member (though the Buxton group is supported by a volunteer). The Blythe House groups in Chapel-en-le-Frith are co-facilitated with staff from the Hospice.

Once individuals start attending a group there is no time limit . They can keep coming for as long as they find it helpful. When they feel ready to move on, they are encouraged and supported to do so, including a final attendance at the group where goodbyes are said. An exit interview with is also offered.

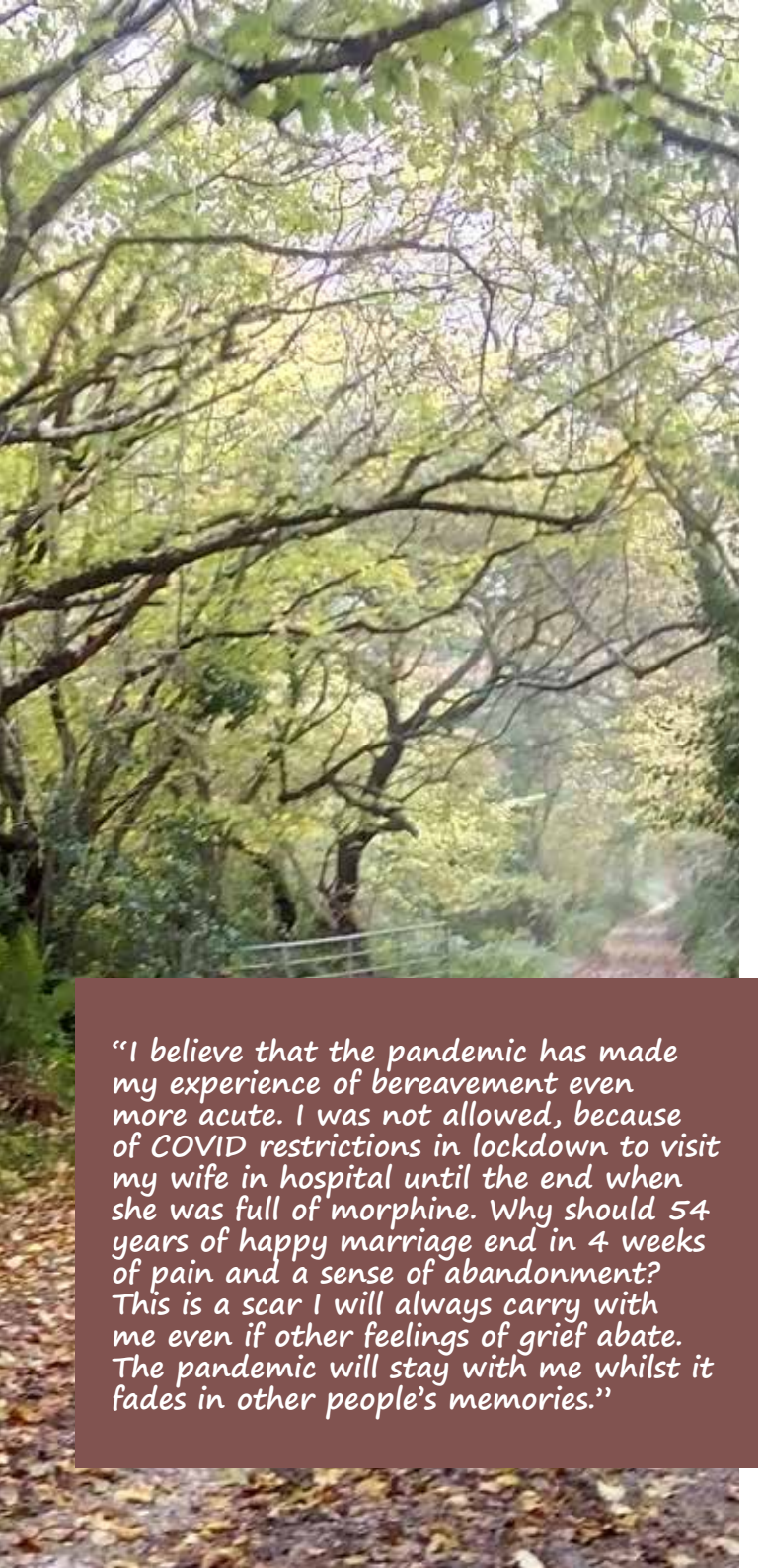
> "I have during the time I've been attending eventually been able to open up more and more and confront the issues effecting me due to this environment and have benefited greatly as a result"

7.4 What is discussed?

The 3 groups observed explored:

- The experience of key personal milestones, events such as birthdays, Christmas, anniversaries (including the anniversary of a diagnosis, bereavement or funeral);
- Triggers and reminders, and how to deal with them – e.g. objects or images (photographs, video footage, social media, cards); hearing music; visiting particular places; times of year or times of day (winter/evening) or just coming home to an empty house;
- Expectations of others – reactions, pace of grief, the reaction of family and friends, helpful or unhelpful, others moving on;
- Key milestones such as being able to attend a family event, visit friends; or to take pleasure in revisiting old pastimes or trying new activities;
- (Re)telling their story – the circumstances leading up to the bereavement and its aftermath;
- Difficult emotions and memories, dark places and feelings – anger, regret, remorse, guilt:

  I have struggled with various aspects of grieving, particularly blaming myself for my son's death. I have now learned to cope better;
- The cyclic and roller-coaster nature of grief and the grieving process;
- The emotional and physical experience of grief, self-care;
- There were also moments of laughter – at the contradictions and absurdity of grieving, at their own reactions and behaviour, at things that their loved one would have appreciated or found amusing.



"I believe that the pandemic has made my experience of bereavement even more acute. I was not allowed, because of COVID restrictions in lockdown to visit my wife in hospital until the end when she was full of morphine. Why should 54 years of happy marriage end in 4 weeks of pain and a sense of abandonment? This is a scar I will always carry with me even if other feelings of grief abate. The pandemic will stay with me whilst it fades in other people's memories."

8. The impact of Covid

The original 3 year National Lottery grant to develop the service was awarded in November 2019. However, a few months later it faced the significant and unprecedented challenge of providing support during the Covid-19 pandemic and successive national 'lockdowns'. For a bereavement support service, there was a further impact: The pandemic both increased the death rate and fundamentally changed the experience of bereavement for those who lost loved ones during that period. As the quote already cited from the Lancet report puts it, some people "died the ultimate medicalised deaths, often alone but for masked staff in hospitals and intensive care units, unable to communicate with family except electronically."[5] The normal rituals of dying, supporting the dying, bereavement, grieving and mourning were severely disrupted.

