

# Dying Well - Views and Experiences of Residents in Blackburn with Darwen



**healthwatch**  
Blackburn with Darwen

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## **Background to Our Engagement**

### **Dying Well Strategy Development**

Blackburn with Darwen Borough Council is developing a 'Dying Well Strategy' for the first time which will form part of the borough's overall Health and Wellbeing Strategy 2023-2028. The reason for the development of this strategy is laid out in a policy document as described below.

"It is our aim for the adults, children and young people of Blackburn with Darwen to live well, before dying with peace and dignity in the place where they would like to die supported by the people important to them.

Poor end of life care and planning hugely impacts families and friends who suffer and find not knowing end of life arrangements stressful, hard work and difficult emotionally, as well as health and care partners, local authorities and local community organisations who may end up dealing with a person's matters that they sadly know little about.

"We also recognise that the loss of loved ones, whether anticipated or sudden, can have a significant and long-lasting impact of individuals, families and communities. We aim for those affected to be able access to excellent bereavement support.

"More people die in hospital than in any other place and this is higher than the England average. There are significantly less people dying in care homes compared to the North-West and England average. Fewer people are identified as being at end of life in primary care than in Lancashire and South Cumbria and in England as a whole."

### **'Getting to Outstanding' for Palliative and End of Life Care**

In addition to the development of this strategy, Blackburn with Darwen Place Based Partnership is working with Marie Curie to undertake a review of palliative and end of life care services and support in the borough, in order to understand how we are delivering against the National Ambitions for End of Life Care and the National Quality Improvement Programme of 'Getting to Outstanding'. In Blackburn with Darwen we want to take a whole partnership approach to defining an outstanding Palliative and End of Life Care Patient journey from the point of identification, through to death and bereavement.

### **Healthwatch Blackburn with Darwen's Engagement**

Listening to people's views and experiences of support for individuals and families/carers is key to developing an approach to end of life care that meets the needs of our residents. Healthwatch Blackburn with Darwen carried out engagement with groups to gather this feedback and share this with Blackburn with Darwen Council's Health and Wellbeing Board and Place Based Partnership. The findings from this engagement are captured within this report.



## Methodology

Healthwatch Blackburn with Darwen carried out six focus groups across the borough in Summer and Autumn 2023 with residents from a range of ages and ethnic backgrounds. The focus groups were framed around four key areas of:-

- The Individual's Needs and Wishes
- Family and Carers' Needs and Wishes
- Involvement of Health and Care Professionals at the end of life
- Talking about Dying within our Community

We engaged with 43 residents through our work and the focus groups we carried out were with:-

BwD Carers' Service Asian Carers Group - 6 members, all British Asian background  
Ash Grove Food Club in Darwen - 5 members, all White British Background  
Kiran Ladies Group in Bastwell - 6 members, all British Asian background  
Little Harwood Ladies Group - 9 members, all British Asian background  
Newground Hub group in Shadsworth - 5 members, all White British background  
Strategic Youth Alliance Youth Forum - 12 members, 9 British Asian background and 3 White British background

Healthwatch Blackburn with Darwen would like to thank all the members of the group for their time and being so open about their views and experiences of a sensitive topic.



## Executive Summary and Recommendations

The findings from our focus groups are included within the body of this report. However, please find below recommendations for organisations within the borough.

### Importance of flexible advanced care planning

There was a lack of awareness amongst people we spoke with about advanced care plans to help ensure that people have choice and control over what happens to them and improve the quality of end of life care they receive. These should be made available on websites of health and social care professionals and voluntary sector support agencies. Residents also felt that professionals should respect individuals' decisions to change these plans and be flexible in the support they provide at end of life.

East Lancashire Hospice delivers education sessions for employees of the local authority, primary and secondary care, care agencies, education settings and voluntary sector on advanced care planning. Increased awareness and uptake of this training would help increase the number of organisations across the borough who can support individuals to do this.

### Respect for individuals' wishes

A key message from residents we spoke with was for professionals to respect individuals' wishes. This was very important for Muslim residents we spoke with - hospital staff should limit touching the body and respect families' refusal of a post mortem.

### Funeral planning

Greater support for individuals and families to plan financially for end of life would be beneficial including joint promotion between the voluntary sector and local law firms of free wills month.

