



**Understanding people's
experiences of bereavement
support in Blackburn with Darwen**

February 2025

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About Healthwatch Blackburn with Darwen

Healthwatch was established under the Health and Social Care Act 2012 as an independent consumer champion to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

There are over 150 local Healthwatch across England. The role of a local Healthwatch is to:

- Listen to people, especially those who are most vulnerable, to understand their experiences and what matters most to them.
- Influence those who have the power to change services so that they better meet people's needs now and into the future.
- Empower and inform people to get the most from their health and social care services and encourage other organisations to do the same.

Find out more at: www.healthwatchblackburnwithdarwen.co.uk

Background to Our Engagement

In 2023, we conducted engagement with residents to understand their views and experiences of 'dying well' in order to support the development of Blackburn with Darwen Borough Council's 'Dying Well Strategy' which will form part of the borough's overall Health and Wellbeing Strategy 2023-2028. From this work, we felt that further engagement would be beneficial to understand people's access to and experiences of bereavement support in the borough.

We know that the local Hospice has waiting lists for support and Cruse Lancashire is closed to new enquiries therefore we felt it was important to understand from our residents of all ages and backgrounds how they are currently coping with bereavement and what support they feel would be beneficial.



Methodology

Healthwatch Blackburn with Darwen conducted a survey of residents across the borough to gather their feedback on support for bereavement between August and October 2024 with 652 responses. We also conducted 7 focus groups with community groups to ensure that we gathered feedback from a range of both men and women, from young people and from residents of minority ethnic backgrounds. These focus groups were conducted between October and December 2024 and engaged with a further 48 residents.

With Thanks

We would like to thank Ann Neville of Darwen Health Care Practice and all of Darwen Primary Care Network in supporting us with the distribution of our survey to patients across 3 GP practices in the borough and all members of the BwD Bereavement Support Task and Finish Group for their support for this project.

We would also thank the Blackburn with Darwen Bereavement Network for taking forward the recommendations from this report.





Executive Summary

The majority of residents who responded to the survey and in our focus groups did not know where to access bereavement support and had not accessed it. People felt that there was little information about what services are currently available and there was little signposting by agencies of residents to this support. Overall, the feeling from residents was that the current provision in the borough was not sufficient to meet the needs of people experiencing grief at the loss of a loved one.

People felt that any future support offer should be tailored to the individual but should include a mix of both in person and online and 1:1 support and group support. Most people felt that this support offer should be offered somewhere close to home and other suggested locations were the GP surgery/health centre and at people's homes. The 'at home' offer was particularly suggested for Muslim women who cannot leave the house for several months following the death of their husband.

Most respondents would want to access pre-bereavement support including financial planning and emotional support but have not been able to access this.

Over half of the survey respondents and all of the focus groups felt that bereavement cafes would be beneficial for residents of Blackburn with Darwen and felt that these should be a mix of both professional and peer support.

103 residents left their contact details in their survey response with an interest in developing local bereavement cafes and several of the focus groups suggested the venues they access as appropriate locations for the cafes.

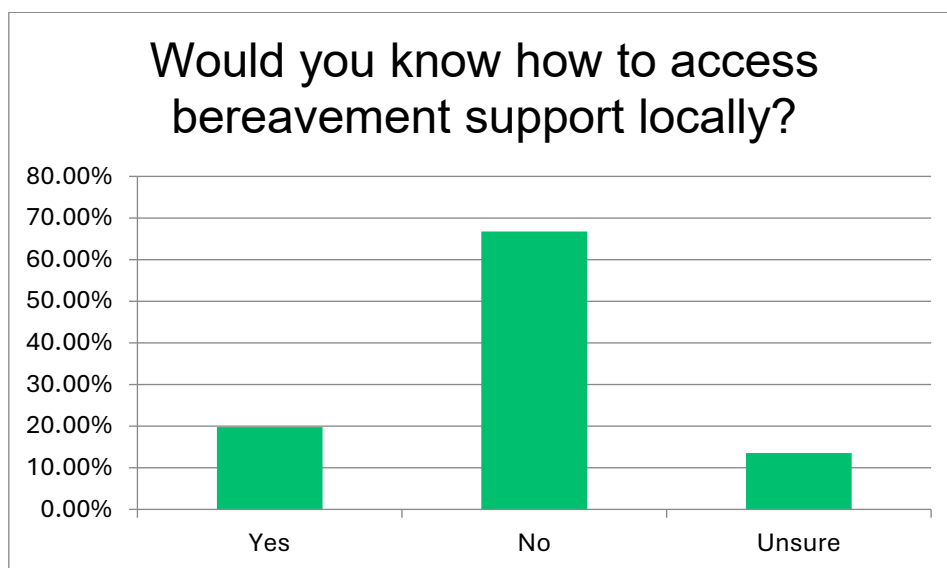
Recommendations

1. We would recommend that Lancashire and South Cumbria Integrated Care Board consider the adequacy of bereavement support provision in Blackburn with Darwen and allocate appropriate funds to increase provision or allocate staffing resources to meet the current gap.
2. We would recommend that Blackburn with Darwen Public Health pursue the piloting of bereavement cafes in the borough, with funding to provide a coordinator role who can provide the professional support to the cafes and support the training of volunteers, drawing on the contacts gained through our engagement.
3. We would recommend that there is better promotion through the Council, primary care and the VCFSE sector of the current provision that exists including online support and practical support available e.g. via the DWP.
4. We would recommend that the bereavement support offer includes an element of pre-bereavement support, including signposting to the Good Grief Trust website.
5. We would recommend that Children's Services, education sector and youth service providers explore appropriate bereavement support for children and young people including awareness raising in PSHE lessons or Wellbeing Assemblies.

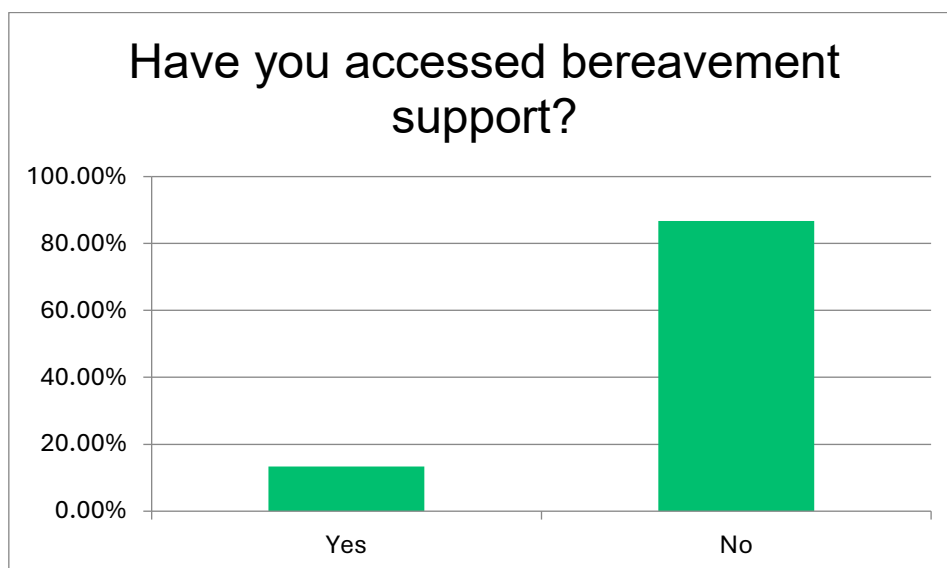


Feedback from our online residents' survey

Below is a summary of responses from 652 residents who took our online survey between August and October 2024. Some respondents did not answer all of the questions where they were not applicable or chose to skip some of the questions.

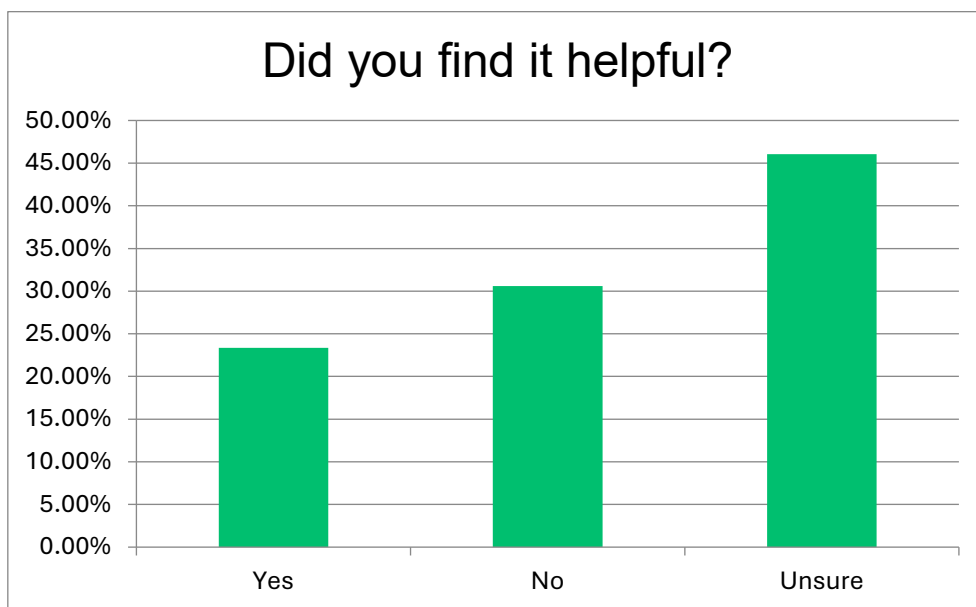
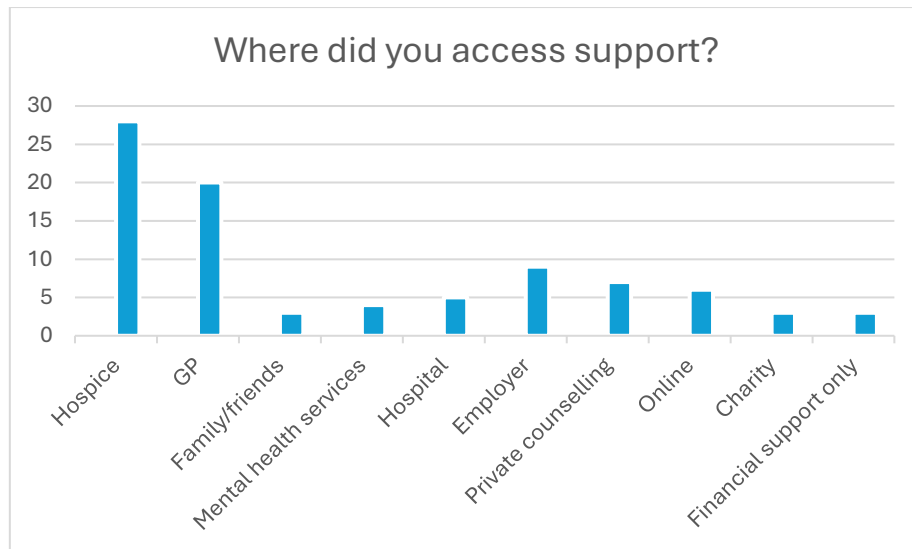