During the initial national lockdown, face to face meetings were forced to cease. The service shifted to a combination of virtual / online (Zoom) support groups and 1:1 telephone support – though face to face groups resumed (with measures in place to minimise infection risk) as soon as this was possible. While people didn't love the virtual groups, they appreciated the efforts made to keep them connected and supported as an interim measure:

> *Invaluable to be able to still meet by zoom rather than nothing. It worked really well for me*
>
> *I received regular supportive phone calls from the group leader which helped me greatly.*

After lockdown, the service had an influx of people whose bereavement was caused by Covid or whose loss was made more painful by Covid measures. Normal feelings of anger, regret, remorse and trauma were intensified by, for example, pandemic related delays in treatment, or the experience of being separated from the person dying and unable to say goodbye. At the same time, face-to-face support from family, friends and social activities were curtailed for long periods, due to Government lockdowns and restrictions on travel and social contact designed to limit the spread of the pandemic. People shared heartbreaking stories, both in the groups and in the survey, of the trauma that this had caused and the impact on their grieving:

> *Losing my brother is bad enough. But to not be able to be with him in his final hours. To not be able to say goodbye to him when he was laid to rest or honour him by carrying him. Phone with a very short clinical committal service robbed me of a very important part of closure*
>
> *I was in the second year of grieving during lockdown: it was very difficult because of the loneliness. I felt as though I lost a year of working through my grief, unable to grow my life around my grief.*
>
> *The most awful aspect was not being able to visit my husband whilst he was in hospital, not being able to get information and not feeling confident he was being cared for properly. Then the total isolation afterwards.*

It also impacted on the restoration aspect of grief work, affecting confidence/willingness to re-engage with social activities and opportunities to do so:

> *The impact of Covid on the bereavement has been v. significant. Other members of the group have lost family/partners with COVID and all of the group are exploring if and when they have confidence to socialise/travel/holiday etc. I have acknowledged a level of anxiety about world travel again + the group is supportive in this regard.*

9. Was it effective?

9.1 The outcomes survey

The original stated aims of the service were to:

- Reduce feelings of desperation and fear after bereavement
- Improve mental health
- Improve self-care
- Increase self-confidence
- Re-engage past interests, hobbies, and in community support networks and activities

The survey questions were designed to provide quantitative evidence of how effective the servuce had been in achieving those outcomes for individuals as well as qualitative evidence about what the groups had meant for them.

It asked about **expectations** of the service and whether they had been met; to what extent the service had **made a difference** to their experience of bereavement; and invited feedback on the **experience** of approaching and using the service.

29 people responded to the survey (not everyone answered all of the questions) - **a response rate of just under 30%** of all-time beneficiaries. Around 60% of respondents were currently attending support groups; 40% were former beneficiaries.

The former beneficiaries had, on average, attended a group for 15 months (range 8 weeks - 3 years). Those currently attending had been doing so for between 1 month and 2 years (average 8 months). 10 of the 11 who had now stopped attending felt that they had been supported in this decision and most gave positive reasons for their departure:

> *The group provided just the kind of support I needed - enough to make me feel able to cope without it.*

> *I was a lot further on with my grief and thought I was coping a lot better*

9.2 Expectations

Asked 'what did you hope the group would offer?' respondents talked about seeking comfort, understanding, help, support, connection and safe space to express and deal with their grief:

> *Time out from the everyday to express self in relation to the bereavement... to meet others experiencing major loss and find ways of coping. To be supported and understood by others experiencing such loss and to have a safe space to express self.*

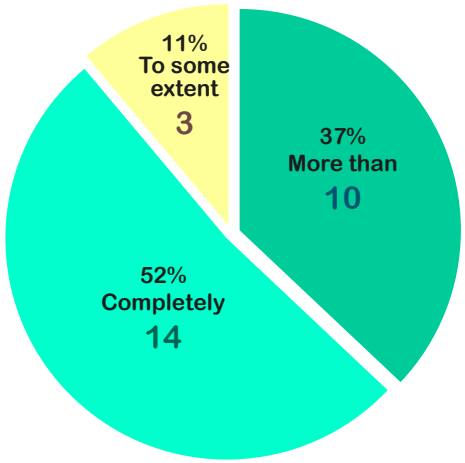
> *For help coping with the rawness inside that I feel unable to speak about to friends and family.*

> *I hoped the support group would help my mental state. I was feeling/thinking could I have done more, should I have done more. Cross with myself and wasn't accepting positive comments/ words from family, friends and neighbours. I was crying on my own so much and felt alone.*

> *I was not able to visit my dying wife in hospital because of COVID restrictions and lockdown last October. It was hard. I felt alone in my grief. Although people were sympathetic I felt unable to fully describe and explain the grief I was holding within myself. I needed to do this.*

> *I wasn't sure what to expect! I hoped it would be a place where I could talk about my loss, share my feelings, be easily understood emotionally. Maybe find some strategies to deal with my emotions.*

Did it meet those expectations?



Of those who responded to this survey question **89% said that the service had either completely met or exceeded their expectations** (52% and 37% respectively). None said it had completely failed to do so.

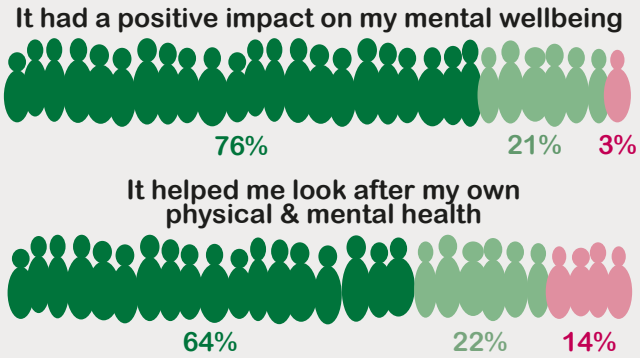
> *Listening to the co-ordinator and other members of the group, I learned that to feel sad, angry and insecure was all part of the grieving process. I felt better in myself being able to talk freely about how I was feeling.*

> *Initially I found it difficult. Often left feeling worse than when I arrived. I think that is to be expected. Listening to other people's problems sometimes doesn't help but eventually, understanding their feelings, empathy and time gave me comfort.*

> *I now have a greater understanding about loss and grieving which I feel is part of coming to terms with a shattering experience. The group meetings have had the effect of making me feel more 'normal' and less on my own with my feelings.*

9.3 Outcomes: Responses to the survey

Health, wellbeing and self care



A number of people commented on how the groups encouraged and reinforced the importance of self-care, both psychological (being kind to oneself, self-acceptance) and physical (rest, exercise, being outdoors, eating well):

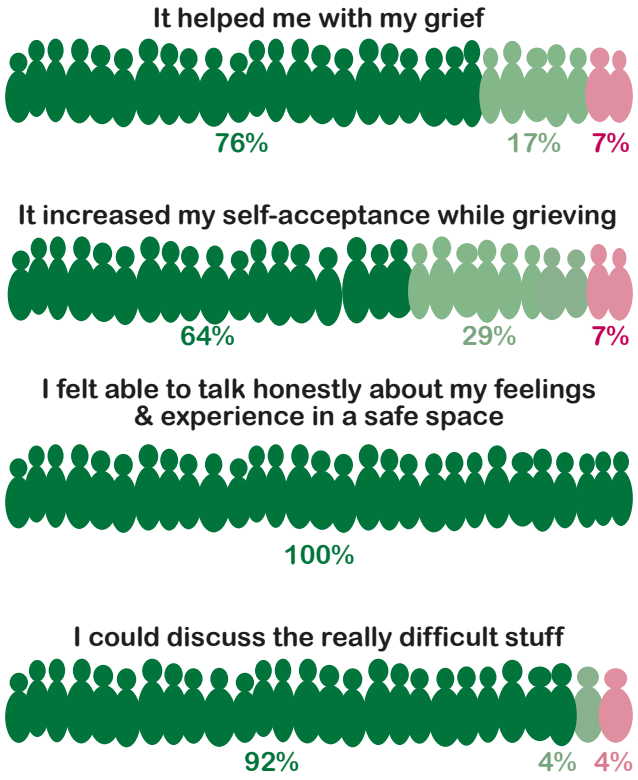
> *The group has reminded me of the importance of staying well. It has also accepted me as an individual finding my own way through bereavement and learning to live with loss in moving forward.*