### Bereavement Support

The need for better awareness and wider provision of bereavement support in the borough was a key theme from discussions in our focus groups. It was clear that people felt that this provision should be person-centred because people's experiences of grief at the loss of a loved one can be very different. A need for 'anticipatory' bereavement support was also highlighted through our discussions.

In addition to our engagement through focus groups, we spoke with the Head of Community Supportive Care at East Lancashire Hospice. The Hospice are carrying out engagement in communities to increase awareness of their services currently, including their bereavement support. This is available to anyone over the age of 16 who is grieving, irrespective of time, cause or relationship, and is registered with a GP in Blackburn, Darwen, Hyndburn or the Ribble Valley. There is no requirement to have had previous contact with hospice services.

Increased promotion of this support across both the statutory and voluntary sector would help increase awareness of bereavement support in the borough amongst residents. However, there is a waiting list for this support, therefore additional funding to extend this provision, for which there is a clear need, would be important to extend their offer.

Although the Hospice only provides support to residents aged 16 and over, we would recommend that they visit youth groups across the borough so that young people are aware of what support is available for their family and carers. An alternative youth offer would be beneficial for young people and should be explored by BwD Public Health.

Promotion of Cruse website by the Wellbeing Service, health and social care professionals as well as the voluntary sector would also help meet the gap in need for bereavement support.

Tailored additional support for carers after a bereavement was felt to be important and we would recommend that BwD Carers Service 'Life After Caring' course is promoted widely to residents and potential joint working between Carers Service and the Hospice be explored.

### **Education for Young People on Death and Coping with Bereavement**

We would recommend that education on bereavement is included within PSHE lessons both in primary and secondary schools to help young people talk about it freely, something they are not always able to do with family and carers. Support should be available from any trusted professional they feel most comfortable to talk with. Wellbeing Champions in schools could also offer peer to peer support.

Young people recommended that a website like Kooth would be beneficial to support them through a bereavement and give them to talk anonymously with young people who have experienced the same loss or to a counsellor. We would recommend that this is explored by BwD Public Health.

Young people also wanted suicide awareness training in schools to help raise awareness and help them deal with the loss of a loved one through suicide. We would recommend that Papyrus provide training for young people across all secondary schools in the borough. We would also recommend that schools take a whole school approach to supporting their students when the school experiences loss of a student to suicide.

### **Role of GP and health professionals in starting the conversation early about end of life**

Individuals and families felt that it would be best if the GP could initiate a conversation about end of life with both the individual and family/carers and then involved wider health and social care professionals in the support required in the last twelve months of life. The wider involvement of professionals should also include organisations such as the Hospice and voluntary sector organisations such as BwD Carers Service.

Equally the role of the faith sector in offering holistic support for individuals and families and carers should be taken into close consideration in this preparation for end of life.

Training for health professionals both in primary and secondary care to have these difficult conversations would help improve the quality of preparation for end of life and help everyone plan palliative care in a way that is person centred and not rushed.



## Findings

### Meeting The Individual's Needs and Wishes

#### Respect for the Individual's Wishes

People we spoke with felt that the individual's needs and wishes should be respected by both family members and health and care professionals. Some stated that engaging family members in discussions about death can be difficult because 'they don't want to talk about it' but felt that talking about making a will early and planning for death is important.



"I want my body to go to medical science. I've discussed it with all my children - I know not all of them agree with me but they've accepted to respect my wishes."

Equally important was respect by medical professionals at the end of life, "they need to listen and not do what they think is best." This was very important for Muslim residents we spoke with.

"The less the body is touched the better. A post mortem should not happen if it can be avoided - family will often not give permission for it."

#### Advanced Care Planning

One lady shared her concerns about having her needs met as a single person at the end of life.

"Information sharing is so important...My worry is who should hold that?...I'm a single person so who will know what I want - who can advocate for me when I can't?"

There was a lack of awareness amongst people we spoke with about advanced care plans which are accessible online to help ensure that people have choice and control over what happens to them and improve the quality of end of life care they receive.

Some people we spoke with had already planned their funeral arrangements because they felt that it would take the pressure off their children when the time comes. Planning is important to help ensure that funerals are a celebration of a person's life and a positive event.

"I'd want my funeral to be fun and I would like people to say goodbye and celebrate my life."