The majority of respondents (67%) did not know how to access support for bereavement locally with 20% stating they did.

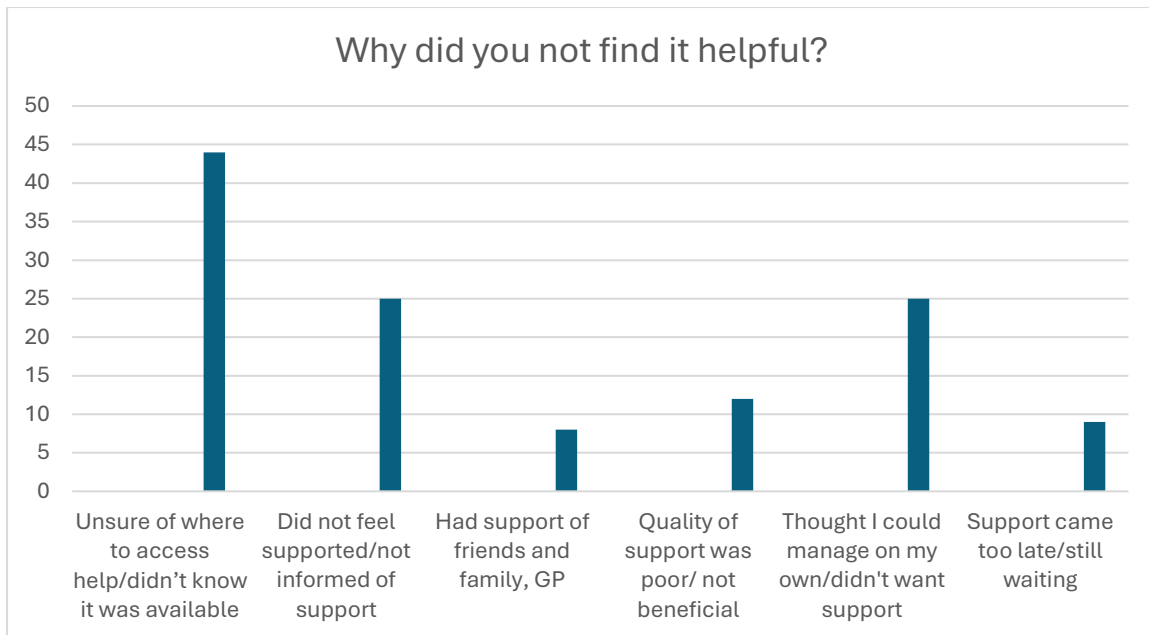


The vast majority of respondents had not accessed any support for bereavement with only 13% stating that they had accessed support.

We asked those who had accessed support who this was from. See a summary of the 88 responses below with the highest being from the local Hospice and their GP.



The majority of respondents were unsure after the support whether they found it helpful. The key themes for why people did not find the support helpful are summarised below.



Some of the individual responses included,

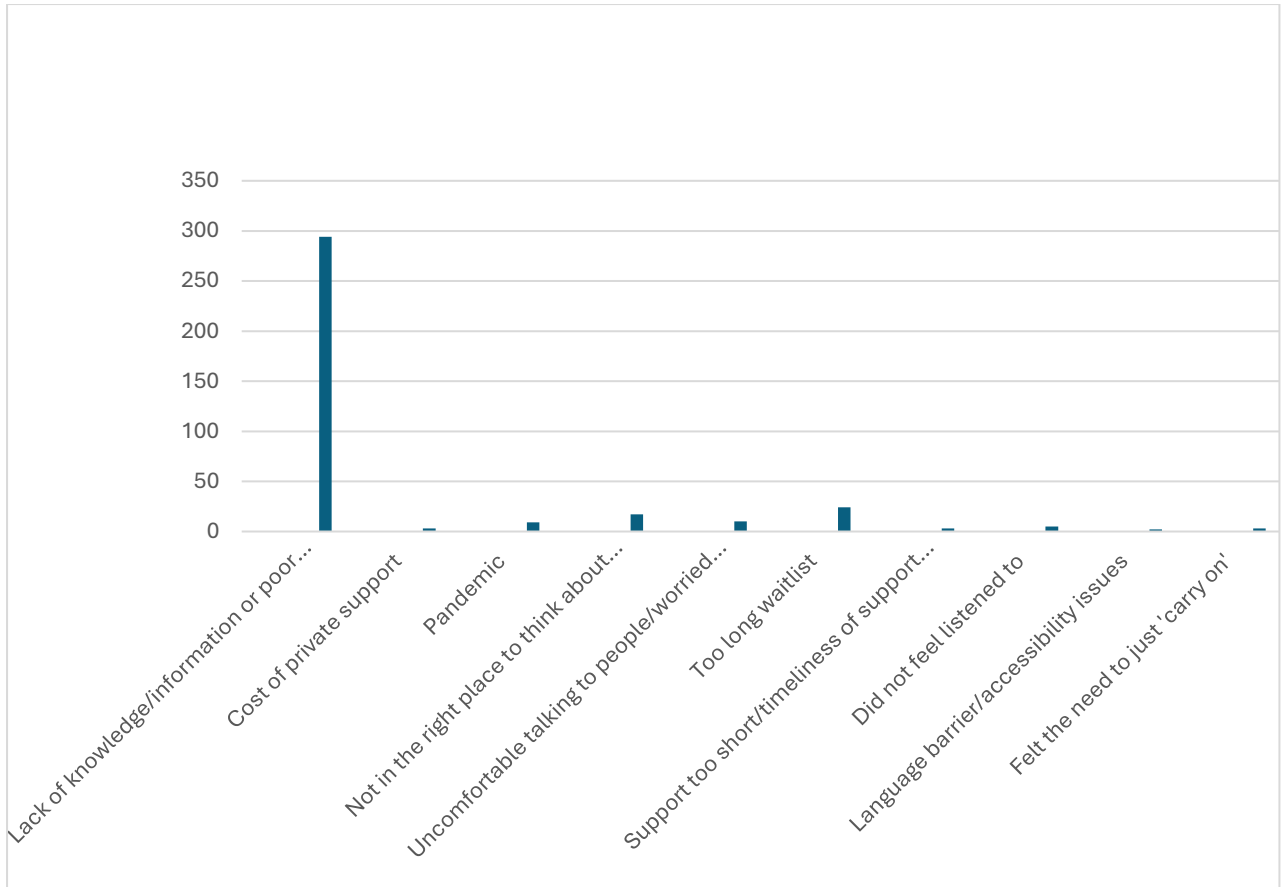


- “I thought I was going to get some support and I'm still waiting that was last year.”
- “You only get a few sessions, by the time you're into it your sessions have run out.”
- “I was given a bereavement number from my gp, but no one answered or even got back to me.”
- “Very little available. Baby loss and miscarriage is traumatic, and I feel I would have benefitted from some kind of follow up support.”
- “Thought I could do it on my own, but God was I wrong.”
- “I was merely asked questions, not the help I expected.”
- “Felt I had to get on with it myself and others wouldn't understand.”
- “Counselling was just a chat - no coping mechanisms given.”