> *The group helps greatly with mental health issues, relating to dealing with simple every day life to dealing with such abject thoughts of taking ones own life.*

One service user told me:

> *If I hadn't come here, I don't think I'd be here now. I've tried [to commit] suicide 15 times, I've had 12 sessions with a psychologist [i.e. but this group was more helpful to me]*

Reduced feelings of desperation and fear: Increased confidence & 'grief work'



Service users reported how both (a) hearing the stories of others, and (b) the insights offered by the facilitator (for example exploring theories of grief or offering books or articles to read), had helped them better understand what they were experiencing. As a result they felt better able to weather the ups and downs with greater equanimity:

> *I can now deal with the triggers which once reduced me to tears. I no longer feel self pity. I am more stable.*

> *Have talked about feelings of worthlessness, helplessness, & suicide when I was desperately low*

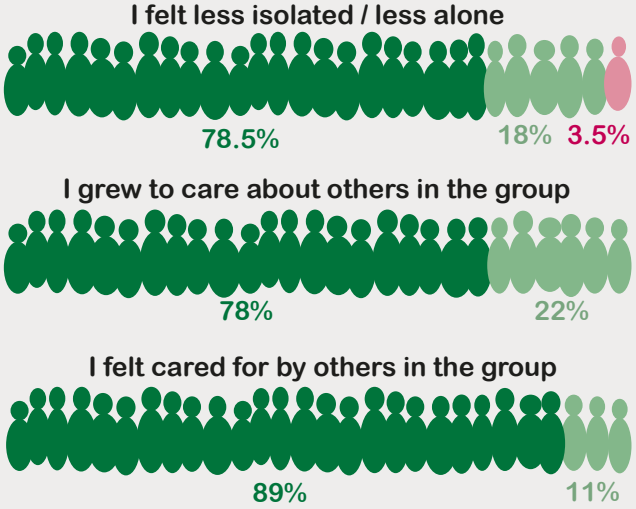
> *Not completely because some feelings are too deep or too intimate - but enough*

A common fear expressed was that grief made people fear that they were going mad, were experiencing something extreme or unusual. Attending the groups had helped them appreciate and accept that extreme feelings were a common experience and a normal part of the journey – to increase their grief literacy:

> *The group helps put things in perspective, confirms what you are experiencing is part of grieving, allows you to let out your emotions without feeling abnormal.*

> *I have during the time I've been attending eventually been able to open up more and more and confront the issues effecting me due to this environment and have benefited greatly as a result.*

Reduced feelings of desperation and fear: Connecting, caring and fellowship



I felt heard, understood and accepted

I felt included

Another common theme expressed was the importance of the fellowship of others in their grief - the presence of others with similar experiences:

> *I have felt reassured that I am not alone in the emotions and experiences I have faced. Others too are going through the maelstrom.*

> *I have met others who have lost multiple family members, children + unexpected death/suicide. Seeing how these members grapple with moving forward or feeling stuck not wanting to has generated care + sensitivity for their experience.*

> *Before I came to the group I was in a] dark place, kept refusing help. The first time I walked in, I felt better after. I was allowed to talk about things hurting. I can't wait to come back, I realised I wasn't on my own.*

The group values of inclusion, respect and acceptance were powerful in reducing the sense of emotional isolation that many individuals felt:

> *The group dynamics encouraged this and I have never come across such mutual care and respect.*

It was also a space where people could safely explore difficulties in their relationship with family and friends, who were not grieving, or who were grieving in a different way and at a different pace; as well as the feelings of disconnection arising from the expectations or lack of understanding of those around them:

> *You can feel lonely in a crowd of friends who haven't experienced what you have been through but the group removed some of that isolated feeling.*

Restoration and re-engagement

I felt more confident to re-engage with wider social activities, when I was ready to do so

The groups are naturally focussed more on loss than restoration, as the purpose of the group is explicitly to set aside time and space and come together to engage in 'grief work.'

However within the group, issues and strategies around re-engagement are discussed, and successes and milestones are celebrated. So the groups encourage and enable more positive engagement in the restoration work (outside the group).

> *I can now cope better with being a lone widower and with living with the memories of over 50 years. I am more positive and can take on new ventures. I have learned to manage expectations. I can now present my identity as a person in my own right - rather than as widower.*

"Grieving has been tiring and bereavement has brought about many changes and new decisions. The group has encouraged me to take time out to look after myself alongside a busy life + new unexpected care responsibilities"

The experience of receiving support

Beneficiaries spoke particularly highly of the supportive environment and values of the group, as a place where they could express themselves authentically, discuss difficult feelings, and feel confident that it was a safe place to do so.

My first contact with those organising the group was friendly and encouraging

100%

It was clearly explained to me what the group was offering & what to expect

85% 15%

The group was welcoming, friendly & inclusive to a newcomer

97% 3%

When I first went to the meetings, the first since lockdown, I wasn't really sure what to expect. However I was welcomed and reassured by the co-ordinator. I was given the opportunity to introduce myself, talk about my experiences.

The groups are well structured & well run

97% 3%

The group is very well run and has a welcoming, understanding and friendly environment.

I feel confident in the staff member facilitating the group

100%

She [facilitator] bring things out of me that I have never spoken of before.

The leadership, structure and nature of the group has meant that I have full confidence and trust in them and I know they understand me

There is a safe & accepting atmosphere within the group

100%

[We can] communicate simply, honestly, openly, [with] humour.

I have been able to say what I really feel without any fear of being judged by others. I have been gently encouraged and not patronised.

The venue where the group meets is comfortable& welcoming

90% 7% 3%

The meetings are held in a very comforting, controlled, private and safe environment

The meeting location is convenient & accessible for me

90% 10%

The time & day of meetings is convenient for me

93% 3.5% 3.5%

Knowing that I could attend for as long as I needed support was important to me

97% 3%

And also knowing if I needed help when I decided to leave the support would always be there.

There is no pressure to leave the group. Everyone is treated as per their needs.

9.4 Would you recommend the service to others?

100% of respondents said they would recommend the groups to other bereaved people.

Many expressed their gratitude for the service they had received, as well as a wish that similar support be made available to all bereaved people everywhere:

For the help, support, care, comfort and a thousand other reasons too numerous to mention e.g. in dealing with anger, sorrow and the massive sense of loss.

We're very blessed, very fortunate [i.e. to have this group]

The group provides confidential, safe + unconditional support for the bereaved and the numerous life changes + challenges this brings.

It builds confidence to move forward alongside the loss without fostering dependency or being too sentimental.