Members of the Little Harwood ladies' group stated that "In Islam you have to make a will so it's just accepted that this will be in place early on." However, when we spoke with members of the SYA forum and their youth workers, some felt that although this is expected according to their religion, this was not always the case in practice. They also stated that some people have two wills in place - one is a religious will and the other is 'for the state'.

For Muslim residents, having family present at the end of life was extremely important as well as a spiritual representative, in whatever setting the individual is in.



## Meeting Family and Carers' Needs and Wishes

### Bereavement Support

The need for better awareness and wider provision of bereavement support in the borough was a key theme from discussions in our focus groups. It was clear that people felt that this provision should be person-centred because people's experiences of grief at the loss of a loved one can be very different.

“Unexpected deaths can really take it out of you. It's draining emotionally. Support to get through it would help.”

“When my mum died, I went through several stages of emotions - anger, resentment and then upset. I had a series of sessions with a counsellor and that really helped me. Emotional support for families and carers is so important.”

Professionals should recognise that everyone is different and need different levels of support and at different times - bereavement support should be available at any point after death. A number of people we spoke to had lost family members during the Covid-19 pandemic and were not able to attend their funeral, missing out on a key part of the grieving process.

“Not being able to say goodbye to my parents who died in the pandemic was really hard. Funerals give that opportunity to grieve but also to celebrate their lives.”

People also felt that 'anticipatory bereavement support' should be provided within the borough to help them deal with coming to terms with losing a loved one.

“It would be helpful if professionals helped you prepare for death. My mum died when I was 19 and I had younger siblings - we just had to deal with it, no one asked us about counselling.”

“I'm really struggling with the thought of losing my mother. I see her every day and I can't bear the thought of losing her or having to tell my son when it happens.”

Young people we spoke to had very little knowledge of bereavement support that is available to them or what services exist in the borough. They felt that bereavement services should attend youth groups so that they are aware of what support is available, particularly for young carers to help them have the skills and knowledge to deal with the loss of a family member.

Members of the group also felt that a resource similar to Kooth (mental health online support) would be beneficial for young people to access for bereavement support where you can be anonymous and ask questions of trained bereavement counsellors or take part in group chats with people who have gone through similar situations.





## Importance of Planning

Planning for death was felt to be important to people to be able to take the pressure off family and carers at an already difficult time.

For many, it was important for family to be present at the death of a loved one in whatever setting.

“Families need to be able to focus on celebrating their loved one’s life, not having to focus on the death - so we need to plan earlier to make things easier for everyone. Some people on here today just won’t talk about it but you have to.”



## Role of Family and the Wider Community

Family provide a great support network in supporting one another at the time of loss of a loved one. One member of our focus group in Darwen had moved up to Darwen a few years ago and commented on the difference she had noticed.

“It feels like families play a huge role in supporting each other locally - it’s not like that in other parts of the country. Maybe it’s because people don’t move away as much but there’s more of a support network.”

Young people felt that they were not included in family discussions around family members dying.

“I’ve just been told “you’ve got to go and say your goodbyes” and nothing more is said about it. We need to be able to talk about it more.”

For the majority of Muslim members of our focus groups, they felt that there was not as great a need for bereavement support because of the huge community support around the family.

“Friends and family have to bring food for 4 days after the death which allows the family the time to focus on themselves. That said, it can mean that you don’t have time to grieve properly because there are too many people around...You just need that space.”

A member of the Youth Forum noted the importance of community groups in supporting families.

“There’s a group called Brookhouse Development group in Blackburn and they go and clean up the graveyard. I’m a member of the group. I think it helps people come to terms with the death of a loved one and they take pride in looking after the graves and making them look nice.”

## Tailored Support for Carers

People felt that there should be dedicated support for carers after bereavement to help them navigate their life after being a carer.

“As a carer you are not just grieving the person, you are grieving the time given to them. Suddenly you are left with a huge gap in your life.”



## Involvement of Professionals

### Person Centred Planning

Residents felt that it was important for professionals to discuss what is right for the individual at the end of life as early as possible and equally important for there to be flexibility allowed in these plans as their needs/desires change.

“It would be good if professionals could start the conversation about dying earlier - particularly when having to deal with palliative care. My dad had palliative care and I just felt like everything was a rush, I had no time at all to think about myself, my family and my emotions about it all.”