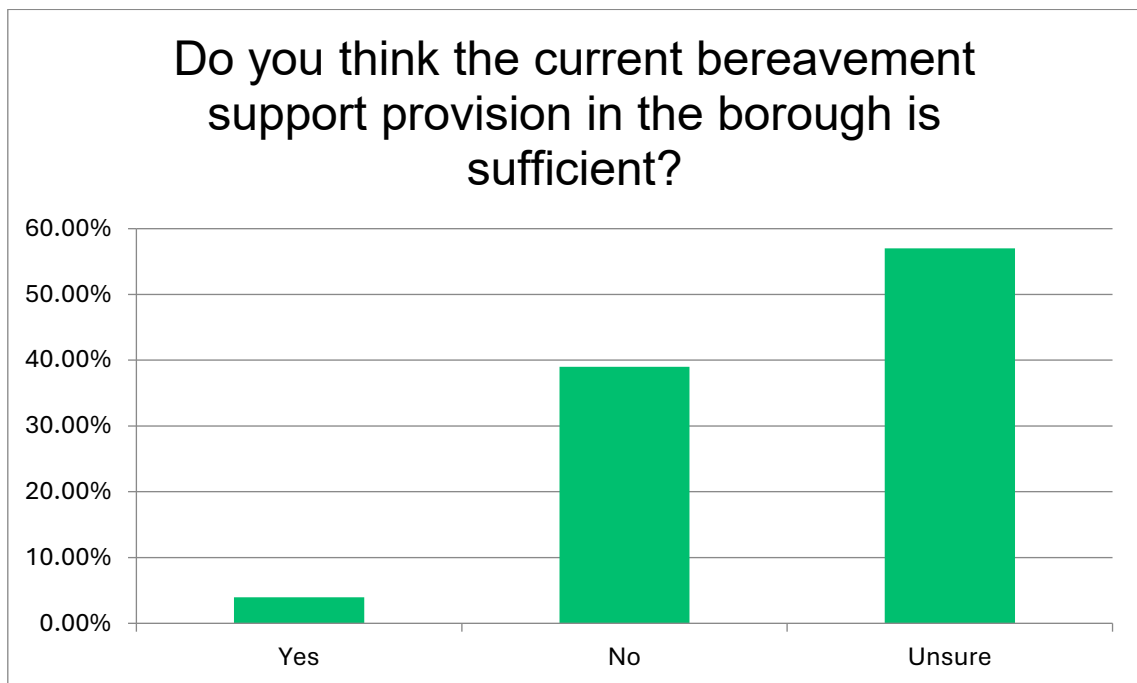


If you did not access bereavement support, what do you think were the barriers that prevented you from accessing it?

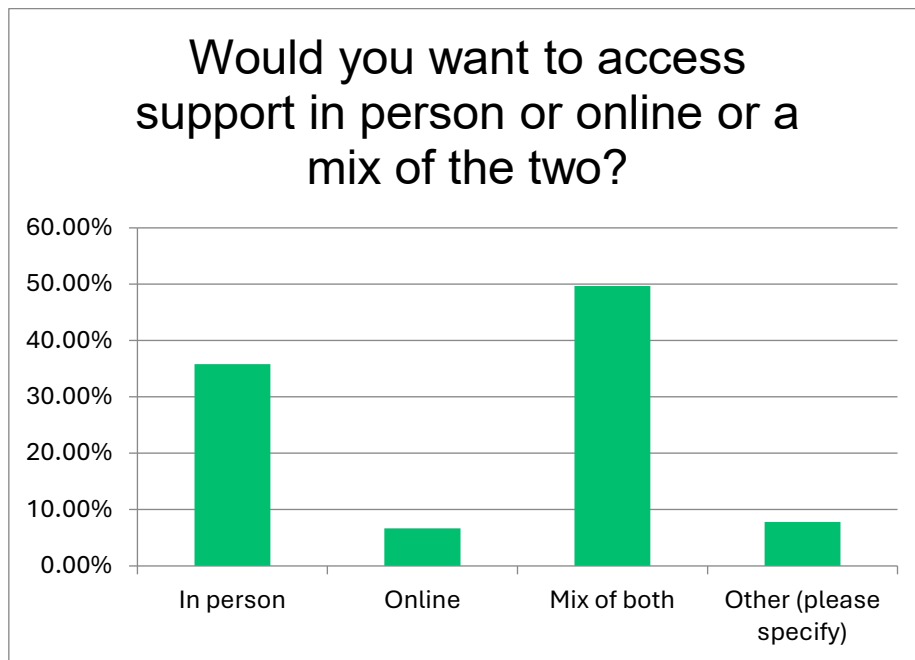
The overriding response was lack of knowledge about what bereavement support is available and poor information and signposting.



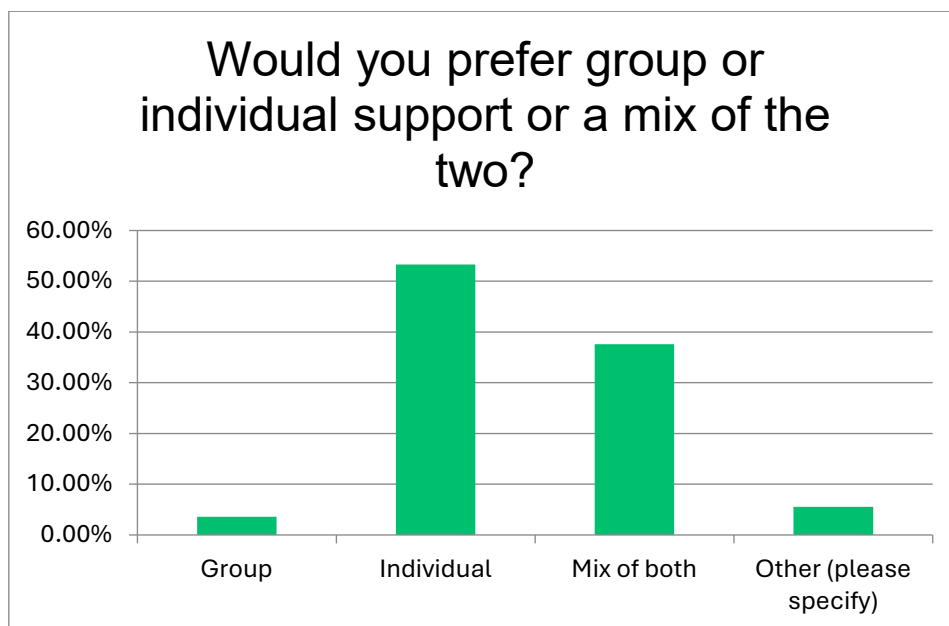
This lack of awareness is mirrored by people's responses to the question below.



We then asked residents what type of support they would want to access for bereavement.



Answers to “Other” included,
“Text or email.”
“I am housebound so would have to be at home.”
“A helpline maybe”
“Home support”
“In person if needed.”



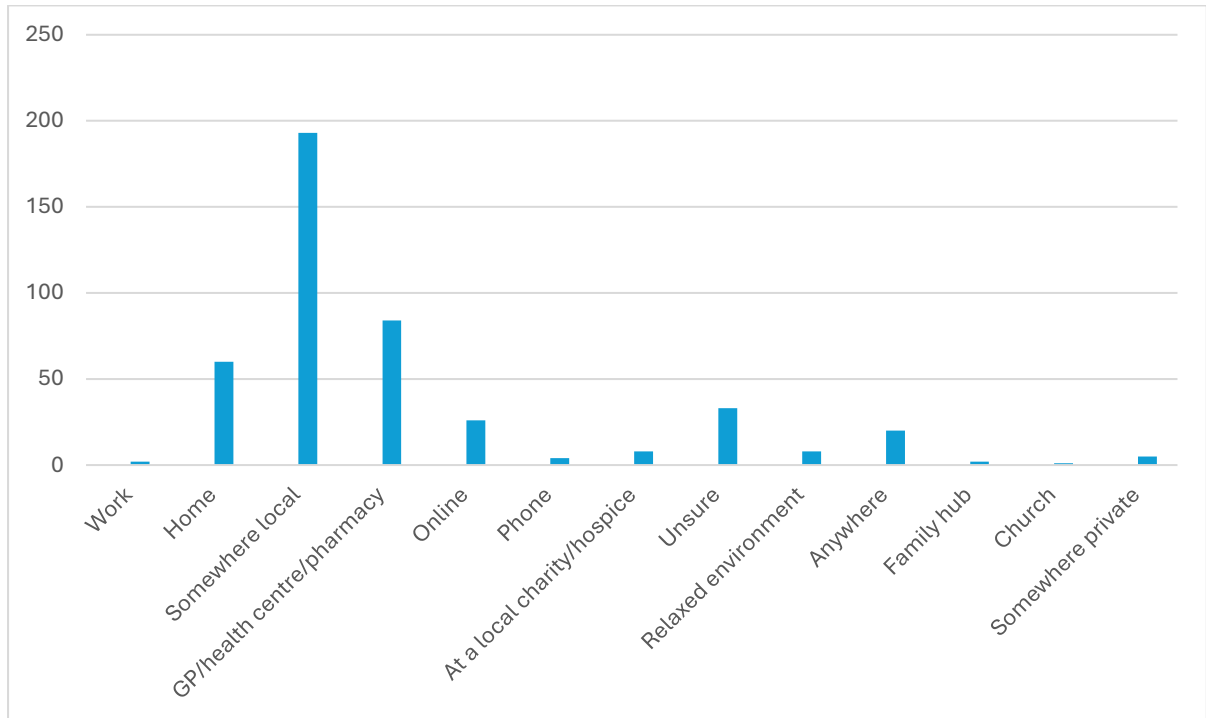
Answers to “Other” included,
“I would prefer to have it with family members.”
“Give both options.”

“Home support”

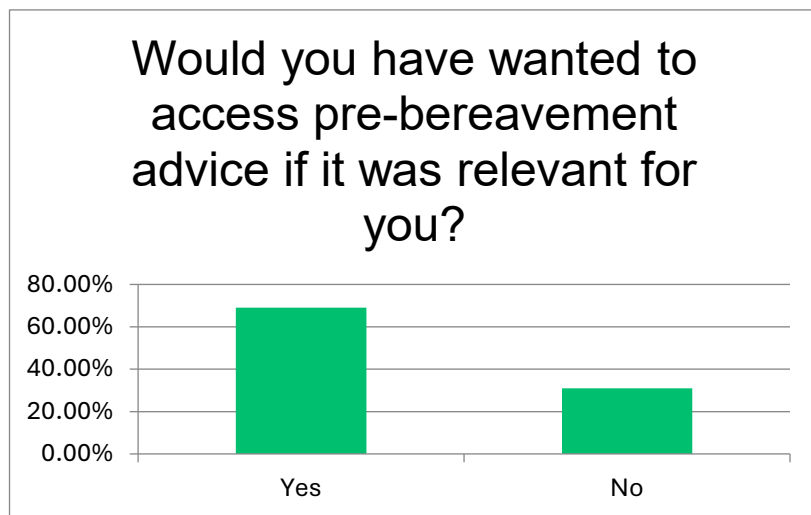
“I would prefer to discuss my bereavement with strangers.”