9.5 Other feedback and suggestions

Respondents were invited to offer feedback, suggestions or any other comments:

Frequency of meetings

Some beneficiaries expressed a wish for more frequent meetings as the gap between the groups sometimes seems long:

> *I wish it was still weekly [nods from the group]*
>
> *I wish it was there every week – I miss it when there are gaps, though I wouldn't necessarily go every week [it would help to know that it was there]. 2 hours wouldn't be too much.*
>
> *Perhaps continue weekly. I feel anyone just starting to attend would find fortnightly too long.*
>
> *Because we meet on a Monday we often missed a meeting due to bank holidays. It is helpful to have as much continuity as possible in regularity of meetings.*

However Blythe House staff expressed the view that *"To do it fortnightly is innovative in itself, monthly is more usual. It's hard work and people need space in between to reflect or put into practice."*

A number of beneficiaries spoke of feeling exhausted or drained after a group session, and the wish seemed to be to mitigate against occasional longer gaps, so a more practical response might just be to minimise disruptions to the normal schedule – for example moving sessions which would fall on a bank holiday to a different day of the week.

Relationships inside/outside the group

There were some different feelings about how attendees might relate to each other beyond the boundaries of the group. Some had formed ongoing friendships, others valued that the relationships they had were specific and special to that context:

> *We don't meet up [with other group members] outside the group – say hello, but not like it is in the group, you have your mask on.*
>
> *If they were people [attending the group] I'd known previously I might not speak so freely.*
>
> *I don't tell people outside what goes on.*
>
> *I made one or two good friends from the group who I still meet and see how they are doing - we can still talk about our feelings which would have been difficult if we had not had the shared group experience to give me the confidence .*
>
> *Friendships do form, but it doesn't morph into just that [a social group].*

One person felt unclear whether she could or should suggest meeting others in the group socially:

> *Being able to feel it's OK to get to know people who come, socially. I feel I shouldn't offer this – ethics? It's not discussed explicitly. You get isolated [after bereavement], people don't know what to say so they don't get in touch.*

It might be helpful periodically to revisit this issue and explore feelings about it within the groups.

Differences between group members

There were some people who felt that having a diverse group , who had experienced different kinds/ circumstances of bereavement, or who were at different stages in their journey, posed challenges:

> *Maybe tailoring the group to people who have lost children so they meet together as I feel a parents grief is different to a husband losing a wife/or vice versa, or to that of losing a parent. Not any less just differe*nt.
>
> *[What do you find unhelpful?]: Men talking quite a lot about what "the wife" used to do*
>
> *I found the arrival of new members into the group made me uncomfortable. They didn't know my 'story' and also, listening to their new grief was distressing for me; I would get emotional and then feel I couldn't say anything because I would probably just sob.*
>
> *I felt it would be better to establish a group of the same people and not have a constant intake of new people. (I appreciate there are logistical problems to this.)*

However many more felt that what they had in common overcame differences in circumstances, or that hearing about other people's different experiences and challenges helped them count their blessings and take comfort that they are not alone:

> *I think we are quite a diverse group, but what we have in common is bereavement. It's hard to hear and watch people suffering, but you do care that they hurt so much too. You know how hard it is.*
>
> *Being able to empathise with people with similar problems lightens my grief.*

More services, more widely promoted

Some respondents also wanted more people to benefit from what they had received – for this kind of support to be more widely available, in more places, and for existing services to be better and more widely publicised. Some had tried to find similar support for family or friends elsewhere, and were surprised and dismayed to find that it was not universally offered.

> *More publicity, it relies on word of mouth so not everyone knows about it.*
>
> *Don't assume the NHS will tell people.*
>
> *It's not widely known, advertise, local outlets.*
>
> *Don't assume people will find out on the internet, I don't use it.*
>
> *Yes have more groups and more frequent times. To me this was a lifeline at a difficult time.*
>
> *Everyone [who needs support] should have a Liz [the service Coordinator/Facilitator]*

10. Defining features: Why it works

The High Peak Bereavement Support Group model has 5 key features which are important to its effectiveness:

10.1 Purpose and focus

The focus of the groups remains firmly and explicitly on bereavement, the experiences of bereavement and grief, and the tasks of grieving and mourning. However within the space, time and structure provided for this work, there is a high degree of flexibility and responsiveness to the individuals who comprise the groups.

Other models of bereavement support group either:

- Limit attendance for a fixed period of time (sometimes with a programme and timetable for the themes and content of each session); or
- Gradually drift into becoming social groups as the original cohort begin to recover and want to keep the bonds they have made, but need less focus on bereavement.

With the former, the schedule may or may not align with attendees' individual grief journeys, resulting in some having to face another ending too soon for their longer term wellbeing, before they are ready to cope.

> *Please continue with this service. I still need to continue to meet. Grieving takes time, It is a process and needs its own time to reach a resolution or as near a resolution that is possible.*

With the latter, the inadvertent 'focus drift' can create a barrier for new attendees, who may be some time away from being able to socialise; as well as disincling people to move on, making the groups less effective (in fulfilling their original purpose) - and less sustainable in the long term.

The space of the groups is created, held and supported by the facilitator, who offers professional insight and intervention where appropriate. This enables participants to focus on themselves and on each other, and on the work of grieving. It also safeguards the boundaries of the group and ensures a 'safe space' where difficult feelings and vulnerabilities can be shared. However activity within the group space is co-created – that is to say, those taking part mutually agree what will be discussed, and the emphasis is on peer support and mutual sharing. As already noted, attendees decide for themselves how long they need support from the group and when they are ready to leave.

10.2 Bounded space

As described, there is a normal framework for each session. At the prompting of the facilitator, the groups start and end promptly at a predefined time and the sessions:

- Start with an initial 'check in', with each person in turn invited to share how they are, how they have been, what is most significant for them;
- Go on to explore, in more detail, particular experiences/issues/topics that have arisen (in this or previous sessions) or that are particularly live or urgent for those taking part;
- End on a positive– a closing round, each person sharing a success and/or one way in which they will look after themselves after the group.

However, within this framework, there is no predefined programme. Generally, the discussion follows on from and explores whatever has arisen in the initial check in and sharing, with individuals encouraged to share their own experiences and feelings, to validate each other's experiences and empathise with the feelings that individuals express

(whatever they might be). When the sessions do include pre-planned exercises or themed discussions, these are a response to what participants have shared in previous sessions.

During the early stages of the initial pilot, the groups had more pre-defined topics and a traditional group work approach (with flip chart and pens), though the facilitator quickly learnt to leave the space open and trust in a more flexible, user-led approach. However the groups maintain an explicit focus on bereavement and grief work, exploring feelings and difficulty, pain and displacement after loss, as well as sharing progress and successes – and acknowledging that grieving involves oscillation between the two.

