

Engaging with local people across Waltham Forest and Redbridge on end of life care services

May – December 2023

Summary of findings

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1. Why are we engaging?

End of life care in Waltham Forest and Redbridge is undergoing transformation to ensure that people across the boroughs have equal access to high quality care and services when they need them – at home, in community settings and in hospital. This programme is linked to the redevelopment of Whipps Cross Hospital.

This document follows on from a previous report '[Engagement with people with life-limiting conditions, carers and public in Waltham Forest and Redbridge](#)' written in 2022 which sought to highlight the features and characteristics of good end of life care services to contribute to the programme to improve end of life care services across Waltham Forest and Redbridge.

The previous piece of work highlights some key areas which it is essential to be addressed within the transformation of end of life care services within Waltham Forest. These are:

- Provision of palliative care is often at a high standard, but some felt there is not always consistency when sudden or urgent services are required. Support from GPs, particularly around diagnosis, and care agencies needs to improve and be better coordinated.
- Support for people who are affected and their loved ones is often not personalised to them or their needs and many people do not have a care plan in place.
- Information and advice aren't always in a form that people can access, use or understand – and doesn't always include broader support that may be available.
- It is important to get compassionate conversations right at every stage, particularly when it comes to prognosis, and for health and care professionals to be approachable, listen to their patients and take their experience on board.
- Providing emotional and mental health support is essential for both people with life-limiting conditions and their loved ones, throughout and including bereavement.
- There is more work to do to ensure a better experience for those who do not have English as a first language, or are excluded in other ways.

This previous engagement report was used to develop [a paper](#) which outlined early options for delivery of services moving forward.

The following report provides insight following more in-depth engagement with local people in Waltham Forest and Redbridge regarding end of life care and bereavement services, aiming to provide more comprehensive insight from local people with experience of using end of life services, either themselves or as a carer, to support the development of more refined proposals for transformation of end of life care services.

2. Our approach to engagement

This engagement with local people aimed to build on insight gathered previously, therefore a range of different methods of engagement were undertaken to ensure experiences of those individuals involved were wide-ranging and represented our diverse populations across Waltham Forest and Redbridge.

2.1 Development of a community working group

A key area of work within this phase of engagement was the initiation of a community working group for the project – aiming to take a participatory approach to co-designing services, with local people working alongside clinicians to shape services.

Group members were recruited via an open expression of interest which was promoted locally in each borough with support from local authorities, hospital trusts and local voluntary and community sector organisations.

Group members offer a representative split of both Waltham Forest and Redbridge residents, represent a diverse range of ethnicities and faiths, and all have some experiences of end of life care services, mostly in caring capacities either currently or in the recent past.

The community working group met regularly between June 2023 and January 2024 to discuss areas of the work to transform end of life care services; focussing on topics such as:

- The essentials which need to be offered within a future community palliative care service
- The role of GPs and primary care within end of life care services
- Support needed for carers of people who are at end of life
- Requirements of a future bereavement service for local people
- The role of end of life care services away from a patient's home, including hospices, acute wards and nursing homes

Each session involved discussions between group members who were able to share their experiences around the topic, and have discussions with clinicians and staff members to start to co-design what future services which work for local people could look like.

All insight from the community working group has been fed into the programme team and Clinical Reference Group in order to ensure all conversations have the voice of people with experience of using services at their core. All themes that form part of the issues and opportunities section of this report have emerged following discussions by the community working group members.

The community working group for end of life care has been recognised as an essential element of the end of life care transformation programme and the group will continue to meet in future months as options for future service delivery are developed.

2.2 Public surveys

In order to hear a broad range of voices on specific areas of the transformation programme, two public surveys were launched. These surveys focussed on gathering insight on support for carers, and bereavement support services. The two surveys were publicised widely

across Waltham Forest and Redbridge via the local authorities, partner organisations and voluntary and community sector organisations. The surveys were designed to gather both qualitative and quantitative insight from local people who may not have the time to be a part of more long-term engagement activity such as the community working group.

Summary of findings from both surveys can be found in appendix 2 (survey for carers of somebody with a life-limiting condition) and appendix 3 (survey for people who have been bereaved). This work focussing on support for carers and bereavement services will be continued moving forwards as programmes are developed.

2.3 Patient and carer interviews

In order to continue providing opportunities for people with experience of using end of life care services to share their insight, a number of one to one interviews were carried out by an independent consultant. Participants for these interviews were identified by community palliative care services across Waltham Forest and Redbridge.

Two examples have been included within this report below to provide examples of the impacts that issues within the end of life care system currently are having on local people.

Sharan's story

"I find it very inconsistent"

Sharan was diagnosed with Pulmonary Fibrosis, a severe lung disease, twenty-five years ago. Over the past two years her breathing has significantly deteriorated, with it becoming especially difficult to deal with in the last six months.

Sharan is being supported by the local district nursing and palliative care teams, and she wishes to stay at home as long as possible.

Sharan explained that there are particular nurses who have been very helpful and caring, and that she has had good support with some of the practical aspects of her care such as organising a hospital bed and mattress. Additionally, she has been offered some forms of therapy, such as reflexology, which she has enjoyed. However, overall, she feels as though she hasn't received very much 'specialist care' and that the support she has had has been very inconsistent.

She noted that at the start of her care she saw staff from both the district nursing and palliative care teams fairly regularly. However, she now rarely sees anyone in person and only receives a call from the palliative care team every few weeks. She thought she might see, and speak with, the same nurse each contact so she could build a relationship but in the five months that she has been supported by the service she has seen three to four different nurses. Whilst she does recognise that services are short staffed; this absence of continuous care has been upsetting.

Sharan described one particular day when she was feeling especially low and was struggling to get her head around her condition and manage her fears about what her life will look like as her health deteriorates. She explained that on that day a nurse just happened to call and told Sharan she would visit her so they could talk. Sharan prepared her questions and then on the day of the appointment she received a phone call informing her that the nurse wouldn't be able to visit as she was unwell. There was no offer to send another nurse or to

rearrange the appointment. She heard no more about this and the conversation never took place.

“It’s just different to how I thought it would be. You know, I thought that palliative; I would get more mental help than anything. Because it’s a hard thing to come to terms with, you know, that you’re going to leave this planet. It really is.”

After this cancelled appointment, Sharan says she has accepted that she will need to deal with the emotional side of dying by herself. Whilst she does have a son and husband, who are both supportive, she feels she isn’t able to talk with them about some things because they get too upset. She also explained that she would like to talk with someone about the different stages she is going to go through as her health deteriorates to ensure she knows what to expect.

During the conversation, Sharan also expressed strong views about a specific ‘treatment’ that a family member had received which she does not wish to happen to her. When her family member was dying, Sharan visited them in hospital and witnessed this treatment, finding it extremely upsetting; an image she has been unable to get out of her head. Sharan's fear of this specific treatment has added an extra layer of anxiety.

“I’m absolutely terrified because I think they will do the same to me. You know, when I get iller. Sometimes you get into hospital and your wishes go out the window, don’t they?”

She explained that she has told a palliative care nurse about this wish and that she saw the nurse writing this down. She assumes this information is in her ‘notes’, but is unclear exactly where this information has been recorded and if this has been shared with other services. This uncertainty has intensified her fear of her wishes being overlooked if she ends up in the hospital.