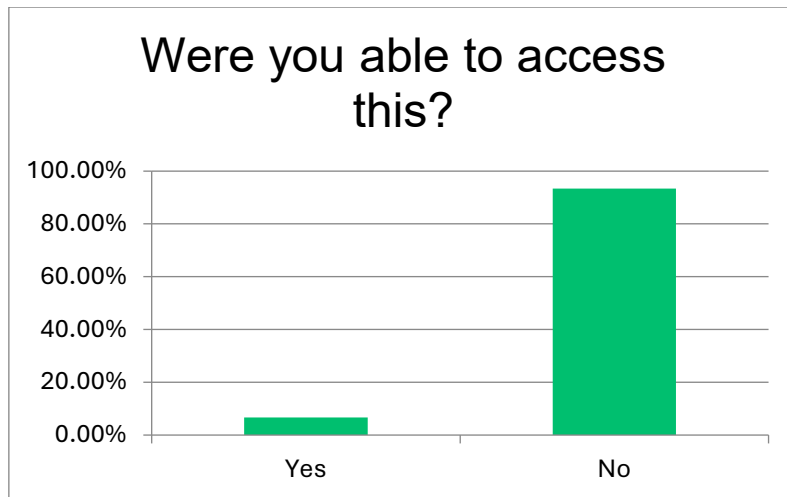
“I think both options should be available. Some people will prefer a group approach, and others would feel more comfortable in a 1:1 setting”.

Where Would You Want to Access Support for Bereavement?



Somewhere local was the overriding response from residents followed by at home and at a local GP practice or health centre.





If Yes What Did This Involve?

Responses included,
 “End of life nurses within hospital setting”
 “District nurses and hospice advice”

“Very limited. I cared for my terminally ill friend for a year. She had Hospice care who were supportive to me whilst she was alive but nothing after. The hospice is short of resources.”

“Counselling from a really nice dementia nurse”

“Information from Marie Curie nurses”

“Family support, conversations”

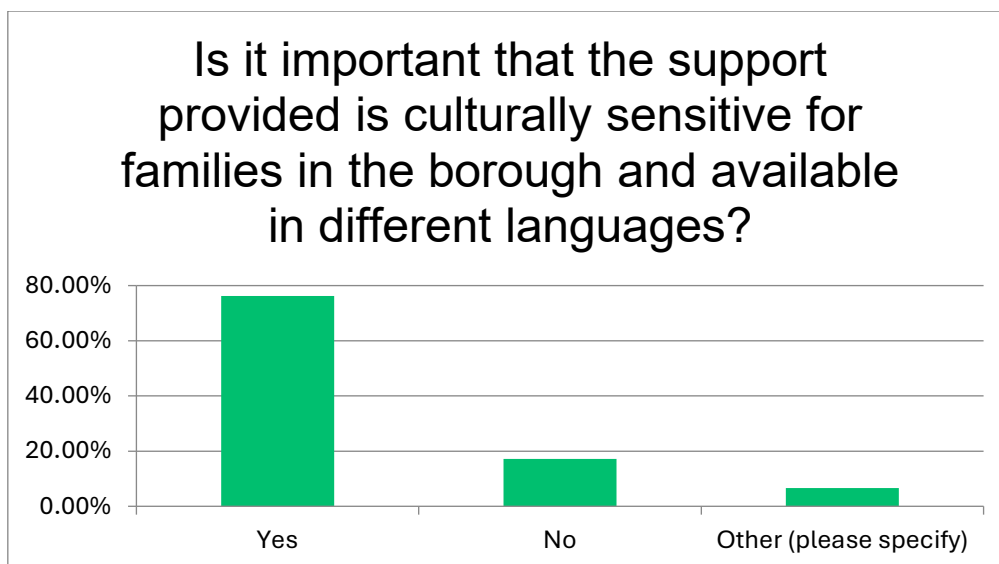
“Books, talking to friends, webinar, podcasts.”

“Hospice did home visits to support medication and everything. District nurses involved.”

“1 to 1 Counselling”

“Meeting with hospital staff & consultant present to answer questions.”





Answers to “Other” included,

“It’s important that is offered and advertised for all not just certain demographics.”

“I would imagine so.”

“It should be the same across the borough. However yes available in different languages.”

“100% everyone regardless of race / nationality/ religion suffers from loss and grief at some point in their lives. The service should be accessible to all.”

If yes, how would this look and feel differently for different communities?



“Different cultures and religions would have support tailored to their beliefs and preferences. Information would be provided in different languages. There would be people from diverse backgrounds, countries, ethnicity etc. working in these support groups so that the correct advice and support can be offered to the whole community.”

“Available according to religion, beliefs, and languages. Written documents in other languages too”

“Everyone would feel comfortable knowing that no matter your background you will be understood and helped accordingly.”

“More trauma-based therapies for families fleeing war zones, BwD is a multi-faith/ language town - accessing services can be difficult if English is not your first language. There may be a need for specific male/female support or group sessions.”

“It would benefit different people if there were interpreters and people that could sign for the deaf.”

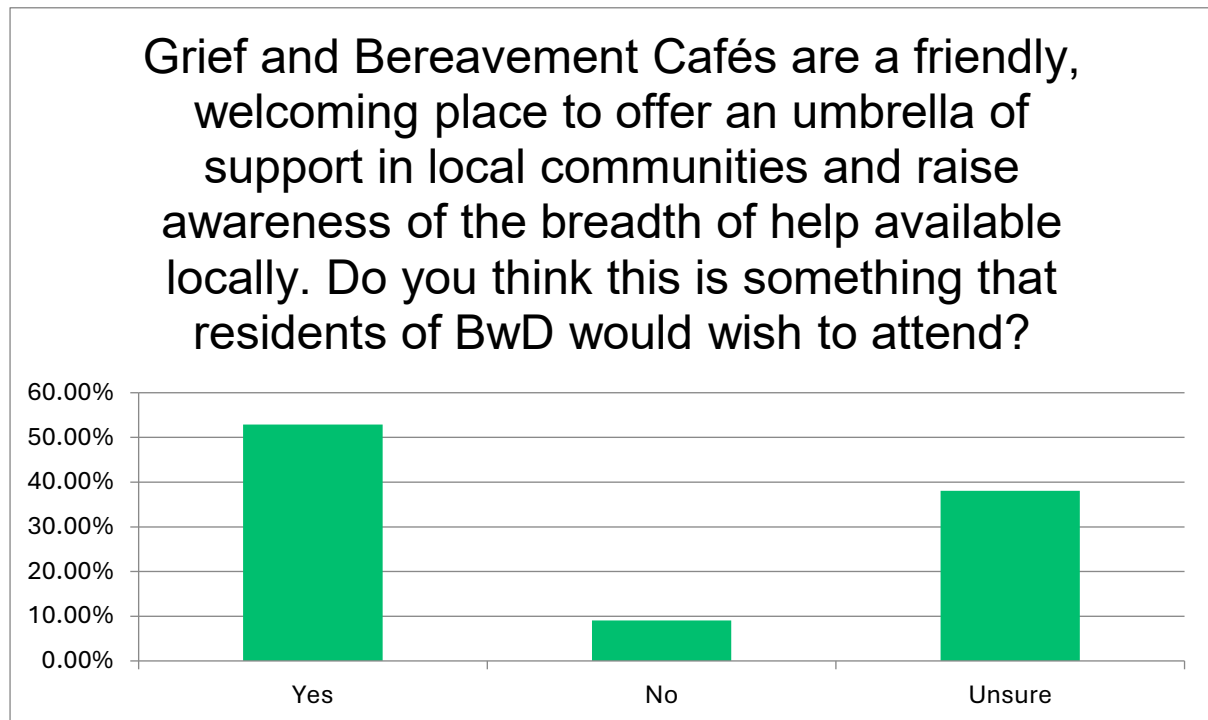
“Having counsellors of different faiths and cultures can help with feeling a connection to your therapist which you need to be able to open up properly and feel heard. Language barriers are also a huge issue for families in Blackburn there are so many different languages spoken here.”

“Unsure. I am White British my counsellor was a South Asian heritage man, and he was amazing. Sometimes it is more about the person’s skill, knowledge, empathy, and kindness, he was incredible.”

“As a Neurodivergent person, I would hope that support understands that I might process and communicate grief differently.”

“Be respectful of their customs, culture, and religious beliefs. Some people cannot leave their homes after a death in the family so maybe home support could be offered.”

“Some cultures view suicide as unacceptable”



Please explain your answer

“I would have used one of these to be able to go where I could talk or listen, would help.”

“Talking to like-minded people dealing with grief would help.”

“Less feeling of isolation /loneliness. Other people’s understanding. Safe place. Ability to make new friends.”

“These should be available for people to access as it is a great idea.”

“More relaxed atmosphere”

“When you lose someone especially your husband you feel very lonely at times be great source of support.”

“Being around people who went through the same loss and being able to hear the other persons experiences would help.”

“I’d like to sit and have a cuppa and know we’re all in same boat.”

“I feel that if the support is shared within the communities and areas, this could work. Unfortunately, people like me work far and cannot access during the week.”

“Can’t always talk to family.”

“Number 1 cafe have a friendship club on Friday 4-5pm and this is run by health providers. It works people are attending and can have individual appointments though those are paid for privately.”

“Grief is a personal & private thing to many.”

“With anxiety I struggle going out.”