“Flexibility in plans at the end of life is really important. I might not want a DNAR but closer to the end I might feel that would be better rather than experiencing a lot of pain.”

People wanted professionals to listen actively to them and respect their wishes. For Muslim members of the community we spoke with, it was very important that the doctor should not do anything with the body.

“It feels like you are fighting the system about where you want to die or a loved one wants to die. It felt like I had to fight my father’s GP to listen to me about my father dying at home.”

“My mum had a massive stroke and clinicians still gave her active treatment despite her being in pain and she refused a feeding tube. It felt like there was no discussion about what was right for her at the end of her life.”

However, there was recognition that it is not always easy to identify people at the end of life and there are unexpected deaths which may not be picked up early by professionals.

### Role of GP in initiating conversations and wider professional support



Residents wanted this initial conversation to take place with their GP with either the individual or family members taking the lead, whichever feels right for the individual and for the conversation to take place with someone they trust. Young people stated,

“They should be trained to have difficult conversations with people and to signpost them to support that is available because none of us know what bereavement support services exist in the borough.”

Members of the groups felt that early conversations would help planning but also help the focus at the end of life be on quality time with their loved one.

“It would help family members to start focusing on their loved one and stop being ‘busy’ with their everyday life and build in time for them in the last months of life”.

They also felt that wider involvement of professionals was important, both within health, social care and voluntary sector.

“I think that although the GP might initiate conversations about end of life, they should not have to take it all on. It would be good if they linked up with social prescribers to make sure that the individual is able to have the social networks they want in the last year of life and also that family and carers can be linked to organisations such as the Hospice or Carers Service so that they are getting the help they need.”

“Dementia is such a horrid journey for both the individual and the family - you need extra support to get through that.”

People we spoke with felt that support around financial planning, advice on care homes and wider advanced care would be helpful to families.

### Importance of the faith sector

The role of faith leaders in supporting individuals and family/carers at the end of life should not be underestimated and in ongoing bereavement support.

“The bereavement service in church just before Advent was a beautiful time to reflect. The church is also planning something similar this year on All Souls Day.”

“A spiritual person should be there to accept their final prayer of faith in Allah.”



## Talking about Dying

### Creating Space to talk about Dying

The majority of residents we spoke with, acknowledged that we do not talk about death enough as a society, with a sense that because we are living longer people want to put off any thoughts of dealing with bereavement.

“Now we’ve become so sanitized and we’re living longer, though not necessarily better, so no one wants to talk about it.”

“It doesn’t seem to be part of British culture to be able to have the time and space to grieve. We’re given 3 days then you have to switch back to normal life.”

People felt that talking about dying was similar to talking about mental health and emotional wellbeing, with many still not opening up about the issue.

“We’re scared of emotions - we need time to grieve and not just ‘keep busy’. It feels like we don’t want to deal with the inevitability of loss.”

We discussed the role of death cafes in our focus groups and some people could see the benefit in them because people often find it easier to talk to strangers or friends rather than family about their experiences of loss - potentially for fear of adding additional burden on family members at a difficult time.

“It’s been easier to talk about dying here than with my family.”

“Family members tend to shut down conversations about end of life because they don’t want to hear it and - children don’t want to consider losing their parents.”

Members of the group in Darwen felt that it would be beneficial for residents to have tours of crematoriums to help allay the fear of what happens there.



### Importance of reflecting on death within Islam

Muslim residents in our focus groups felt that because death is reflected on regularly within their spiritual books and in daily prayers, it is much more accepted within their community.

“Spiritual guidance is really important for us, particularly as you get older, say from 50 onwards. You start to prepare yourself for it.”

One youth worker at the youth forum also commented on the mosque’s role in supporting families both financially as well as spiritually at the time of loss of a loved one. Mosques have death committees to help families with the financial burden of funerals.

“Death is seen as a joint responsibility and everyone pays their respects.”

However, it was still felt that although death was more readily accepted, people still struggled to talk about it.

## Educating Children and Young People

Several members of the focus groups reflected on the role of pets in children's lives in helping them to learn about the cycle of life and how to deal with bereavement. One woman stated that there were good books for young children to learn and talk about death.

“My granddaughter is 5 and she's convinced family members are going to die. I've found some nice children's books which help talk about death and I think having pets help children be more aware of life and death.”