“That’s all I worry about. That’s my worst fear ever. If I got there (hospital) and there was nobody there that knew my wish. And they stick it on me. I couldn’t bear it”

Alexandra’s story

“I was reassured that we will have everything that is needed at home”

Alexandra’s husband was diagnosed with Bowel Cancer in 2020. After his diagnosis, he received treatment at UCLH but in 2022, he was told the cancer was incurable. At the beginning of June 2023, his health started to deteriorate and he was in significant pain which led to a two-week period of recurrent admissions to UCLH. He was discharged home and died three days later. He was 56 years old.

Alexandra described these last few days of his life.

On the day her husband was discharged from hospital Alexandra was advised to call the local palliative care team to ask them to visit as soon as possible to assess the situation. Because it was a Saturday evening, she decided to wait until the morning to make the call.

When she called the next day, no one responded, so she left a message. An hour later her husband’s condition began to deteriorate so she called again explaining in her message that it was urgent; again, there was no response. At 10pm, she realised her husband’s condition was continuing to worsen and she really needed help. Again, she called the team but continued to get no response.

She cared for her husband through the night and called the palliative care team again on Monday morning leaving a desperate message. Eventually, after an hour, someone called back and she was informed that they wouldn't be able to send a nurse that day. Alexandra describes having a "*desperate conversation*" with the person on the phone and an hour later a nurse arrived at their house. The nurse quickly realised that her husband was dying and told Alexandra that it was too late to move her husband to the Margaret Centre and that it would be best not to disturb him.

Alexandra knew her husband didn't have a strong preference about where he wanted to die; he just wanted to be in the place that was best for him and where he would get the best care. During one of his admissions to UCLH he had a conversation with the palliative care consultant and expressed that his biggest fear was that dying would be painful. Alexandra was reassured that if he stayed at home he would have everything he needed, so she agreed not to disturb him.

Alexandra described the nurse as being very organised and she quickly put a package of support in place. Within two hours their GP arrived, accompanied by two paramedics. The GP prescribed injectable medication, which included morphine; all to be given via a syringe driver. Shortly after, a district nurse arrived and arranged for carers to visit four times a day. By midday, everyone had left, and Alexandra felt reassured that the care at home just might work.

By 5pm, Alexandra had begun to get concerned that her husband would need pain medication overnight. As she hadn't heard from any of the services since the morning, she called the district nurses to ask when they would come to inject the morphine. They told her that they do not bring the medication and that she needed to contact her GP. Alexandra called their GP and, when she eventually got through on the phone, was informed that she needed to contact her local pharmacy to obtain it. However, when she called the local pharmacy she was told they did not have any of the injectable medications in stock, including the much-needed morphine.

Alexandra explained how, without this pain medication, she had sprayed liquid morphine into her husband's mouth in the hope that it would provide some relief. But, because it was a lower dosage, it was not as effective as the injectable morphine would have been.

During the night, her husband became increasingly agitated and the night sitter explained that he needed more pain relief. Alexandra phoned the Rapid Response service to ask if they could bring the injectable morphine or if there were any other local services that have it. Alexandra described being utterly shocked when the person answering the phone did not appear to have any awareness of her husband or his situation. They informed her that they couldn't provide the medication but that they would let the team know in the morning about her request. In desperation, she called St Joseph's Hospice to ask if they could supply the medication but was told that because she was 'out of area', they couldn't help.

As soon as the pharmacy opened at 9am, Alexandra phoned them to ask if they could have the injectable medication ready and that she would collect it as soon as the carers arrived and she was able to leave the house.

The district nurses then arrived with extra equipment but without the syringe driver, because they had run out. She was told that someone would need to collect one from Chingford later that day or the next. The carers arrived by 10.30am and Alexandra eventually was able to go to the pharmacy to collect the injectable morphine; the other injectable medications were still not available. The district nurse returned to administer the injection and left by 11am. Alexandra was once again. Her husband died at 12.30pm. He had been without effective pain medication for 20 hours.

*"I made 14 phone calls that morning by his bed trying to organise everything....
to see who was doing what...why did he have to go through this?
So senseless, so traumatic. It didn't have to be like this"*

3. Key issues and opportunities identified

The two stories identified above clearly show some key issues that are currently being experienced by local people who are receiving end of life care.

Insight from all engagement activity has been analysed and the following issues have been identified as common themes and important for the transformation of end of life care services across Waltham Forest and Redbridge to address.

3.1 Community palliative care offer is inconsistent depending on where people live

Insight across both patient interviews and from discussions with the community working group show that people living in Redbridge generally feel they receive better care in the community. Patients within Redbridge have access to a Hospice at Home service, which patients reported positive experience of.

Experiences within Waltham Forest were not so positive. As there is no access to care in the community 24/7 patients are not receiving the same level of care. Those with experience of community care in Waltham Forest additionally felt that different parts of the system did not work well together to provide care in a joined-up way. Again, this differed in Redbridge, where different organisations deliver the Hospice at Home model in partnership.

Experiences across both boroughs reported issues with accessing medication easily within the community, although there were some positive examples of this in Redbridge within the Hospice at Home service. Currently urgent medication is not easily accessible to everyone who needs it.

Opportunities identified through engagement with local people to address this issue are:

- Ensuring community palliative care support is available 24/7
- Having one point of contact to co-ordinate an individual's care
- Ensuring urgent medication is available and there are staff able to administer medication out of hours

3.2 Both community and inpatient services are too reactive in providing care currently

Feedback shows that care is currently not proactive enough for people's needs at end of life. Examples were provided where neither people, family or staff were aware of how to make a referral into an inpatient unit, such as a hospice or the Margaret Centre.

Experiences that people shared showed that there is an emphasis on a person in need of palliative care or their family needing to advocate on their own behalf in order to access services currently, rather than the system supporting them to provide the care they require proactively.

Opportunities identified through engagement with local people to address this issue are:

- Ensuring better communication between staff within different organisations providing care
- Putting in place a more efficient way of making referrals into inpatient care facilities e.g. hospices
- Carrying out thorough assessments for patients receiving care at home to ensure they have full access to all support in a timely manner

3.3 Advanced care planning and Universal Care Plans are being underutilised and patients and their carers are not aware of them or their role

Universal Care Plans are relatively new, replacing a previous programme called 'Co-ordinate my care' – Universal Care Plans play a key role in supporting people with life-limiting conditions, however there was little experience of Universal Care Plans within those involved in this piece of engagement work, showing their use needs to increase significantly.

Many people shared experiences of a person needing palliative care being transferred to a new part of the system to receive care, and staff not knowing their needs or wishes – which the increased use of Universal Care Plans would alleviate.

Opportunities identified through engagement with local people to address this issue are:

- Raising awareness of advanced care planning within staff and with people needing palliative care, their families and carers
- Ensuring end of life wishes are being discussed, recorded, and shared
- Enabling services to be proactive in reaching out to people in advance of care being needed urgently

3.4 People and their carers are struggling to know who to go for to get help / support / information which is causing them to 'fall through the gaps'

There is currently no 'one stop shop' for information relating to end of life care. People in Redbridge have access to a phone line, through their Hospice at Home service, however there is no equivalent for people in Waltham Forest.

Lack of information was highlighted as a major issue by community working group members, who shared experiences of having to spend time finding information themselves on behalf of the person they cared for, as there was no easy way to access this. There is concern for people in need of end of life support who do not have anybody who is able to find out this information for them.