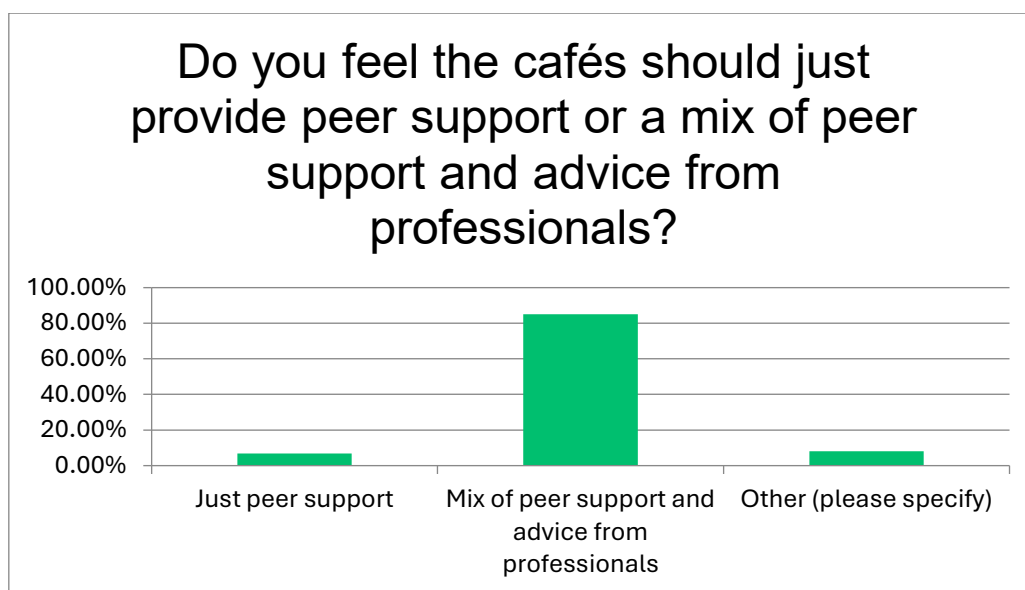
“Some people are more private than others and don’t want to share with a group.”

“Personally, I’m more comfortable with individual access but understand others would prefer group.”

“I think older people such as my mother would struggle to get to cafes regularly.”

“When you are enveloped in grief going to a cafe would have taken more courage than I had.”

“These could work but also, they could easily be taken over by non-neutral persons.”



Answers to “Other” included,

“Peer support with occasional visits from professionals timetabled in so you know they are going to be there.”

“Only from professional people.”

“peer, unless the professionals have been through it as well, however if they haven’t dealt with the loss of a loved one then i would struggle to take advice from them as they don’t understand how difficult it is and can be offering things that are all good on paper but not in the real life situation”

“Just peer support but with info on how to contact the professionals.”

“Bring everyone in - different topics on different sessions.”

Is there anything else you would like to add?

Additional areas of support required



“Any form of bereavement support would help the community.”

“Advice/help with form filling and notifying relevant people/professionals after bereavement.”

“Cafes should link into other council services; bereavement can be at the root of dramatic and negative lifestyle changes.”

“Working families struggle, unfortunately I have struggled for over a year. Fortunately, I have a student doctor in my home and got some really good support however not all have that. I feel in communities people want to feel listened to but do not know how to access due to their language barriers or even scared to discuss how they feel. Communities need mental health first aiders...Working with young people I have gained a lot of experience and am a mental health first aider however could not practice this on myself due to grieving.”

“Maybe fewer waiting lists etc for people wanting counselling, accessing services such as Minds Matters etc.”

“Employment support would be good. I was threatened with disciplinary action after taking time off after the death of my dad.”

“I think we need to include... forms of support not just counselling, financial support, funeral costs and community support.”

“Carers need more GP input when someone attends a practice with a loved one, they should be offered follow-up contact of some sort as standard practice. Also do not resuscitate conversations should be had much sooner and more commonly. Anyone with mid stages dementia should have a GP talk to them about it before they lose capacity.”

“It would have been nice to have some follow up from the health professionals involved in looking after my loved one or a representative from there.”

“There needs to be something available for children to access for bereavement support.”

“Help with dementia support when the person doing the care passes away. You are left to take over the role with no clue what to do.”

“I think a multi layered approach would be good. Breaking the isolation and normalising that grieving is not a straight line is really important.”

Improved information and signposting



“There should be more information available for families and be easier to access. Carers need more support to. Accessing services or a database of services available for end-of-life care.”

“Signage in surgery and on GP app”

“It’s very important for healthcare professionals to offer support after bereavement rather than resorting to prescribing medication as a coping mechanism.”

“I do believe there should be more awareness brought in around grief at a younger age as it’s the one thing that all humans have in common.”

“It would be nice to have had contact from local GP on bereavement.”

“Would be useful to have information about what support is available as soon as possible after bereavement, as part of information provided by funeral directors when arranging the funeral or by the GP or hospital staff certifying the death. Whilst many will not be ready to access support at that point, having and reading the information and knowing where to go to get support could encourage those bereaved to seek it at a later stage.”

“I would appreciate better communication between NHS departments. 3 days after my mother in laws death the paramedic, who had been visiting, returned for another visit; within a week Blackburn Hospital rang to arrange a scan; other similar contacts were made and 6 months later a man called to check her bath. Surely, in this computerised world, it should be an easy thing for all departments to be told and updates made to records.”

“Through my GP there were referrals to services that no longer existed or long waits for NHS. I had to source my own counselling but can get it through work. Others might not have this option. Sourced more through the hospice and the telephone system and general administration was a bit chaotic but still they were doing their best.”

Personal experiences



“This would have helped me years ago.”

“GP surgery staff were not helpful. Said they had a bereavement service for which I waited several weeks only to be told to contact the Hospice where I had to wait several more weeks. Bereavement support should be available immediately.”

“It’s all well and good offering this service but my grandad is being told he is on a 12-week waiting list, this is far too long to wait for support”.

“These groups will attract those that have lost children, partners, parents etc it could be triggering or create anxiety for people to hear others’ stories. Personally, I could not sit and listen to child loss if I went for my own bereavement due to already having anxiety about losing a child. These groups can be fantastic but sometimes they are not healthy for some.”

“As an employee of the NHS I can safely say I am ashamed on before of the NHS for the woefully inadequate provision of support for bereaved individuals. The wait for support is unacceptable and harmful. This underfunding and lack of provision is will fully detrimental to all, especially as suicide is the main killer of men in my age bracket.”

“Lots of people are still grieving losing a loved one in the pandemic. No one wants to talk about it now, but lots of people still suffering trauma.”



Summary of Focus Groups Feedback

We conducted focus groups with the following community groups: -

- Asian Carers Group at BwD Carers Service - 12 women aged between 25 and 75, all British Asian
- Resolve Group at Care Network - 5 women and 4 men, 3 British Asian and 6 White British aged between 30 and 60.
- Rise and Shine Group at Darwen Health Centre - 4 women and 2 men, 5 White British and 1 British Asian aged between 19 and 50
- St Lukes drop-in session - 3 White British men (all vulnerably housed) aged 40-60 and 4 White British women aged 60-75.
- Talk Ourselves Well group - 7 men aged 23-62, 5 White British, 1 White Other, 1 Chinese
- Darwen Youth Zone group - 7 boys aged 14-17 White British, 2 girls aged 16-18 White British

Total - 48 residents engaged in focus groups.

Would you know how to access bereavement support locally?

Only 3 people in the groups knew where they could access bereavement support. Only one person had had received some form of bereavement support. She had received a support call from the hospital's bereavement team every two weeks then on a monthly basis and they tried to get counselling for her, but she received a letter with appointments at a time which was not suitable for her around her working hours. Another person had attended one session with MacMillan at the hospital, but this support was stopped because it was during the pandemic and one lady knew that financial support was available from DWP because of her husband's job.

People shared that they wish that they had known that support was available at the time when they needed it.

"I lost my husband, and I felt that I was really down for about 7-12 months. I think it was worse because my husband died in Saudi, so nobody knew locally knew about it. I felt like I had no support for six months, not even from the Carers Service. I was too depressed and didn't know where to look for help. Family was falling out too. I like coming to this group, but I've been more scared to come out of the house and see people.

"My mother died suddenly from a cardiac arrest 2 and a half years ago and I've just not wanted to leave the house. Others in this group have had to force me to come out with them."

"People don't know that you can go to the GP for support and just feel that all they will do is give you medication."

“My husband lost his mother about 2 years ago and he’s just completely shut himself off. He takes time off when it’s the holidays, but he doesn’t spend time with me and the children, he just stays at home and works in his room. He’s only just started coming down to watch some TV with us over the last couple of weeks. He’s not talked to anyone about it. I want to support him as his wife and get him to live in the present because he has me and the children to be with.”

One man had lost a close friend and took on the role of next of kin and because he knew his friend was end of life, he rang East Lancashire Hospice to ask if he could access support after his death, knowing he would probably need this. At the time of his death, he was given a pack by the hospital team and offered help, but he was not in the right place to access it at that point. 10 months later he received a call from the Hospice asking him if he wanted bereavement support but by then it was too late, he had managed to get through his grief by himself although it had been difficult, and he had organized a walk in memory of his friend which helped him process his loss.

People felt that there was a lack of signposting to support and no knowledge about criteria for support. He felt that people tend to only access support when they hit crisis point and saw help as a rare resource and thought that agencies must prioritise who they can support.

If you did not access bereavement support, what do you think were the barriers that prevented you from accessing it?

The most significant barrier for people we spoke with was lack of knowledge of what support is available locally. Some felt that the restriction on timescale for accessing support of 3-6 months post bereavement from some agencies was not helpful at all. “Some people could be suicidal during those first 3-6 months and help will be too late.” “It needs to be recognised that that’s a really difficult time.”