However, members of the SYA forum felt that more should be done with older children and young people. The overriding feedback from the group was that schools should talk more about it with students - including death and bereavement as part of PSHE lessons and ensuring that they can have support from an adult they trust.

“Teachers should be told if a young person has lost a friend or family member so that they can be sympathetic to their situation and help them get back on track. We would want to talk to someone we know and trust about bereavement - that could be a teacher, youth worker or maybe a school counsellor or the mental health in schools team.”

They also felt that suicide awareness training should be offered in secondary schools. They commented on the impact on the whole school when a young person dies by suicide. One school put extra support in for students in that year group but a whole school approach would be beneficial.

Members of the group also suggested that Wellbeing Champions (students) could also have training around death and bereavement so that can offer peer to peer support and help signpost young people to agencies or staff who could offer further support.



## Appendices - Focus Groups

5 members from Shadsworth Newground Hub (29/6/23) All White British



### The Individual's Needs and Wishes

"I want my body to go to medical science. I've discussed it with all my children - I know not all of them agree with me but they've accepted to respect my wishes."

"I'd want my funeral to be fun and I would like people to say goodbye and celebrate my life."

"When I had a heart attack, my wife and I decided then to start putting money aside to pay for our funerals so that our children don't have that pressure."

"My dad knew exactly what he wanted and that made things so much easier for me and my brother. I'd want to tell my children the same. Planning is so important."

### Family/carers' Needs and Wishes

"Covid was horrible and denied so many people of the opportunity to say goodbye or to mourn properly."

"When my mum died, I went through several stages of emotions - anger, resentment and then upset. I had a series of sessions with a counsellor and that really helped me. Emotional support for families and carers is so important."

"Families need to be able to focus on celebrating their loved one's life, not having to focus on the death - so we need to plan earlier to make things easier for everyone. Some people on here today just won't talk about it but you have to."

### Involvement of Professionals

"I think that although the GP might initiate conversations about end of life, they should not have to take it all on. It would be good if they linked up with social prescribers to make sure that the individual is able to have the social networks they want in the last year of life and also that family and carers can be linked to organisations such as the Hospice or Carers Service so that they are getting the help they need."

“Dementia is such a horrid journey for both the individual and the family - you need extra support to get through that.”

### **Talking about Dying**

“My gran aged 9 helped her mum lie people out. People were used to talking about and seeing death then. Now we’ve become so sanitized and we’re living longer, though not necessarily better, so no one wants to talk about it.”

“Having pets has helped talk about death with children and helping them realise about life cycles. It also helps introduce them gently to the mourning process.”

## 5 members from Ash Grove Food Club, Darwen (12/7/23) All White British



### The Individual's Needs and Wishes

"It's so important to make sure the individual's wishes are respected by professionals at the end of life. They need to listen and not do what they think is best."

"Information sharing is so important to make sure an individual's needs are met. My worry is who should hold that? I don't want anyone medicating my emotions at the end of life. I'm a single person so who will know what I want - who can advocate for me when I can't?"

"We need to be able to talk about needs and wishes earlier. Especially where someone might have the onset of dementia."

"It's hard to think about writing a will but people should do it sooner rather than later."

"I've written my will and I've planned my funeral including the poems and songs I want. My family all know."

### Family/carers' Needs and Wishes

"Access to emotional support before a loved one dies and after is really important. There should be 'anticipatory death support' - I'm really struggling with the thought of losing my mother. I see her every day and I can't bear the thought of losing her or having to tell my son when it happens."

"Counselling is really important for families - people have a fear of losing someone and need support to deal with grief and the process of dying."

"Getting a loved one to a GP to start the conversation about end of life can be a problem if they are in denial."

"As a carer you are not just grieving the person, you are grieving the time given to them. Suddenly you are left with a huge gap in your life."

"It definitely helps family members if the individual starts to prepare for end of life themselves. It just takes some of the pressure off at a difficult time."

"Not being able to say goodbye to my parents who died in the pandemic was really hard. Funerals give that opportunity to grieve but also to celebrate their lives."



“It feels like families play a huge role in supporting each other locally - it’s not like that in other parts of the country. Maybe it’s because people don’t move away as much but there’s more of a support network.”