Opportunities identified through engagement with local people to address this issue are:

- Providing the opportunity for information provided to people at diagnosis to refer to throughout their prognosis
- Putting in place a 'one stop shop' for information which is easily accessible to all
- Ensuring the identification of people who do not have a support system, and provision of additional support to help them navigate the system

- Integrating with non-clinical community support services – e.g. compassionate communities model

3.4 People feel that staff providing care are often not trained sufficiently in having compassionate conversations

A theme from all engagement activity was that a need for increased staff training is essential across the whole end of life care system. It is essential for all staff who are in contact with either people needing end of life care, or their families or carers, to have accurate and up to date information to provide, and to be able to speak to people, their families or carers in a compassionate way.

Opportunities identified through engagement with local people to address this issue are:

- Facilitating methods of sharing best practice amongst staff
- Putting in place a training programme which is available to all staff who may come into contact with somebody at end of life

3.5 People do not know what to do when somebody dies

Insight from our engagement with local people who previously cared for somebody with a life-limiting condition who has now passed away - through interviews, survey and our community working group - shows a clear gap in information provided to informal carers about what needs to be done when somebody dies.

Insight shows the additional stress this has on informal carers, with examples being provided of individual's having to find out this information themselves. Positive examples were provided of the role of funeral directors, and the guidance they provide to individuals who may know they are going to die.

There is particular additional information which needs to be considered for individuals who, due to faith, have specific requirements around death and burial – again positive examples were provided of support provided by faith organisations around this.

Opportunities identified through engagement with local people to address this issue are:

- Ensuring all family members are in touch with their loved one's single point of contact to liaise with in advance of a death and after a death
- Being proactive in ensuring families have the information at an appropriate time before the death
- Ensuring that good information is provided to people at diagnosis to refer to throughout their prognosis
- Creating and promoting a 'one stop shop' for information which is easily accessible to all

3.6 There is inadequate support / information for carers

Exploring the views of carers was a key part of the engagement work, with both a dedicated survey specifically for carers of somebody with a life-limiting condition and a dedicated community working group session focussed on support for carers.

The insight gathered portrays the key role informal family carers play in the lives of people with a life limiting condition, and the strain this can often put on carers.

The insight tells us that access to information about support for carers is not good enough. People told us that even if support services are in place they did not know how to access these, and knowing how to navigate around the end of life care system on behalf of the person they are caring for is difficult.

A recurring theme was that carers did not know whether there was any emotional or practical support available to them, or whether they would be eligible to receive this.

Opportunities identified through engagement with local people to address this issue are:

- Increasing the awareness of carers assessments for family of people with life-limiting conditions
- Providing respite opportunities
- Creating one place which holds accurate and up to date information relevant for carers is essential – this needs to cover information about providing care, as well as information on financial support and respite support
- Putting in place training opportunities for carers would be useful to enable them to understand the person's condition and what they can do to help
- Having a single point of contact to be able to go to would significantly reduce the impact on carers' lives
- Ensuring the same support offer is made no matter what type of care the person with a life-limiting condition receives (e.g. in the community, or in secondary care)
- Investing in support for carers in the community through voluntary sector organisations who can provide befriending or buddy schemes

3.7 There is no consistent offer for people who are bereaved currently

A theme across all engagement activity was an inconsistency in bereavement support across Waltham Forest and Redbridge. People told us they didn't feel listened to or emotionally supported during their bereavement.

Often people whose loved one died after receiving care in hospital, or an inpatient setting, received better support around bereavement – however, this was not the case for people whose loved one died at home, in the community.

The insight shows that people who have been especially impacted by bereavement need therapeutic bereavement counselling, at the point of bereavement and often later too.

Opportunities identified through engagement with local people to address this issue are:

- Developing a joined-up bereavement 'offer' across agencies/professionals – someone to follow up with people following death of a loved one and help them sensitively and at the right time/s around information and navigation
- Ensuring there is community support for bereavement with things such as grief cafes and short-term compassionate emotional support
- Ensuring support is equitable and personalised, considering diversity, and acknowledging that support cannot be a one-size fits all solution

4. Continued engagement

Engaging with local people will always remain an important element of the work to transform end of life care services in order to make sure that future services reflect the needs of local people.

We have committed to continue working alongside the Community Working Group which has been set up as part of this work, to continue discussing and testing any further planned approaches with them.

In addition, we are aware there is more work to be done to ensure that future services reflect the needs of our diverse communities across Waltham Forest and Redbridge, and will therefore be focussing on this moving forward. This will involve specific engagement work with unserved communities, such as our homeless populations, people with both physical and learning disabilities, our LGBTQ+ communities and with people who do not speak English as their first language.

This work will be ongoing throughout the course of the transformation programme and will ensure that our services put the experience of people using them and their loved ones at the centre.

Appendix 1

What do carers of somebody with a life-limiting condition most want and need?

Summary from survey - Autumn 2023

- Informal family carers play a vital role in supporting the care of somebody with a life-limiting condition
- Carers become an after-thought in providing care to somebody with a life-limiting condition and their role is often underappreciated
- Family members are required to learn how to 'navigate the system' on behalf of the person with a life-limiting condition they are caring for
- The impact of being a carer for somebody with a life-limiting condition is significant and often has a significant negative impact on somebody's life
- Support available for carers is not good enough
- If support is available, people do not know where to find information about the support or how to access the support