Several members of the groups felt that men would be less likely to access support, and some men felt that professionals would judge them. “You’ve just got to deal with it on your own because that’s what we do.”

“Men will not talk in the same that women will and just put a front on and hide their emotions. They do not want to join groups because they feel that people gossip. Mosque involvement would be helpful, and barbers being trained to be able to have conversations with men would be helpful because they chat with men all the time. Men might speak to the Muslim burial society too.”

Lack of support from employers was raised by members of one of the groups.

One lady had tried to access a support group outside of the borough but because she was the only person there bereaved by suicide; she did not feel that she could relate to others in the group.

None of the groups we spoke with felt that the current bereavement support provision in Blackburn with Darwen was sufficient.

Would you want to access support in person or online or a mix of the two?

The majority of people we spoke with stated that they would prefer to access support in person, but some felt that an option of both would be helpful and that it should be tailored to the individual. One person suggested text messages in different languages initially would help people know about support services available to them and phone calls as an alternative to online.

“There should be bereavement support for children too - both in school and Madrassahs.”

The young people we spoke with felt that in person support would be good and that bereavement should be covered within PSHE lessons, with one member of the group suggesting a monthly ‘Wellbeing Assembly’ with a focus on emotional support for students in school. This would fit with a whole school approach to support young people’s wellbeing.

Would you prefer group or individual support or a mix of the two?

People felt that everyone’s experience of grief as a result of bereavement is hugely different therefore a mix of both individual and group support would be beneficial. Some felt that they would need 1:1 support before considering joining a group but others felt that socializing with others who have been through similar experiences was important.

“It can be easier to talk to strangers than to family because you don’t want to be a burden on them.”

One of the groups felt that support should be tailored to the individual and more flexible than a rigid number of sessions of support. One person felt that after each session, a counsellor could check in with the individual as to how they feel they are coping and base the level of support on that.

Young people felt that support for a young person should be tailored to the individual but that group support in schools would be beneficial either as year groups or as peer support groups (friendship groups identified by the school).

Where would you want to access support for bereavement?

All members of the groups felt that a community setting would be good or at home for some. People suggested the locations where they currently meet e.g. Kingsway BWD Carers Service, St Lukes Church as possible venues for a bereavement support group and offered to support in setting up the groups.

The young people we spoke with felt that school would be most appropriate because they saw youth centres as ‘somewhere they can relax’ but did not want any stigma attached to accessing support in school e.g. being called out of lessons for one-to-one support.

Would you have wanted to access pre-bereavement advice if it was relevant for you?

None of the members of the groups had accessed pre-bereavement support but felt that this would be beneficial for some residents, including the practicalities of managing the end of life of a loved one and signposting to other services. The group of adults with learning disabilities were less sure about accessing this support. “You want to stay hopeful that they might pull through so don’t want to think about them dying before it happens.”

Other feedback included: -

“Yes, it would be helpful if someone is very sick, and you have a longer end of life. My husband didn’t want anyone to know he was ill so it would have been good but don’t know how I would have managed to access it.”

“Noone tells you what you have to do and how you then have to carry on functioning as well.” “I wouldn’t have a clue what to do if I lost my mother.”

Is it important that the support provided is culturally sensitive for families in the borough and available in different languages?

All of the groups felt that this was important, and support tailored to the needs of different communities. Some people recognised also that grieving periods and the timescales for funerals varied across different communities, and this should be reflected in the support available.

Women at the Asian Carers group stated, “It would have to be available in different languages and informed by Islamic practice. When women lose their husband, they cannot leave the house for 4 ½ months under Islamic rule. It can get really lonely and mental health issues can creep in. You cannot be around men and cannot have a laugh with people. Home visits during that time would be beneficial. Especially as you do not always want to talk to family about everything.”

Members of the Resolve group stated, ““It needs to be so that it is meaningful for people and so people can understand.”

Do you think that bereavement cafes are something that residents of BwD would like to attend?

All of the groups we spoke with felt that bereavement cafes across the borough would be beneficial for residents and all of them felt that the cafes should be a mix of peer and professional support.

“Yes - having an open space where you are not judged, and you can see smiling faces of people who have been through the same thing as you would be good.”

“It would be good to train community members up to help talk to people about bereavement. They couldn’t take on a counselling role but if they could do some of the basics, I think that would be great.”

“It would be particularly helpful for people who don’t have a good support network and stop them from being lonely.”

“The sessions would be good if they were a drop in and you didn’t have to sign up to attending every week because grief comes in waves and sometimes you might not feel up to going but would still have that contact with members of the group.”





Community Offer

Currently there are bereavement support groups in the borough for two specific groups of residents. Speak Their Name is a peer support group for residents bereaved by suicide and Lancashire Mind have recently launched a Baby Loss and Miscarriage Service, Together After Loss' which provides free 1:1 therapy and peer support groups.

There is no wider 'bereavement café' in the borough therefore we visited a group in Bolton to understand how this offer is delivered.



The session we joined was well attended with about 20 people in the room, predominantly women with only one man in attendance.

The session was facilitated by a lady who had experienced the loss of her husband, and it was very much focused on peer support. Whilst the session gave members the opportunity to share how they are managing, the conversations were focused on offloading of emotions and there was little building of hope and coping strategies. A professional counsellor or social prescriber may have been better placed to facilitate the group and manage the difficult conversations differently. We noted that three ladies left the session part way through because they were upset by the discussions and there was no apparent follow up with them.

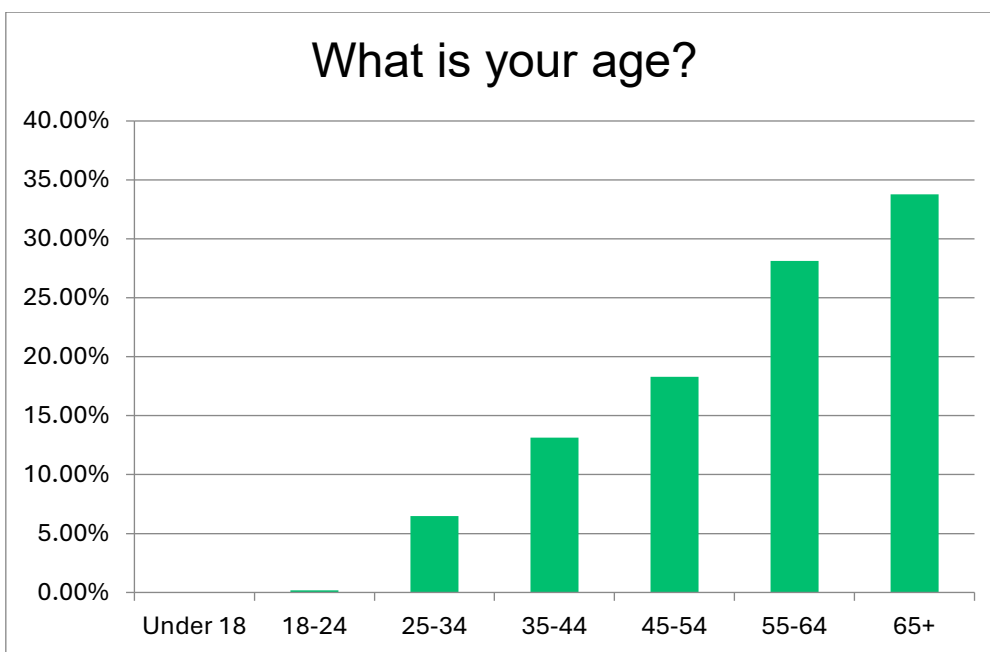
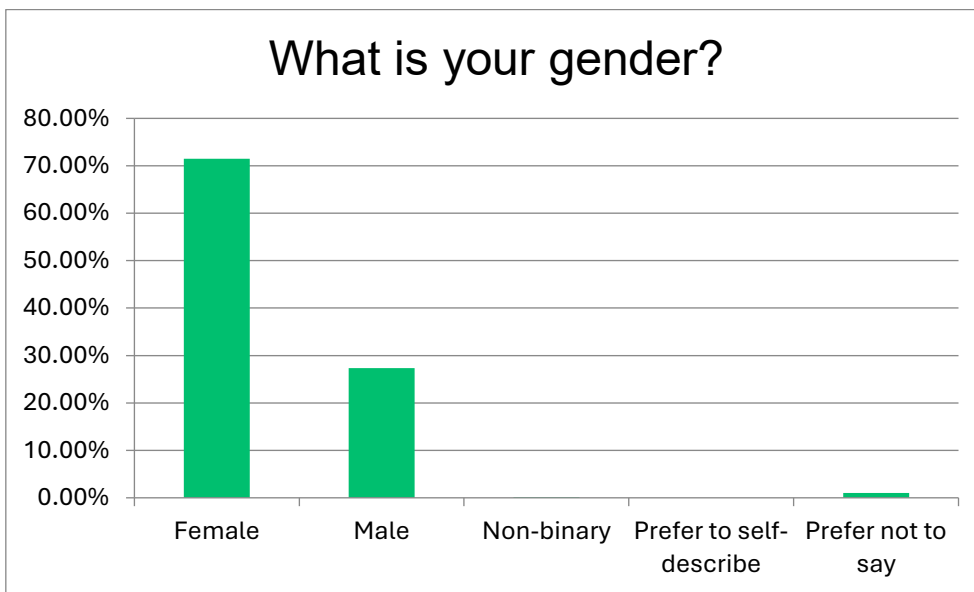
Ann Neville, a Practice Manager from Darwen Healthcare and member of our BwD Bereavement Support Steering Group told us that she attends sessions in Oswaldtwistle hosted by Champs Funeral Services. Lianna Champ has been a grief expert for over 30 years and is also a published author with her book, **How to Grieve Like a Champ**. Their sessions, 'Life After Loss' are hosted by their team and bring in professionals from diverse backgrounds to speak with the group, helping them to develop coping strategies and learn how to have hope after the loss of a loved one.