### **Involvement of Professionals**

“Flexibility in plans at the end of life is really important. I might not want a DNAR but closer to the end I might feel that would be better rather than experiencing a lot of pain.”

“My mum had a massive stroke and clinicians still gave her active treatment despite her being in pain and she refused a feeding tube. It felt like there was no discussion about what was right for her at the end of her life.”

“It would help a lot if GPs or other health professionals could start a conversation with the individual and the family about them being close to the end of life so that everyone can have time to plan but we just don’t know how much time someone has really got. It’s not that easy.”

“It feels like you are fighting the system about where you want to die or a loved one wants to die. It felt like I had to fight my father’s GP to listen to me about my father dying at home.”

“Support for advanced care planning would really help. Finding a good care home and working through the financial burden is hard.”

“The bereavement service in church just before Advent was a beautiful time to reflect. The church is also planning something similar this year on All Souls Day.”

### **Talking about Dying**

“It needs to be a really sensitive conversation about dying.”

“We’re scared of emotions - we need time to grieve and not just ‘keep busy’. It feels like we don’t want to deal with the inevitability of loss.”

“It doesn’t seem to be part of British culture to be able to have the time and space to grieve. We’re given 3 days then you have to switch back to normal life.”

“The coffin used to be at home for a while in the past so there was a way to grieve and talk about death whereas now that doesn’t happen and we’ve become detached from the process of dying. People are living longer too so people don’t want to think about it.”

“It’s been easier to talk about dying here than with my family.”

“It would be helpful to have a tour of a crematorium - people really don’t know what happens in them.”

“My granddaughter is 5 and she’s convinced family members are going to die. I’ve found some nice children’s books which help talk about death and I think having pets help children be more aware of life and death.”

## 6 members from BwD Carers' Service Asian Carers Group (31/7/23) all British Asian



### The Individual's Needs and Wishes

“It’s really important to talk about what you want. I have told my daughters that I want a DNAR but they just refuse to listen to me, whereas I know that I really don’t want resuscitating - if it’s my time then it’s my time.”

“I’ve already sorted out money for my funeral and I know exactly what I want to happen. It just makes it easier for the family.”

“My family members don’t want to talk about it but I do - whenever I try to bring it up with my children they just keep shutting down the conversation.”

### Family/carers' Needs and Wishes

“It would be good if families and carers could have bereavement support - it’s a really hard time for everyone.”

“Unexpected deaths really take it out of you. It’s draining emotionally. Support to get through it would really help.”

### Involvement of Professionals

“It would be good if professionals could start the conversation about dying earlier - particularly when having to deal with palliative care. My dad had palliative care and I just felt like everything was a rush, I had no time at all to think about myself, my family and my emotions about it all.”

“It would be helpful if professionals helped you prepare for death. My mum died when I was 19 and I had younger siblings - we just had to deal with it, no one asked us about counselling.”

### Talking about Dying

“We just don’t talk about it enough - one lady has just left the room because she doesn’t want to even think about it but we need to be able to. It’s completely natural and happens to all of us.”

“It’s as if we’re closed off from death nowadays, because people are living longer

## **Kiran Group - 6 members from the Bastwell area (5/9/23) all British Asian**



### **The Individual's Needs and Wishes**

It is important for family members to respect the wishes of the individual but more so for healthcare professionals to do so. A spiritual representative should be there at the end of life in whatever setting the individual is in.

The less the body is touched the better. We have heard a lot from people about catheters and other pipes being left in the body - these need to be removed before the body is laid to be washed and shroud placed on it. A post mortem should not happen if it can be avoided - family will often not give permission for it.

### **Family members' needs and wishes**

Family should be with the individual at the time of death. We don't feel there is as much need for bereavement support because we have our family and the wider community who support us through the grieving process. Community is very important to us - it might be different if a person does not have many connections with family though.

### **Involvement of professionals**

The doctor should not do anything with the body. I think it's up to individuals as to whether they want to know if they are in the last 12 months of life. It might be better to talk to family instead.

### **Talking about death**

Death is much more accepted within our community because in Islam we have spiritual books which talk about death and we include it in our prayers. Spiritual guidance is really important for us, particularly as you get older, say from 50 onwards. You start to prepare yourself for it.