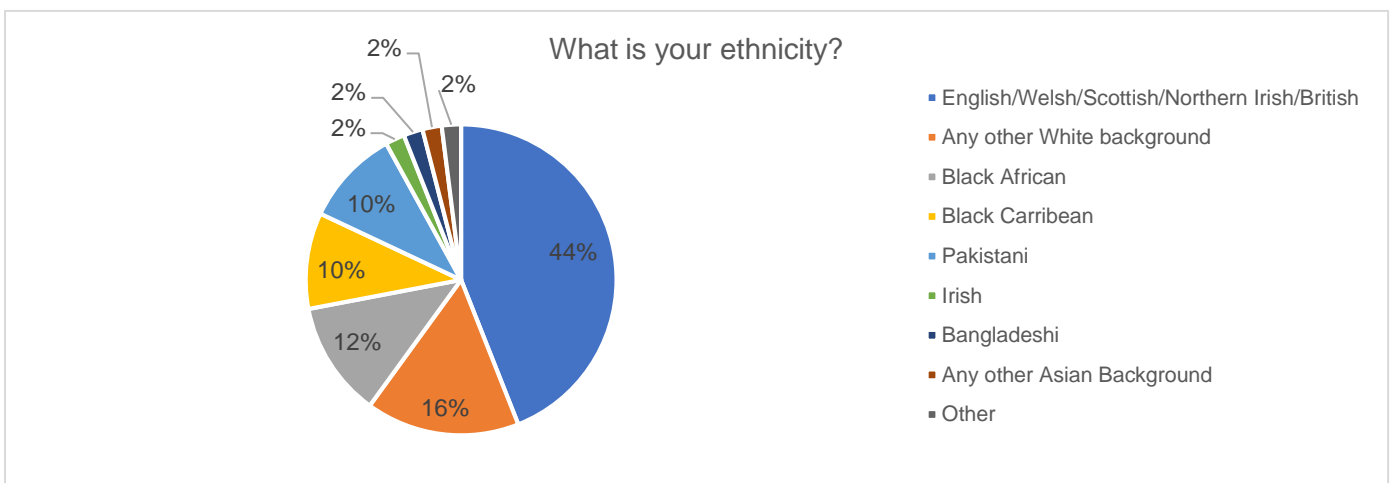
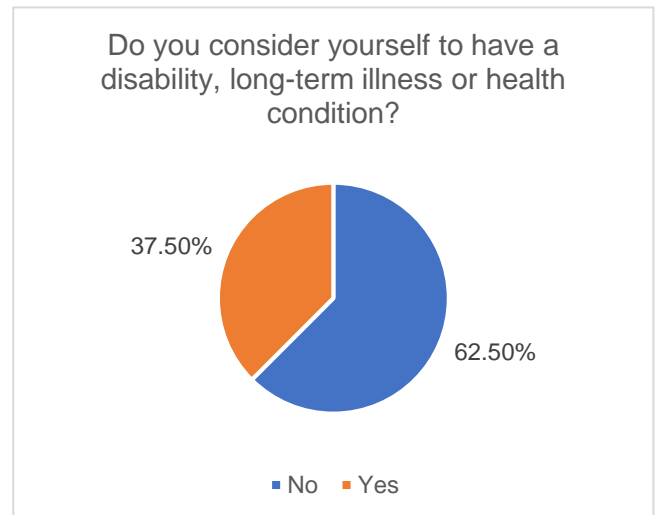
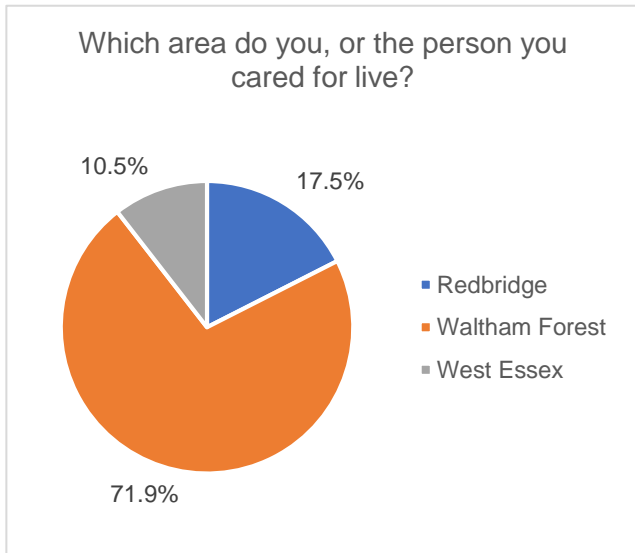
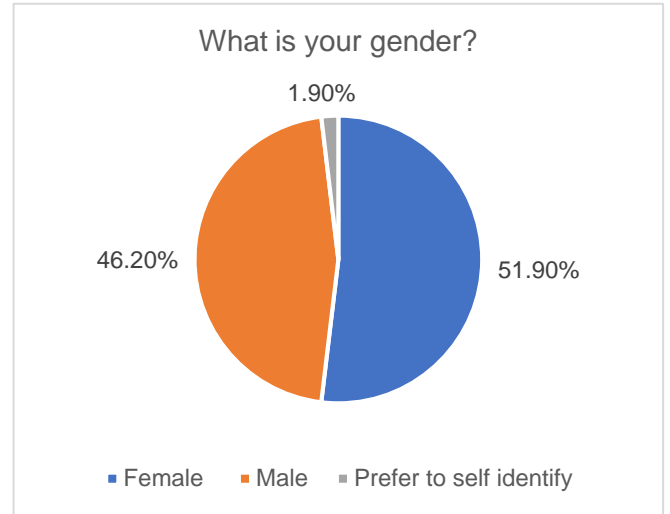
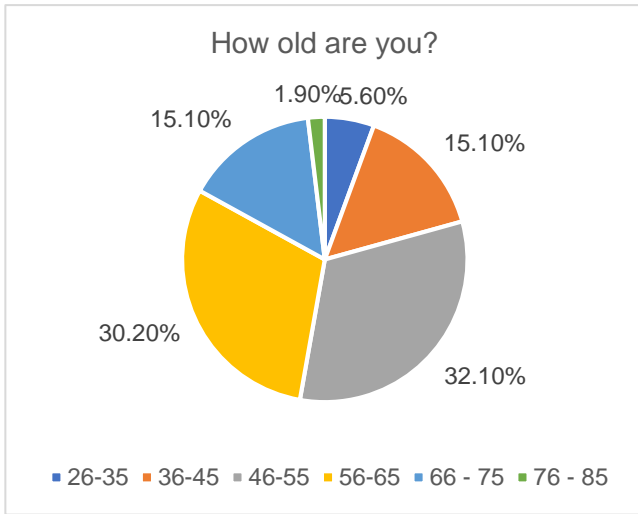
"It's a good job I work from home, I was having to be on the phone all day trying to follow up with various different teams to make sure that my father got the care I needed"

"I really just worry about what people do who don't have any family to look after them, it feels like I'm doing the job that people get paid to do... what about people who don't have anyone"

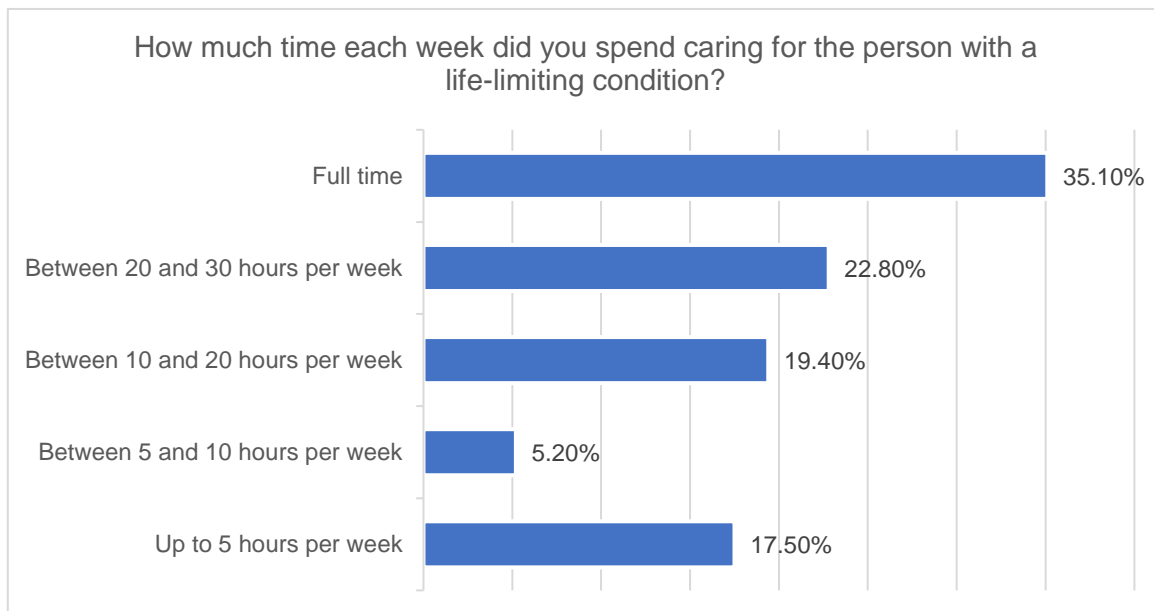
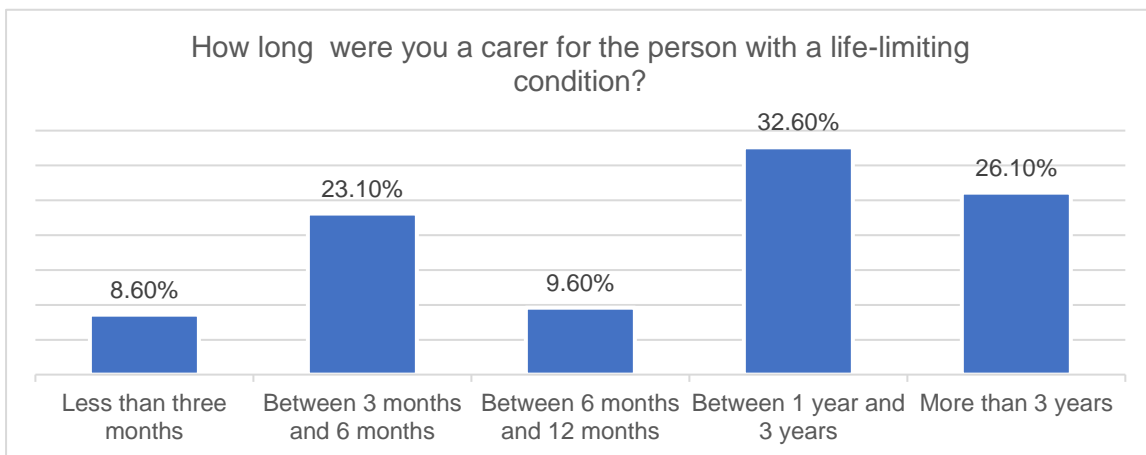
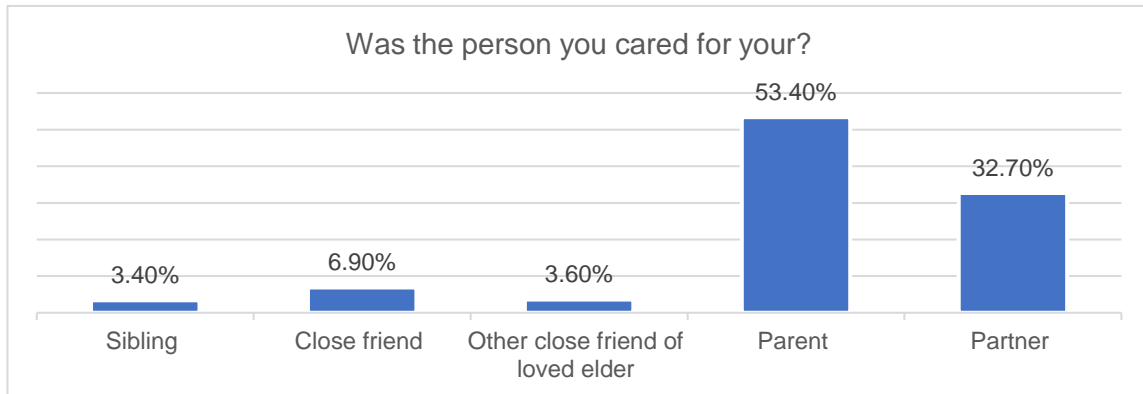
"I just feel out of the loop, nobody tells me anything... I have no idea what to do if my husband's condition gets worse, I wouldn't even know who to call"