We feel this model would work best for residents in Blackburn with Darwen, based on the feedback received both via the survey and our focus groups.

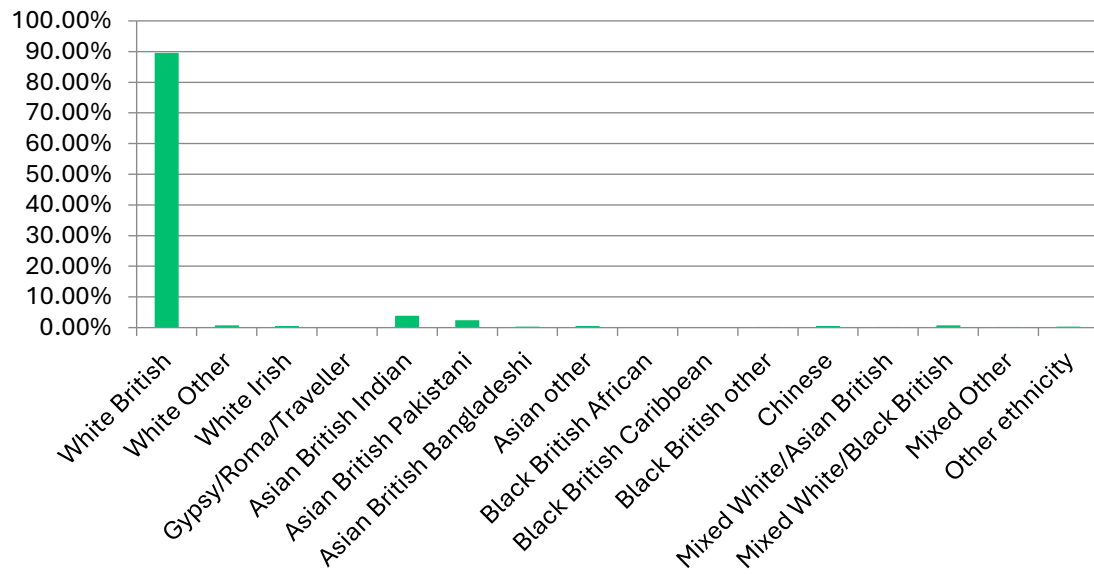


Appendices

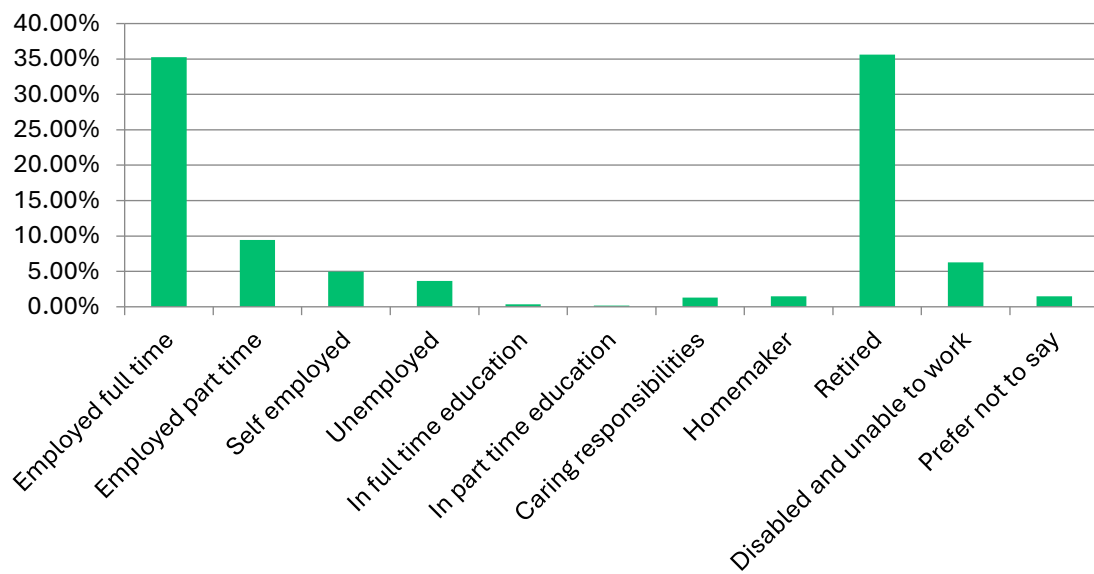
Survey Respondents' Demographic Information



What is your ethnicity?



What is your employment status?





Focus Groups Feedback

Asian Carers Group - BwD Carers Service

Would you know where to access bereavement support locally?

None of the group knew where to access support. One suggested the internet might be an option.

Have you accessed bereavement support?

None of the group had accessed support. However, several members of the group wished that it had been available both for themselves and family members.

“I lost my husband, and I felt that I was really down for about 7-12 months. I think it was worse because my husband died in Saudi, so nobody knew locally about it. I felt like I had no support for six months, not even from the Carers Service. I was too depressed and didn’t know where to look for help. Family was falling out too. I like coming to this group, but I’ve been more scared to come out of the house and see people.

“My mother died suddenly from a cardiac arrest 2 and a half years ago and I’ve just not wanted to leave the house. Others in this group have had to force me to come out with them.”

“People don’t know that you can go to the GP for support and just feel that all they will do is give you medication.”

“My husband lost his mother about 2 years ago and he’s just completely shut himself off. He takes time off when it’s the holidays, but he doesn’t spend time with me and the children, he just stays at home and works in his room. He’s only just started coming down to watch some TV with us over the last couple of weeks. He’s not talked to anyone about it. I want to support him as his wife and get him to live in the present because he has me and the children to be with.”

“Neighbours always used to check in on each other and for the first 2-3 weeks after the loss of a family member they would come round with food every day, or you could spend time with them. It feels like since Covid that community spirit isn’t the same and everyone is on their phone rather than actually spending time together.

“There should be bereavement support for children too - both in school and Madrassahs.”

“Sometimes you don’t feel you can speak to your family about everything, and you want someone else to talk to.”

If you did not access bereavement support, what do you think were the barriers that prevented you from accessing it?

“Language barriers, just knowing what is available. None of the group knew about the hospice bereavement support offer and did not know that the Carers Service provides a ‘Life After Care’ group but this only runs when there are enough people to pull a group together.”

“Men will not talk in the same that women will and just put a front on and hide their emotions. They probably don’t want to join groups because they feel that people gossip. Mosque involvement would be helpful, and barbers being trained to be able to have conversations with men would be helpful because they chat with men all the time. Men might speak to the Muslim burial society too.”

“Men go blank it’s like they are heartless”

Do you think the current bereavement support provision in the borough is sufficient?

No

Would you want to access support in person or online or a mix of two?

Both

Would you prefer group or individual support or a mix of the two?

Individual would be good because everyone’s experiences of grief are different, but some group support would be helpful.

Where would you want to access support for bereavement?

Here at Kingsway would be good. We feel comfortable here talking to each other about a lot. Counselling here would be really helpful.

Would you have wanted to access pre-bereavement advice if it was relevant for you?

Yes, it would be helpful if someone is very sick, and you have a longer end of life. “My husband didn’t want anyone to know he was ill so it would have been good but don’t know how I would have managed to access it.”

None of the group had accessed pre-bereavement support.

Is it important that the support provided is culturally sensitive for families in the borough and available in different languages?

Yes.

How would this look and feel differently for communities?

It would have to be available in different languages and informed by Islamic practice. When women lose their husband, they cannot leave the house for 4 ½ months under Islamic rule. It can get really lonely and mental health issues can creep in. You can’t be around men and cannot have a laugh with people. Home visits during that time would be beneficial. Especially as you don’t always want to talk to family about everything.

Do you think that bereavement cafes are something that residents of BwD would like to attend?

Yes - having an open space where you are not judged, and you can see smiling faces of people who have been through the same thing as you would be good.

“Nobody talks like they used to, everyone on their phones or WhatsApp”

Do you feel the cafes should just provide peer support or a mix of peer support and advice from professionals?

Mix of both

Would you like to be involved in setting up a bereavement support group?

Yes - here at Kingsway

Resolve Group - Care Network

Would you know where to access bereavement support locally?

None of the group knew where they could access bereavement support.

Have you accessed bereavement support?

One member of the group stated that he had been referred to a group up at the hospital by either his GP or MacMillan. However, this was just before the Covid pandemic, and he attended one group session then they were stopped due to the pandemic.

Did you find it helpful?

No because it was just one session.

If you did not access bereavement support, what do you think were the barriers that prevented you from accessing it?

All of the group felt that the greatest barrier was not knowing where to go for support. Some members of the group felt that the restriction on the timescale for accessing support of 3-6 months post bereavement from some agencies was not helpful at all. "Some people could be suicidal during those first 3-6 months and help will be too late." "It needs to be recognised that that's a really difficult time."

We need to look at what's working well in other parts of the world. How do others offer this support?

Do you think that the current bereavement support provision in the borough is sufficient?

All of the group felt that it was not sufficient.

Would you want to access support in person or online or a mix of the two?

All of the group felt that they would want to access support in person.

Would you prefer group or individual support or a mix of the two?

There was a mix of responses from members of the group. Some wanted one to one because grief is a very individual thing but others felt a group session would be good so you can listen to others experiencing the same things as you.

Where would you want to access support for bereavement?

"In a familiar setting"

"At home"

Several stated "in a community setting"

Would you have wanted to access pre-bereavement advice if it was relevant to you?