10.3 Rites of passage: Entering and leaving the group

In its early pilot stage, the group was open access (times/dates were advertised and anyone could attend). However, learning from the initial pilot was that initial preparation and assessment were needed safeguard the boundaries and focus of the groups. Access to the groups is now preceded by an initial referral (which can be self-referral) to the service. A 1:1 conversation(s) with the service Coordinator then takes place to:

- Ensure that individuals clearly understand the group's purpose and focus, how the sessions work, and what will be expected of them as a participant. This is backed up with written guidelines clarifying what is expected within the group and what members can expect of the facilitator;
- Confirm they are at a stage in their grieving where they feel ready and able to participate - to articulate their grief as well as hearing the stories of others. For newly bereaved people the experience can be too intense and raw for them to feel able to do this, so individuals are normally asked to wait until 3 months after their bereavement (though there is some flexibility). However there is no limit on how long ago the bereavement was;
- Assess whether the group will best meet their needs. For example, sometimes individuals who have other, more complex needs are referred. While they may have experienced a bereavement, this is not the main cause of their distress or the issue with which they predominantly need support. In this case, a referral is made to other more appropriate support services.

Once individuals start attending a group there is no time limit for participation. They can keep coming for as long or short a time as they need to, and move on when they decide they are ready. However the focus, as described above, remains on bereavement and grief work. As a result, when exploring this at each fortnightly meeting is no longer where they need to be, people naturally move on.

Sometimes, the entry to the group of new people, who are at an earlier stage in their grief, can lead longer term members to reassess the place that grieving plays in their life now, and how much time and energy they need to allocated to this. After a while, people naturally want to re-engage with life in other ways. This happens when they decide, and there is no pressure or expectation.

Those who are ready to move on are supported to do so, and are encouraged to discuss this transition with the Coordinator. Once the decision is made they are encouraged to return one last time, say their goodbyes (and let others say goodbye to them), reflect on the experience and celebrate the transition to this new phase of their journey. In other words there is a (low key, but defined) 'rite of passage' out of the group, as a milestone in the bereavement journey, which helps maintain the clarity of purpose and boundaries of the group. So far, no-one has ever asked to return to a group once they have said their farewells:

> *I found listening to new members' experiences distressing and felt I was unwilling to take myself back to the early days of my grief*
>
> *I felt the group had helped me to come to terms with losing my husband as much as it possibly could.*
>
> *It almost felt like a celebration - I was asked to explain why I felt ready to leave. I think this is important for other members of the group to see - that you can get to a slightly better place.*

10.4 Finding fellowship in grief

Telling their stories, and hearing those of others on a similar journey – as well as input from professionals experienced in bereavement support where appropriate – leads to increased 'grief literacy': Greater awareness and understanding that difficult and disturbing feelings are part of the normal process of grieving. They are not going mad, or failing to 'get over it'; they are not unique in having those feelings, nor in feeling overwhelmed by them. They are to be expected, and the quality and intensity will change over time.

The groups' size (maximum 12 members; average attendance is 7 people) is relatively small: *The numbers attending the group are relatively low so I don't feel overwhelmed.* Membership is fairly stable over time (though punctuated by entry and exit from the group as described); as a result powerful relationships of sharing, support and fellowship develop, mitigating the feelings of loneliness and isolation which can arise from the experience of grief.

I cannot think of another arena where I can express my vulnerable self. I have found my voice and others in the group have either had similar experiences or validated my need to grieve in my own way. Openly, honestly and authentically - without the 'masks', without the pretence + without all the effort of other relationships.

Hearing about the experiences of others, their ups and downs, struggles and successes, members of the group become companions in their journey and feel less alone:

I think we all care for each other... I definitely find myself thinking of others in the group eg if they were celebrating their birthday, anniversary, sharing the happier times as well as the sad.

10.5 Holding the group

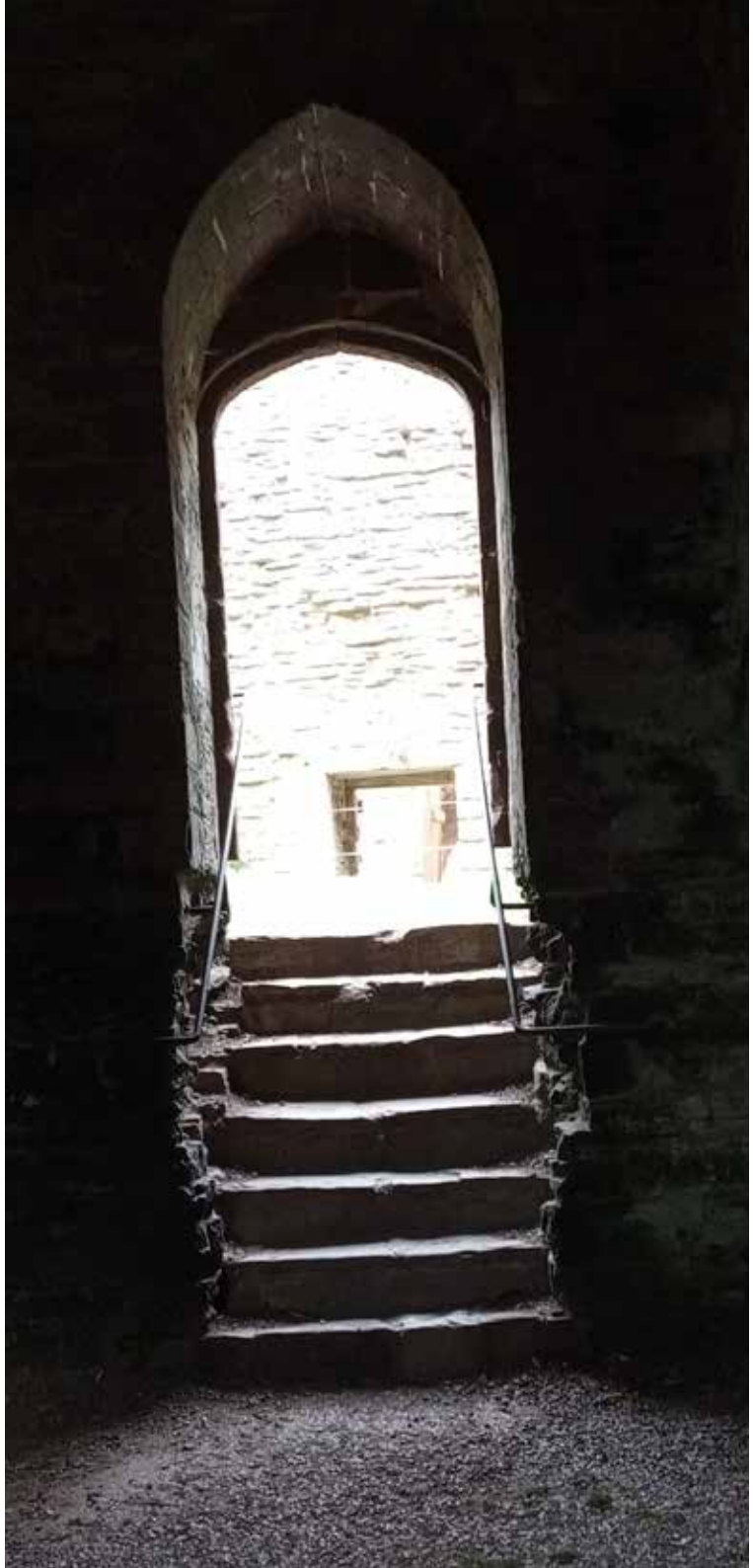
While sharing of lived experience is a (possibly the) key element of the model, however it is not an (unstructured, wholly, participant-led and -run) Peer Support Group. It might be better described as **facilitated therapeutic group support.**

Experienced, qualified and skilled professional facilitator(s) deliver the sessions. The role incorporates the following important functions:

(i) **Maintaining the boundaries:** carrying out the initial assessment and preparatory work with an individual who has been referred to the services, and supporting individuals in their transition out of the group.