"No-one was really explaining what was happening to her, what I could expect. You know, we continued to have hope, you know, but it was false hope.....So it's almost like no one wants to say that she was dying, but they know how these things end."

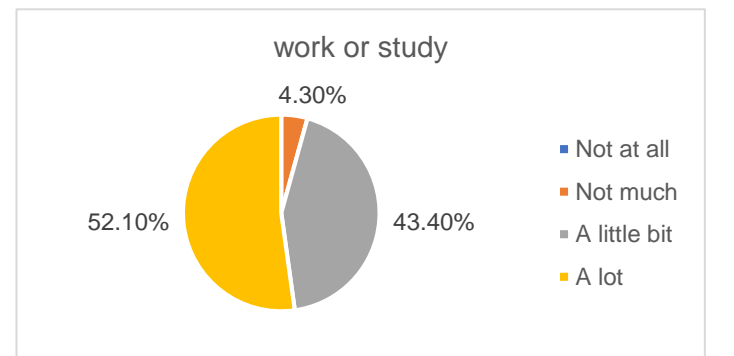
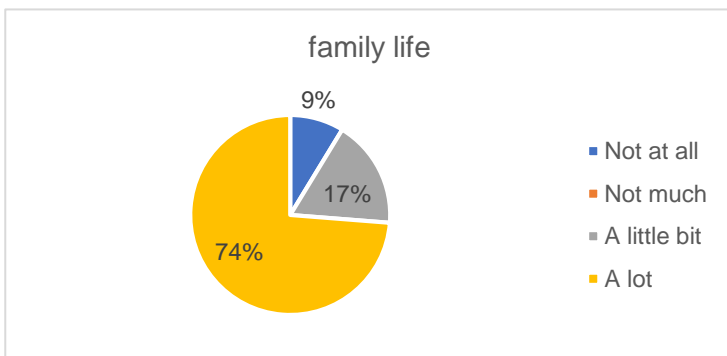
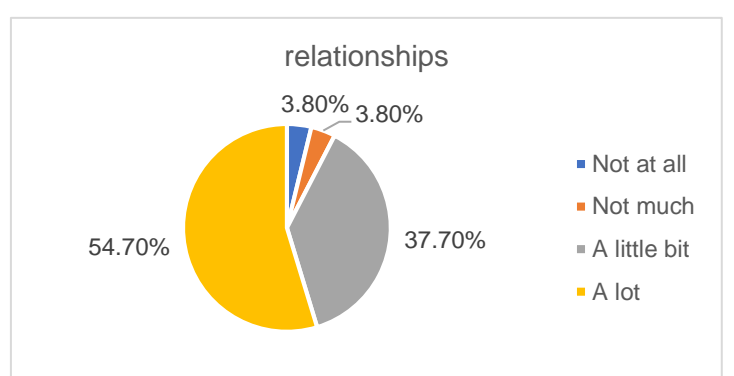
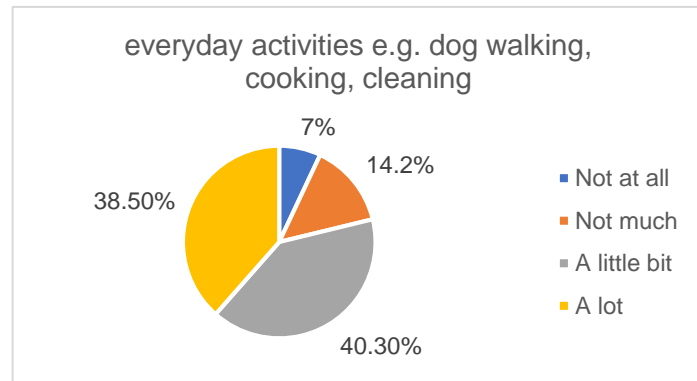
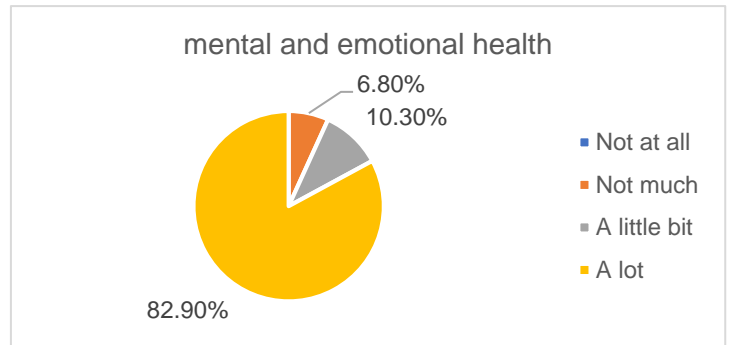
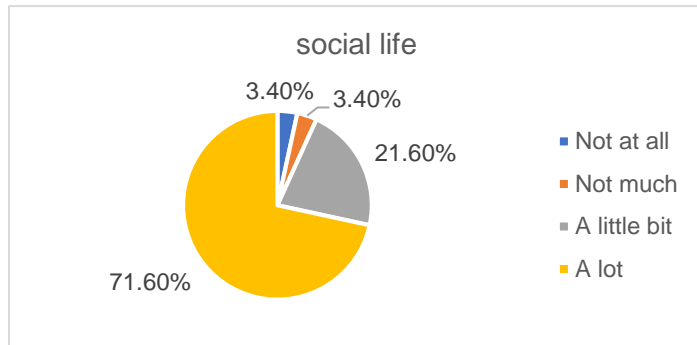
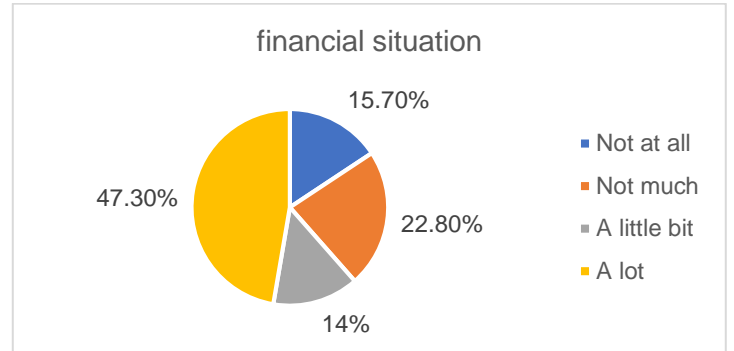
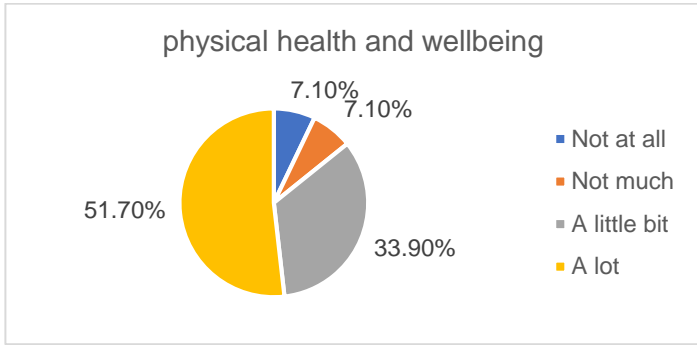
Who answered the survey?