A lot of the group were unsure if they would want this. “You want to stay hopeful that they might pull through so don’t want to think about them dying before it happens.”

None of the group had accessed pre-bereavement support.

Is it important that the support provided is culturally sensitive for families in the borough and in different languages?

All of the group felt this was important. “It needs to be so that it’s meaningful for people and so people can understand.”

Do you think that bereavement cafes are something that residents of BwD would like to attend?

All of the group felt that a bereavement café offer would be beneficial. “It would be good to train community members up to help talk to people about bereavement. They couldn’t take on a counselling role but if they could do some of the basics I think that would be great.” “Yes, you need to be able to talk to people who understand and have been through something similar to you.”

Do you think the cafes should provide just peer support or a mix of peer support and advice from professionals?

All of the group felt that it should be a mix of peer support and professional advice.

Would you like to be involved in setting up a bereavement support group?

The group were keen on something to be set up at Care Network as part of the Resolve Group.

Rise and Shine Group - Darwen Health Centre

Would you know where to access bereavement support locally?

None of the group knew where they could access bereavement support except one member.

Have you accessed bereavement support?

One member of the group had received support from the hospital's bereavement team. She received a support call from the team every two weeks then on a monthly basis and they tried to get counselling for her, but she received a letter with appointments at a time which was not suitable for her around her working hours.

Did you find it helpful?

It was limited and because I live in Darwen, but I am registered with a GP in Bury, I have struggled to access support locally.

If you did not access bereavement support, what do you think were the barriers that prevented you from accessing it?

No one reached out when my father passed. I travelled to Bolton for a group, but I didn't feel comfortable because the others there had not lost someone through suicide.

Do you think that the current bereavement support provision in the borough is sufficient?

All of the group felt that it was not sufficient.

Would you want to access support in person or online or a mix of the two?

All of the group felt that they would want to access support in person but felt that alternative ways to access support should always be offered and tailored to the individual. One person suggested text messages in different languages initially would help people know about support services available to them and possibly phone calls as an alternative to online.

Would you prefer group or individual support or a mix of the two?

There was a mix of responses from members of the group and people felt that it depended on the person. Some felt that they would need 1:1 support before considering joining a group but others felt that socializing with others who have been through similar experiences was important.

Where would you want to access support for bereavement?

All felt a community setting would be most appropriate.

Would you have wanted to access pre-bereavement advice if it was relevant to you?

Several of the group felt this would be important, including the practicalities for preparing for the death of a loved one and signposting to other services. “Noone tells you what you have to do and how you then have to carry on functioning as well.” “I wouldn’t have a clue what to do if I lost my mother.”

None of the group had accessed pre-bereavement support.

Is it important that the support provided is culturally sensitive for families in the borough and in different languages?

All of the group felt this was important. They recognized also that grieving periods and the timescales for funerals varied across different communities, and this should be reflected in the support available. One person felt that dignity means different things to different people.

Do you think that bereavement cafes are something that residents of BwD would like to attend?

The group felt that this was definitely worth trialling. “It would help people know that they’re not on their own and they should not be isolated.” “It would be particularly helpful for people who don’t have a good support network and stop them from being lonely.” “The sessions would be good if they were a drop in and you didn’t have to sign up to attending every week because grief comes in waves and sometimes you might not feel up to going but would still have that contact with members of the group.”

Do you think the cafes should provide just peer support or a mix of peer support and advice from professionals?

All of the group felt that it should be a mix of peer support and professional advice. “Knowing where to turn is the most important thing.” People need support through the end of life and support to be open to their grieving process.

St Lukes Church Focus Group

Would you know how to access bereavement support locally?

Only one member of the group knew where bereavement support was available in the borough because her husband gives bereavement financial advice at the DWP.

One member stated that she had lost her partner of 36 years and her sister within twelve months, and she did not know where to access support - her friends were her most important network at that time.

One stated that when her first husband died of cancer she did not know where to go for help initially - he died within 6 weeks of being diagnosed. However, she stated that Macmillan had been helpful.

None of the group had accessed bereavement support.

What do you think were the barriers that prevented you from accessing it?

The main barrier for the group was lack of knowledge of what support is available for bereavement. The men in the group felt that people are ashamed to ask for help and they are afraid of being judged by professionals. 'You've just got to deal with it on your own because that's what we do. Go on a mad one for a week then get back on with life.'

Do you think the current bereavement support provision in the borough is sufficient?

None of the group felt it was sufficient.

Would you want to access support in person or online or a mix of the two?

All of the group felt that they would prefer support in person.

Would you prefer group or individual support or a mix of the two?

The group felt that a mixture of the two would be most beneficial although it is very personal, sometimes it helps to speak with strangers who have been through the same thing. 'It can be easier to talk to strangers than to family because you don't want to be a burden on them.' 'I could rant and rave in front of others but not everyone is comfortable to open up in the same way'.

Where would you want to access support?

Some felt a community setting would be best and the women all offered to support having a bereavement café at St Lukes Church community centre.

Would you have wanted to access pre-bereavement advice if it was relevant to you?

The women felt this would be helpful if it covered the practicalities of what you need to deal with.

None of the group had accessed this advice.

Is it important that the support provided is culturally sensitive for families in the borough and available in different languages?

All of the group felt that this was important, and support tailored to the needs of different communities.

Do you think bereavement cafes are something that residents of BwD would like to attend?

The group felt that these would be good especially if they could set one up at St Lukes Church.

Do you feel that the cafes should just provide peer support or a mix of peer support and advice from professionals?

All of the group felt that it was important that the cafes should be a mix and having support from a professional whose advice they trusted.

Talk Ourselves Well Focus Group

Would you know how to access bereavement support locally?

Only one member of the group knew where bereavement support was available in the borough, and he stated that it was because of his job that he knew about it.

He lost a close friend and took on the role of next of kin and because he knew his friend was end of life, he rang East Lancashire Hospice to ask if he could access support after his death, knowing he would probably need this. At the time of his death, he was given a pack by the hospital team and offered help, but he was not in the right place to access it at that point. 10 months later he received a call from the Hospice asking him if he wanted bereavement support but by then it was too late, he had managed to get through his grief by himself although it had been difficult, and he had organized a walk in memory of his friend which helped him process his loss.

Two members of the group had experienced a number of bereavements in a short space of time, which were difficult to deal with but were not offered any support at the time.

Another felt that there was a lack of signposting to support and no knowledge about criteria for support. He felt that people tend to only access support when they hit crisis point and saw help as a rare resource and thought that agencies must prioritise who they can support.

None of the group had accessed bereavement support.

What do you think were the barriers that prevented you from accessing it?

The main barrier for the group was lack of knowledge of what support is available for bereavement. Some also felt the culture and pressure to 'just carry on' was a barrier to accessing support, as well as lack of support from employers. One member of the group was allowed 1 day off work and then had to return following a bereavement whilst another felt that work 'offered the space but not the support' to deal with a bereavement. Members of the group felt that support should also be offered to partners of people dealing with grief because it can be hard for them to manage.

Do you think the current bereavement support provision in the borough is sufficient?

None of the group felt it was sufficient.

Would you want to access support in person or online or a mix of the two?

All of the group felt that they would prefer support in person.

Would you prefer group or individual support or a mix of the two?

The group felt that a mix of the two would be most beneficial because grief is a very personal thing but also felt that it was important to share with people who are going through the same thing to know that you are not alone in your

experiences. They felt that support should be tailored to the individual and more flexible than a rigid number of sessions of support. One felt that after each session, a counsellor could check in with the individual as to how they feel they're coping and base the level of support on that.

Where would you want to access support?

Some felt a community setting would be best, but one member felt that the setting would not really matter to someone who is really struggling with grief, as long as they have access to talking counselling.

Would you have wanted to access pre-bereavement advice if it was relevant to you?

The group felt that this would be very beneficial. One felt that this can sometimes be harder than after the loss of a loved one. One member felt that advice on managing all the practical arrangements that are needed would be beneficial.

None of the group had accessed this advice.

Is it important that the support provided is culturally sensitive for families in the borough and available in different languages?

All of the group felt that this was important, and support tailored to the needs of different communities.

Do you think bereavement cafes are something that residents of BwD would like to attend?

The group felt that these would be good especially if they could be a drop-in.

Do you feel that the cafes should just provide peer support or a mix of peer support and advice from professionals?

All of the group felt that it was important that the cafes should be a mix and having support from a professional whose advice they trusted.

Darwen Youth Zone focus group

We spoke with the group of seven young people about support generally for young people in the borough for bereavement. All of the group felt that support was very limited for young people and that whilst there is support in schools for mental health, that did not extend to cover bereavement. When asked whether they would prefer support to be available in school or in a youth centre setting, all of the group felt that school would be most appropriate because “you want to be able to relax” in a youth centre setting. However, there were a mix of responses as to who should provide that support e.g. safeguarding staff members, pastoral staff or mental health in schools teams. There was a consensus however that the support should be provided “by someone we trust and can talk to, and it should be tailored to the young person’s needs”.

All of the group felt that group support would be beneficial in school and that this did not happen enough, particularly when there had been a loss of a student. They felt that group support would work either as a year group offer because they tended to liaise most often with their own year group or as more targeted support as a ‘peer support’ network for friendship groups which teachers identify amongst their students.

Suggestions from the group were that this could be offered in PSHE lessons alongside wider awareness raising about bereavement. One boy suggested that once a month their assembly could be a dedicated “Wellbeing Assembly” aimed at supporting young people’s overall emotional wellbeing including support for bereavement. All of the group felt that creative therapy, including different types of arts, would be a useful approach to supporting young people who are experiencing bereavement, giving them an alternative means of expressing their emotions.