(ii) **Taking responsibility for the mundane tasks** of organising and planning the sessions, booking space, providing refreshments, setting up the space and tidying up afterwards:

[What did you find helpful?]: The gentle management of the meetings and the efficiency of their organisation.



(iii) **'Holding' the session structure** by opening/closing the group and keeping it to time, and by refocussing the discussion when it drifts, for example, into general chat or other topics:

We all get the same time to speak. Liz [facilitator] keeps us focussed, on track. They [facilitator and volunteer] just run the group as it should be done, always end on a positive.

Our facilitator is first class, she knows when to stop and start us.

(iv) **Inviting and prompting contributions**, ensuring everyone has the chance to contribute and quieter attendees are actively invited to speak, if they wish:

Facilitator ensures everyone gets to speak and is given time.

(v) **Reflecting** back what has been said, checking understanding; summing up and suggesting themes the group might wish to explore:

I felt I could raise any topic and the facilitator was great at bringing it out as a discussion item

The group is balanced in terms of input/contribution from the members & the facilitators are particularly skilled here in terms of focus, encouragement + picking up/exploring key points.

(vi) **Creating a safe space.** The facilitator defines and embodies the values, culture, behaviours and pace which make the group a safe place to be: Empathetic, inclusive, unhurried, respectful and confidential. Encouraging attendees to support, affirm, and encourage each other rather than offering advice, comparison or judgement; allowing silence to occur and not being too quick to talk into the silences:

11. Enablers & risks

At no time did I feel me talking about grief + bereavement was rushed or not understood. I feel safe knowing I wasn't being judged of feeling too emotional.

Right from the start, it was stated that whatever we said in the room was completely confidential.

What's said stays within these 4 walls – confidence.

(vii) **Reassuring/validating** as needed, particularly when anxiety or embarrassment are expressed, or if raw or difficult feelings have been expressed: "We're a bereavement support group. You be what you be":

You can say how you feel in a safe environment where people understand

(viii) **Making connections and offering insights:** Linking back to what's been said by others in the group, or in previous sessions; offering relevant insights from grief theory that might aid understanding of a topic that has arisen.

I have left meetings being able to put my emotions into context rather than letting them spiral downwards. Reference to models of grief has helped. I have reflected further on what everyone has said in the following days.

(ix) Finally, **safeguarding the welfare** of individual attendees, intervening where needed within the session and following up any cause for concern outside and between meetings; signposting to other sources of support as appropriate.

Functions **(i) – (iii)** maintain clarity of purpose and keep the group focussed, allowing attendees to focus 100% on themselves and their grief work.

The parameters of the group were clearly set. We quickly established trust in our counsellors and in one another. It was clearly understood that what was said, was said in total confidence and remained within the four walls. Everyone has had the time and space to talk about their grief and everyone has listened and understood. The group encompasses people with different back stories and different backgrounds but we all have the same range of emotions. Any digressions have politely and gently been brought back to the main purpose of the group

Functions **(iv) – (vi)** create the environment within the group, enabling attendees are able to experience and share their feelings – however difficult or disturbing – uncensored, in confidence, together with peers who are feeling or have felt similar things, and who understand better than anyone else could.

I have always felt safe in the fact discussions within the group remain confidential.

I was given the time and space to articulate my feelings. I needed to work through my emotions and was able to shed tears. Before I held back my emotions and thoughts and this built up stress within me. Everyone was patient with me and with one another - leaders and group alike.

Functions **(vii)** & **(viii)** build self-care and grief literacy. Attendees learn from each other, with professional input as appropriate, to better understand what they are experiencing, and to develop coping mechanisms:

I look forward to the support and chance to share. I feel better, if exhausted, afterwards. It's reinforced that there is no right way, no time limit etc & that the path forward is not straightforward or easy.

Finally function **(ix)** safeguards the wider wellbeing of individual attendees, beyond what the group can realistically offer:

Even if I didn't want to discuss difficult things openly, I felt that the group leaders could be approached after the meeting.

The initiation, development and success of the service, widely acknowledged by service users, volunteers and partners, owes much to the vision and commitment of a High Peak CVS staff member (originally working 4 days per week, later full time) who set it up and who now coordinates and facilitates the groups. She brings professional counselling qualifications and many years' experience of group work, as well as personal passion for the initiative.

Reliance on one individual is always a considerable risk. The charity has acknowledged the need for additional capacity and succession planning, and the second tranche of grant funding included provision for a second staff member to share the facilitation role. However, two rounds of recruitment were required to find the right candidate and this delayed the second phase of delivery.

Partly for this reason, this report recommends that remuneration of staff is reviewed and costed into future plans and budgets. As the current Coordinator put it*: "Given the right person with the right skill set, this model has just proved itself portable and beyond individuals and personalities".* However, it does need *"the right person with the right skill set".* Both staff are paid below market rate; rising costs of living, and competition with more generous salaries and terms offered by other sectors, may make recruitment and retention even more of a challenge in future.

Another powerful enabler has been partnership with other agencies, enabling the service to draw on wider, complementary expertise in the provision of end of life care and bereavement support for families. Blythe House Hospice staff were particularly positive about the service's genuine commitment to collaboration and co-production, which, they feel, has made best use of their knowledge, skills. and experience. The resulting relationships of trust and understanding ensure effective and ongoing referral pathways.

"They understood me. So I was not abandoned alone in my grief. It was so hard to access any sort of support for me and my wife during lockdown. Nobody seemed to want to know or help. You have helped and listened. Listening is so important, yet so rare."

12. Conclusion

At a time when people across the whole world are experiencing loss and grief on a scale not seen in living memory, High Peak CVS has piloted an innovative approach to supporting people struggling with bereavement. It has learned lessons that could be relevant to communities everywhere. This report set out to evaluate this new approach and found it to be highly successful, effective and able to provide valuable learning to other communities looking to support bereaved people

It has delivered a successful, community-based bereavement support service which makes a tangible positive difference to the wellbeing, social connection and self-care of those who use the service, supporting them in their both grief work and transition to the next phase of their lives.

The Bereavement Support Groups offer peer support and fellowship on this journey, a safe space where people can - fully, authentically and without judgement - express their experience of their loss, and gain increased insight into the tasks of grief and mourning.

The recent Lancet Commission report, *The Value of Death: bringing death back into life,* calls for a whole-system Compassionate Communities approach in which death, dying and bereavement, are understood and valued as normal life experiences, and where support is provided within communities rather than removed and medicalised.

Such an approach would require better awareness and literacy about dying and grief, as well as support for those experiencing them. The High Peak CVS Bereavement Support Service service aligns with this vision of community-based support, at a time when this is needed more than ever.

The full impact of the Covid 19 pandemic on grief and grieving is not yet fully known. What is clear is that both the scale of the loss and the circumstances of bereavement have had a significant - in some cases traumatic - impact. It has made grieving particularly difficult for those who lost loved ones, at a time when the pandemic restrictions separated them from both the person dying and from the support of family and friends; as well as disrupting the usual rituals of mourning.