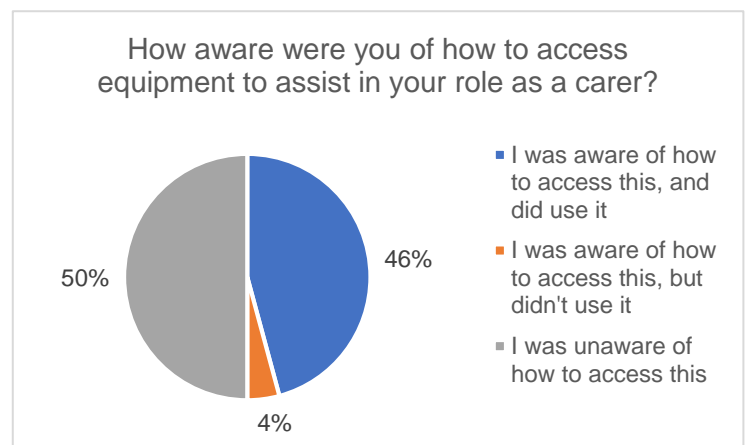
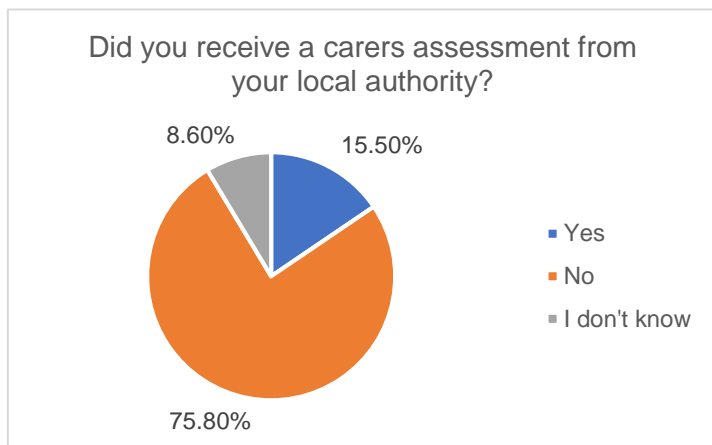
What impact did being a carer of somebody with a life-limiting condition have?



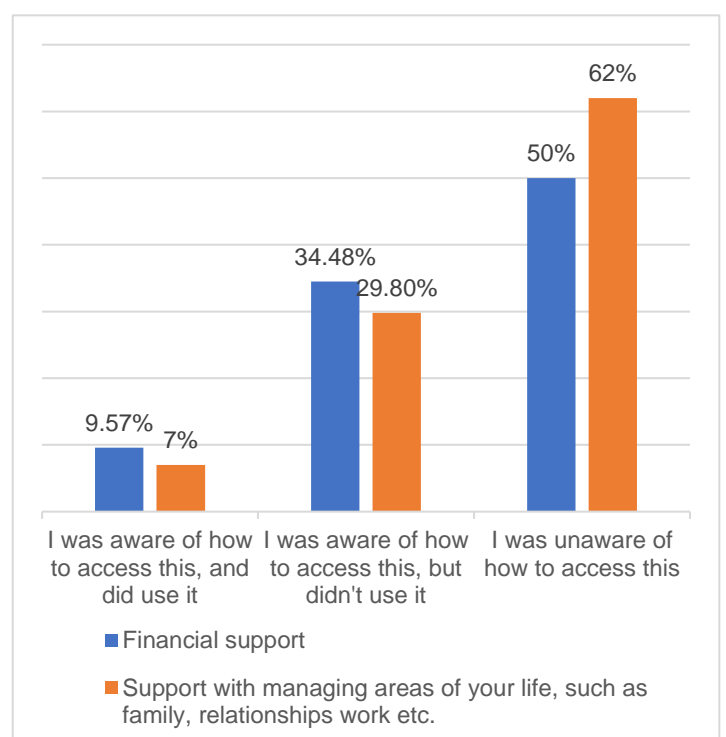
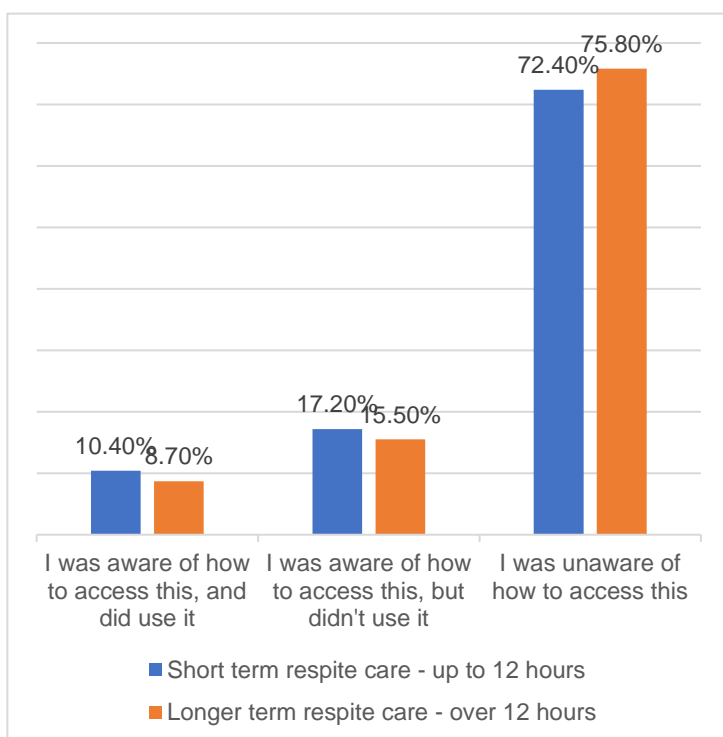
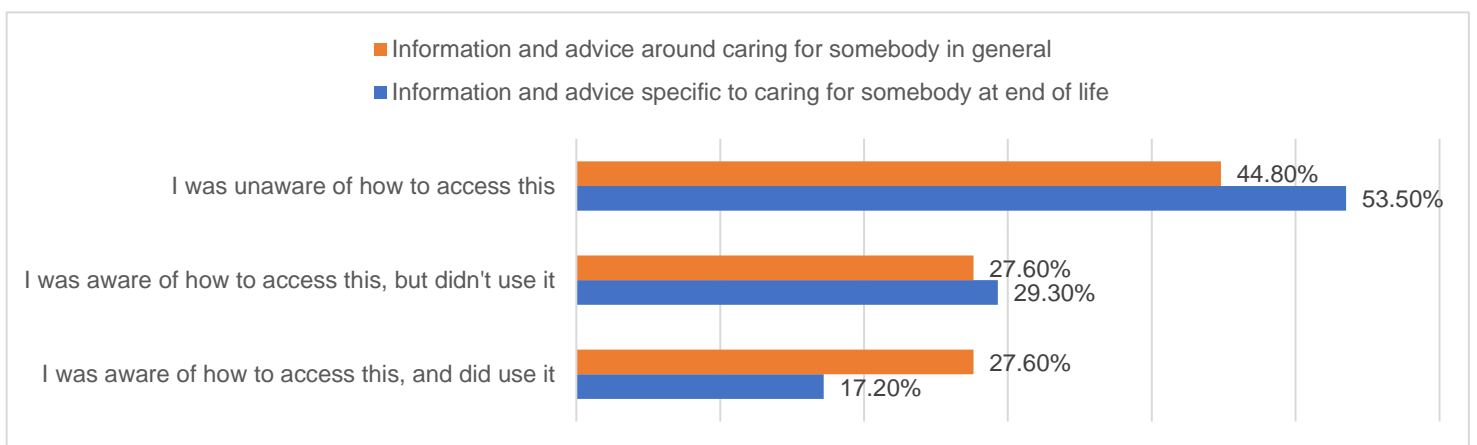
How has being a carer impacted your:



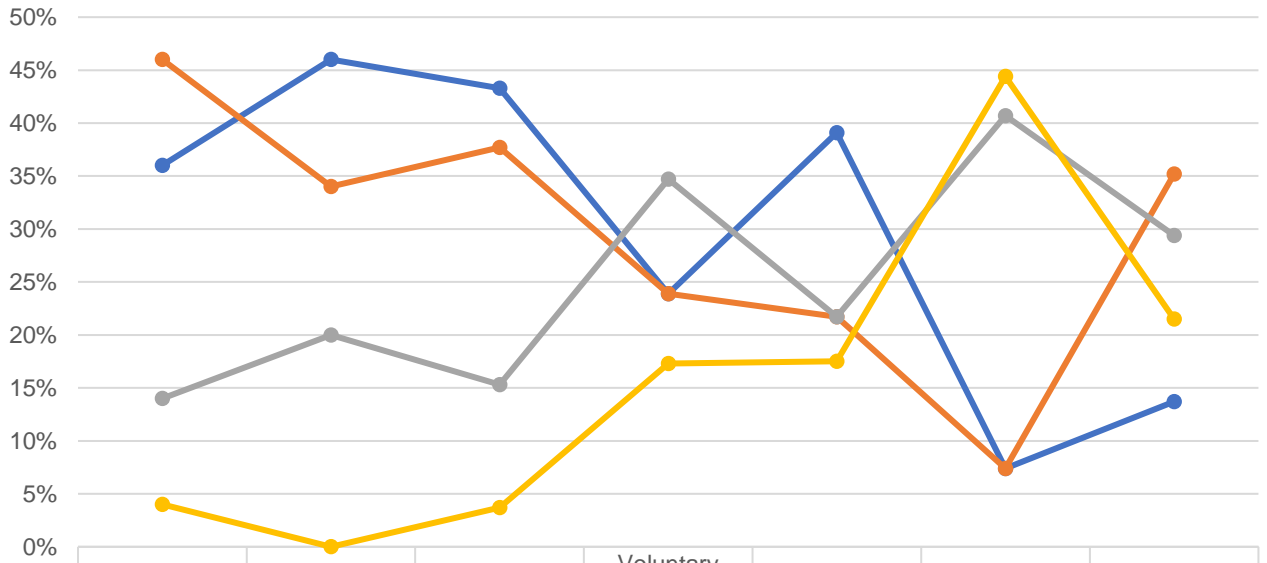
How well supported were you in your role as a carer?



How aware were you of how to access the following support available to you as a carer?



How well supported do / did you feel in your role as a carer by the following?



	Your GP	Other health professionals at your GP practice	Local authority, including social services	Voluntary sector organisations such as MacMillan, Marie Curie, Age UK, Carers First, Citizen's Advice	Your faith leader and community	Family / friends	Hospital staff
Not at all	36%	46%	43.30%	23.90%	39.10%	7.40%	13.70%
Not so well	46%	34%	37.70%	23.90%	21.70%	7.40%	35.20%
Quite well	14%	20%	15.3%	34.70%	21.70%	40.70%	29.40%
Very well	4%	0%	3.70%	17.30%	17.50%	44.40%	21.50%

● Not at all
 ● Not so well
 ● Quite well
 ● Very well

What type of support for you as a carer, would make / would have made the biggest difference to your life?

- Knowing how to access financial support
- Not having to chase up community nursing staff myself
- Being able to contact a GP for advice when necessary
- Being able to get urgent medication 24/7
- Co-ordinating of all the services my mother received
- A more sensitive approach from people providing care
- Somebody to help navigate the complex NHS system
- Information being given to me, rather than having to go looking for it
- Someone to chat to who is experiencing the same situation
- To get any kind of training on how to look after somebody who is dying at home
- Not having to co-ordinate everything myself
- Professional carers turning up when they are supposed to
- Really practical support – somebody do to the food shopping, cleaning around the house
- People being honest with us about how near the end of life my partner was
- Knowing how to access hospice beds when we needed it
- Respite support
- Knowing at what point my parent needs to stop being cared for at home
- People considering my needs as a carer with a long-term condition
- Feeling less like I was on my own
- Having a GP, I felt like I could go to for support
- Efficient and timely communication with and from health and social care organisations
- Actions faster and not having to spend endless hours on the phone accessing service
- Getting the right information at diagnosis
- Knowing what support was available to me as a carer
- Comprehensive guidance with timeline of possible events, contact numbers and emails to people who could help with the above
- My workplace being more understanding
- Social and health services responding and in timely fashion
- Having nursing staff who really listened to our needs
- Advice on how to manage, how to access paid care, how to manage persons finances
- More reliable palliative care provision to reassure me my partner was being cared for properly
- Having somebody who advocated for my needs as a carer – it was exhausting chasing things up all the time
- Feeling like I would be okay financially if I gave up work to co-ordinate my parent's care – I had no clue what financial support we could have got
- Being listened too by the cancer nurses in the hospital and having our plans and requests actioned so that my father could have come home for his end of life care