**Little Harwood Ladies Group - 9 members from Little Harwood (18/9/23) all British Asian**



**The Individual's Needs and Wishes**

In Islam you have to make a will so it's just accepted that this will be in place early on. We always ask for forgiveness in our prayers too so at the end of life, you are at peace. It's important that family are there for the individual at the end of life or if they aren't a spiritual person should be there to accept their final prayer of faith in Allah.

**Family members' needs and wishes**

There is a lot of family and friends around at the point of losing a loved one. Community plays a big part so you don't have the same need for bereavement support as in other cultures. Friends and family have to bring food for 4 days after the death which allows the family the time to focus on themselves. That said, it does mean that you don't have time to grieve properly because there are too many people around...You just need that space.

**Involvement of professionals**

It would be good if professionals could start the conversation early about end of life. It would help family members to start focusing on their loved one and stop being 'busy' with their everyday life and build in time for them in the last months of life. Some people might not want to hear the news though or might deteriorate because they know they are at end of life. It might be better if health professionals talked to family members first.

**Talking about death**

In Islam you should remember death in your prayers 5 times a day so it is in our minds a lot. However it doesn't mean we're good at talking about it! It's easier to talk with friends about it than with family. Family members tend to shut down conversations about end of life because they don't want to hear it and - children don't want to consider losing their parents.

**SYA Youth Forum 12 young people (9 British Asian and 3 White British) (31/10/23)**



**The Individual's Needs and Wishes**

The person's wishes should be respected. You would want people to die at home surrounded by family if possible but we know that this can't always be the case.

We should celebrate people's lives - other countries make funerals more of a celebration, we should do that here too.

Parents don't talk about death with us or even preparing for it. None of us know if our parents have a will. In Islam you are meant to have a will and some people have two - one for the state and one for religious purposes. But practically I'm not sure how many people actually make one.

**Family/carers' wishes**

I think family and friends would be enough of a support network for me if I lost a family member but it might be different for other people. You could probably talk to friends about things more than family members if they are grieving too.

Bereavement services should attend youth groups so that they are aware of what support is available, particularly for young carers to help them have the skills and knowledge to deal with the loss of a family member.

There should be something similar to Kooth for young people to access for bereavement support where you can be anonymous and ask questions of trained bereavement counsellors or take part in group chats with people who have gone through similar situations.

Young people aren't included in family discussions around family members dying. I've just been told "you've got to go and say your goodbyes" and nothing more is said about it. We need to be able to talk about it more.

There's a group called Brookhouse Development group in Blackburn and they go and clean up the graveyard. I'm a member of the group. I think it helps people come to terms with the death of a loved one and they take pride in looking after the graves and making them look nice.

### **Involvement of Health and Care Professionals**

If health professionals know that someone is in their last 12 months of life then they should have the conversation with the individual so that they can prepare for end of life and think about what they want to achieve in that time. They should speak with the individual first and then it's up to them whether they speak with family members and involve health or care professionals in the conversation with family.

You would want to have the conversation with someone you know and trust. Often you don't see the same GP all the time - you would want it to be your family GP who knows you.

They should be trained to have difficult conversations with people and to signpost them to support that is available because none of us know what bereavement support services exist in the borough.

They should always check people's records before appointments - notes are often ignored and the right conversations might not take place because of this.

### **Talking About Dying**

Different cultures and religions treat death differently and it is talked about more in some communities. Mosques have a death committee so if a family can't afford a funeral, they will help them out. Death is seen as a joint responsibility and everyone pays their respects.

We have heard of death cafes in other places in the country and they might help people if they know that they can go and talk about their experiences of grieving with people who are going through the same thing. It can be quite isolating for people, especially if family members are dealing with their own emotions.

Schools should talk more about death and bereavement, it could be included within the PSHE curriculum. Teachers should be told if a young person has lost a friend or family member so that they can be sympathetic to their situation and help them get back on track. We would want to talk to someone we know and trust about bereavement - that could be a teacher, youth worker or maybe a school counsellor or the mental health in schools team.

There should be suicide awareness training in schools. This has a massive impact on students in schools where a young person has died by suicide. One girl in year 10 in my school died by suicide and the school put in extra support for students in her year. It would be good if support could be put in place for the whole school though.

Wellbeing Champions in schools could have some training around death and bereavement so that they can be peer support and help signpost other young people to agencies or staff who can help.