Most bereaved people do not need support beyond that offered by their normal support networks. However, some individuals will seek external help due to a more complicated experience, of grief that feels overwhelming, disturbing or prolonged, whether this arises from the particular circumstances or nature of the bereavement (including, at the present time, the effect of Covid); or because they do not have people around them able to provide the support they need. A culture of limited grief literacy makes the individual journey even harder for individuals to navigate. Existing social and medical care services often lack the capacity or expertise to respond.

The High Peak CVS Bereavement Support model offers a proven approach to help both individuals and communities address these challenges.

13. Recommendations

In considering the future of the service, it is recommended that High Peak CVS:

1: Stabilise and embed the learning to date

Following a period of growth and the disruption of Covid, the service needs a period of stable delivery time to consolidate: To build a robust staff and volunteer team, to establish planned new groups to complete district-wide coverage, and to reflect on the experience to date, in order to inform decisions about its future.

During the remaining grant period the service intends to create new groups in Hope Valley, New Mills and an additional evening group, probably in Buxton. This will establish a High Peak-wide service, enabling all who could benefit to access a local support group.

High Peak CVS will also, during this time, need to secure longer term funding, to sustain service delivery beyond the current grant period.

2: Carefully explore options for future growth

The charity has developed an innovative model for a demonstrably effective, preventative bereavement support service. This offers a community-based 'Compassionate Communities' intervention of the kind called for in the Lancet Report, which meets an identified need and gap in existing provision.

There are other support providers. Cruse offers 1:1 bereavement counselling (though it has a waiting list) and telephone support; other national organisations offer online/virtual support groups; there are specialist support services (e.g. for people bereaved as a result of suicide or loss of a young child). The service signposts or refers to these when appropriate.

A number of Support Group attendees expressed surprise and dismay to find that, having tried to find support for friends or relatives in other areas, similar services were not universally available.

The Lancet report's recommendations should be read in the context of a more general shift in health and social care policy away from a medical, condition-focussed model, towards more community based, preventative, holistic support. The implementation of new NHS Integrated Care Systems offers opportunities, both within Derbyshire ICS and beyond, for this initiative and its learning to have wider application.

This could be by scaling up delivery to cover a wider geographic footprint, and/or by enabling replication in other areas (for example, developing toolkits or providing consultancy to other potential providers).

Another issue to consider is how the model might need to adapt to meet the needs of different cultures or communities. The norms of grief and mourning vary between cultures, and the pressures or issues that arise for individuals will similarly have a degree of cultural variability.

Consideration should be given to the role High Peak CVS might want to play in any wider expansion of provision. There is a risk that either rapid expansion, or providing support to numerous other providers wanting to replicate the model elsewhere, could draw capacity away from local, frontline delivery.
An independent examination and analysis of all possible options would be a worthwhile investment.

3: Review staffing and remuneration

As discussed above, the role of the Facilitator in supporting and the groups, as well as ensuring continuity of care for those who attend them, is key. The project has recognised the emotional and personal demands of the role and built in robust formal supervision from the start.

However remuneration of staff also needs to be considered. Small charities in particular can rarely

match the salary levels or employment terms (e.g. pensions, sick pay, maternity/paternity leave, health or life insurance) offered by public sector institutions, the private sector, or even larger charities. The short-term nature of much voluntary sector funding means that posts are often time-limited and insecure. There are relatively few opportunities for internal career progression or professional development.

While some candidates will sacrifice pay and perks for the satisfactions of working for a charity, too high a discrepancy will narrow the field of potential candidates and increase the likelihood that experienced staff will be lured elsewhere. Both current staff are paid well below market rate for their professional qualifications and level of experience.

There is a cost to having facilitators with the right professional qualifications, skills, experience and values. If the model is to be sustained, the service needs robust and stable staffing, and the charity needs to be confident that appropriately qualified and experienced staff can be attracted and retained.

To safeguard continuity of service, the charity should review salaries in comparison with the wider market rates for similar roles, and ensure remuneration for staff posts is fair and appropriate to the skills and experience necessary. An appropriate pay structure should be costed in to future funding bids.

Both staff are qualified, accredited and experienced counsellors. According to NHS Careers: "Counsellors on entry are typically paid at band 5, 6 or 7." [12] At 2021/22 rates this ranges from £25,655 for a band 5 entry-level post (less than 2 years' experience), to £45,839 for a band 7 post with 5+ years' experience. [13] Few salaried Counsellor posts advertised a starting rate below £26k FTE, with most NHS roles in the Band 6/Band 7 range (c.£32-£36k) and other sectors at least band 5 (c. £25.6 - £31.5k)[14]

4: Increase visibility and reach

To make sure that all those who could benefit from the support, are able to access it, the service should increase the visibility of its offer, both by developing professional referral pathways and relationships, and by marketing and promotion to wider audiences.

The service has strong relationships with Blythe House Hospice which supports and refers to the service as part of its wider support to individuals and families through end of life care and beyond. However, inappropriate referrals from other professionals is sometimes an issue. Both staff and service users reported that medical professionals tend to offer medication or mental health treatment to people struggling with bereavement.

As noted above, there is a general system shift towards prevention and community support (evidenced, for example, by NHS investment in social prescribing). Building relationships with potential referrers would help increase referral pathways, develop clear understanding of what the groups offer and raise awareness. This is not an easy task, given pressures on public services and turnover of staff, but would merit greater investment.

Several service users also made the point that the service is not necessarily widely known to the general public. Longer term the service would benefit from a strategy (and budget) for marketing and promotion aimed at wider and diverse audiences, to increase visibility and ensure that the service actively reaches out to all those who could benefit from its support – including more vulnerable / excluded communities.

5: Explore ways to improve bereavement awareness and grief literacy

Another potential area for development is around the second Compassionate Communities function: Increasing literacy and raising awareness about bereavement, grief and how to support people through the grieving process. A recurring theme from the evaluation is that bereavement is made more difficult because family, friends, services and professionals alike struggle to understand and to provide appropriate support. The project has provided a small amount of training and there is potential to develop this further.

One way to approach this might be a 'social action movement' approach such as that used by the Alzheimer's Society for its Dementia Friends programme. This was delivered as one element of its wider Dementia Friendly Communities approach. The programme trains volunteer Ambassadors to deliver short (45 minute) information sessions which focus on increasing understanding of the lived experience of Dementia and simple ways to support those living with the condition and their families and carers. Those who attend the sessions are encouraged to sign up as Dementia Friends. [15]

A similar approach to raising awareness around bereavement could be explored, drawing on the rich seam of knowledge and evidence provided by the bereavement support groups, the experiences and stories of those who have attended them and who have lived experience to contribute. Those who have moved on from the groups could be invited to be part of the development and, potentially, delivery of such a programme.

Notes & references

[1] The Small Charities Coalition defines a 'small charity' as having annual income below £1m. NCVO categorises as 'medium charities' those with an income between £100k and £1m. https://blogs.ncvo.org.uk/2019/01/21/small-charities-key-findings-from-our-data/

[2] Publicly available from the Charity Commission's website https://register-of-charities.charitycommission.gov.uk/charity-search/-/charity-details/3998312/accounts-and-annual-returns

[3] ⅓ of grant 1 (£123,933 over 3 years) = £82,622 plus ½ of grant 2 (£51,706 over 2 years) = £25,853. Total for years 1 & 2 = £108,475 ÷ 99 beneficiaries = £1,095.71

[4] Sallnow L, Smith R, et al. Report of the Lancet Commission on the Value of Death: bringing death back into life *Lancet* 2022: 399: 837–884. Available at https://www.thelancet.com/commissions/value-of-death

[5] Sallnow L, Smith R, et al. 2022 Report of the Lancet Commission on the Value of Death, as above: 837

[6] Sallnow L, Smith R, et al. 2022 Report of the Lancet Commission on the Value of Death, as above: 870

[7] Richard Smith. *The public health of death, dying, and grief has been neglected, but now is the time.* Lancet Commission on the Value of Death 2020, published online Jan 2020 https://commissiononthevalueofdeath.wordpress.com/2020/01/05/the-public-health-of-death-dying-and-grief-has-been-neglected-but-now-is-the-time-2/

[8] O'Connor MF. The Grieving Brain: the surprising science of how we learn from love and loss. New York: HarperOne, 2022: xvi-xvii

[9] Worden JW. Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner (5th edition) New York: Springer. 2018

[10] Margaret Stroebe M & Schut H. The Dual Process Model of Coping With Bereavement: Rationale and Description. *Death Studies* 1999: 23 vol 3: 213.

[11] Sallnow L, Smith R, et al. 2022 Report of the Lancet Commission on the Value of Death, as above: 870

[12] NHS Careers website https://www.healthcareers.nhs.uk/ accessed 18/03/22

[13] According to NHS Careers website https://www.healthcareers.nhs.uk/working-health/working-nhs/nhs-pay-and-benefits/agenda-change-pay-rates/agenda-change-pay-rates (accessed 18/03/22),
Agenda for Change NHS pay rates 2021/22 are:
Band 5: <2 years' experience £25,655;
2-4 years £27,780; 4+ years £31,534
Band 6: <2 years' experience £32,306;
2-5 years £34,172; 5+ years £39,027
Band 7: <2 years' experience £40,057;
2-5 years £42,121; 5+ years £45,839

[14] For example:
Bereavement Service Counsellor Coordinator £28,746 (Hospice, Nottinghamshire)
Counsellor - Bereavement & Support Service (Hospice, Oldham) £25,655 - £31,534
Bereavement Service Counsellor £32,306 to £39,027 (NHS, South Tyneside and Sunderland)
Counsellor, (NHS Trust, Lancashire) £32306.00 to £39027.00
Counsellor (University, Bradford) £36,382 - £40,927
Counselling Coordinator (Mental Health Charity, Belfast) £31,675 - £34,404 a year
Advertised on NHS jobs website https://www.jobs.nhs.uk/ & Charity Job website https://www.charityjob.co.uk/ (accessed 18/03/2022)

[15] Alzheimer's Society Dementia Friends website: https://www.dementiafriends.org.uk

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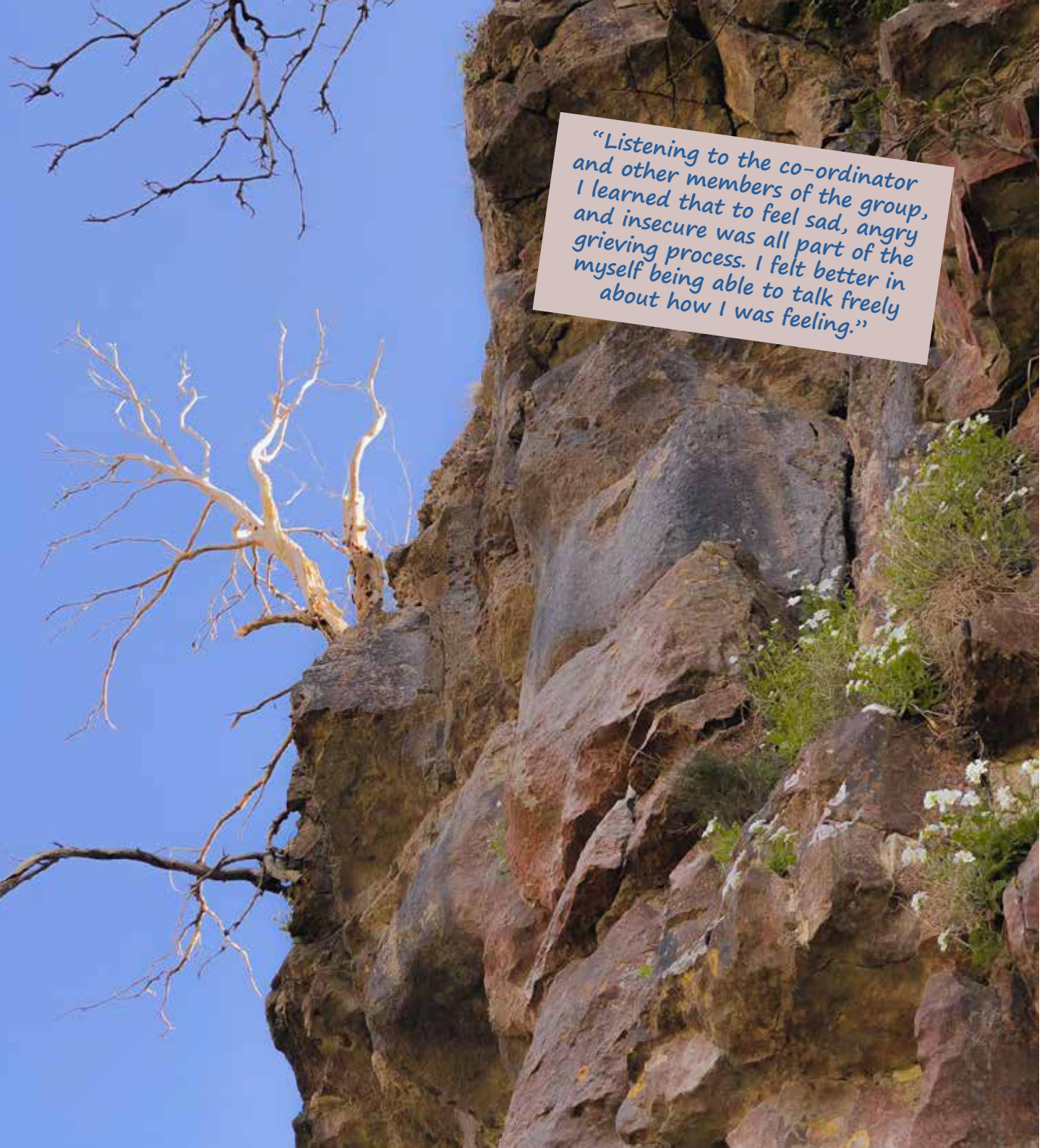

"Listening to the co-ordinator and other members of the group, I learned that to feel sad, angry and insecure was all part of the grieving process. I felt better in myself being able to talk freely about how I was feeling."

High Peak CVS
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