Appendix 2

What do bereaved people want and need? Summary from bereavement survey Autumn 2023

- Most of all, to be **listened to and emotionally supported**
- A **joined-up bereavement 'offer'** across agencies/professionals – someone to follow up with people following death of a loved one and help them sensitively and at the right time/s around information and navigation
- This should be **easily accessible and promoted** – perhaps a 'one-stop shop' approach with self-referral where one professional can act as a navigator to all support available
- Support for people whose loved one died in hospital is often there, but there is a need for **better support for people whose loved one died in the community**
- There is a need for **support for 'normal grieving'** with things such as grief cafes and short-term compassionate emotional support
- People who have been especially impacted by bereavement need **therapeutic bereavement counselling, at the point of bereavement and often later too**
- Support needs to be **equitable and personalised, considering diversity, not a one-size fits all solution**

"I cared for my mother for the last 11 years at home while being a mum to my children.

It was hard but my mother was a big part of mine and my children's life. And since she's gone it's been hard not just for myself but my oldest daughter and she's almost 15.

I see the change in her and her mental state of mind and I feel as though the school hasn't helped her. And my own GP practice hasn't helped me. I have silent cries during the day, bad thoughts, no sleep. I can't eat I've lost almost two stones.

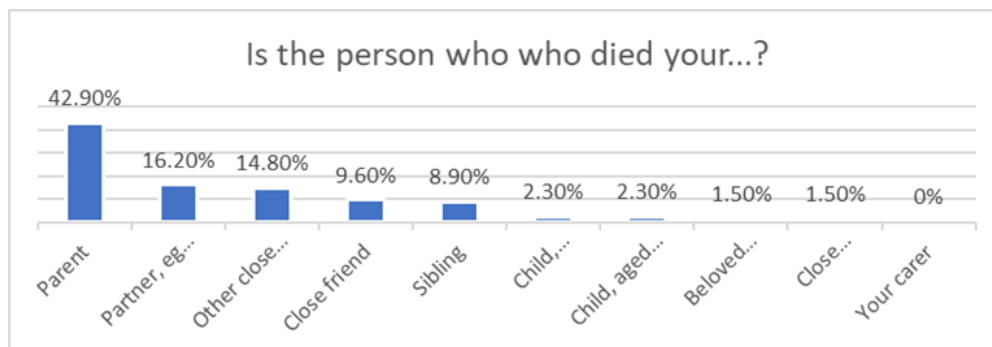
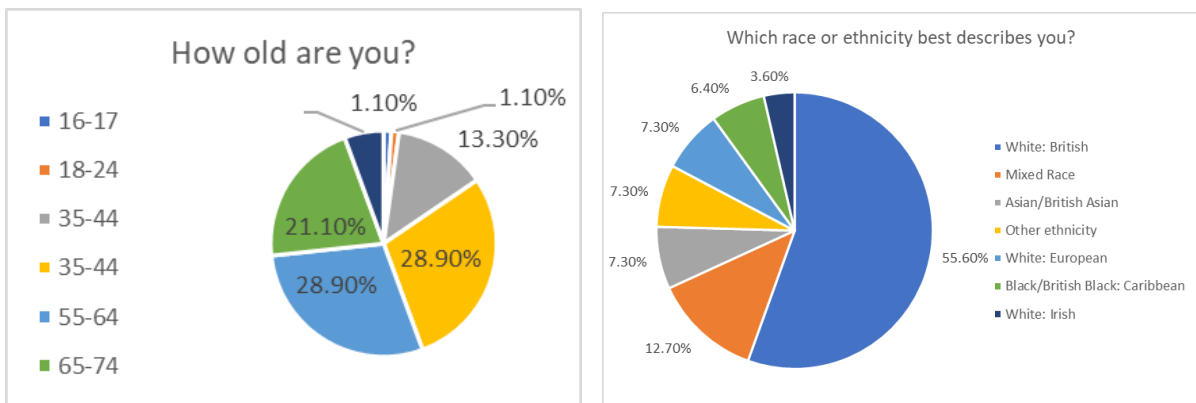
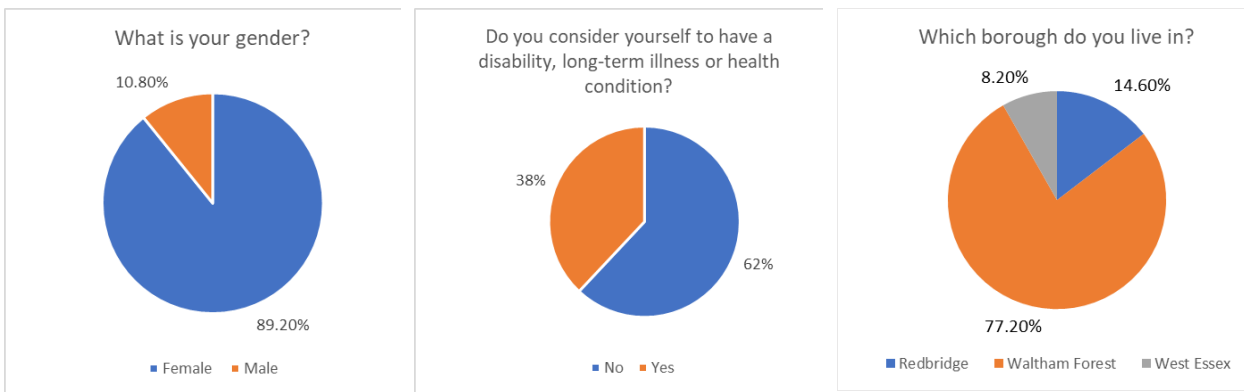
I miss my mum so much but I know my children need me."

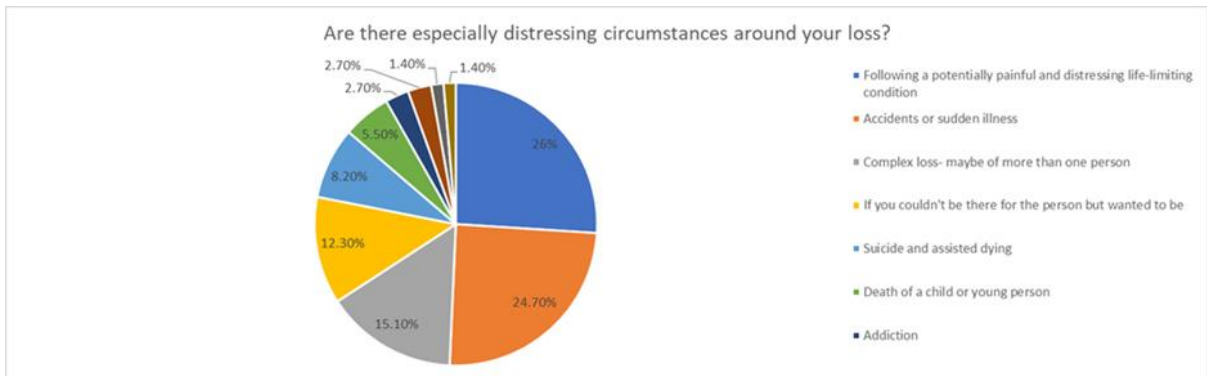
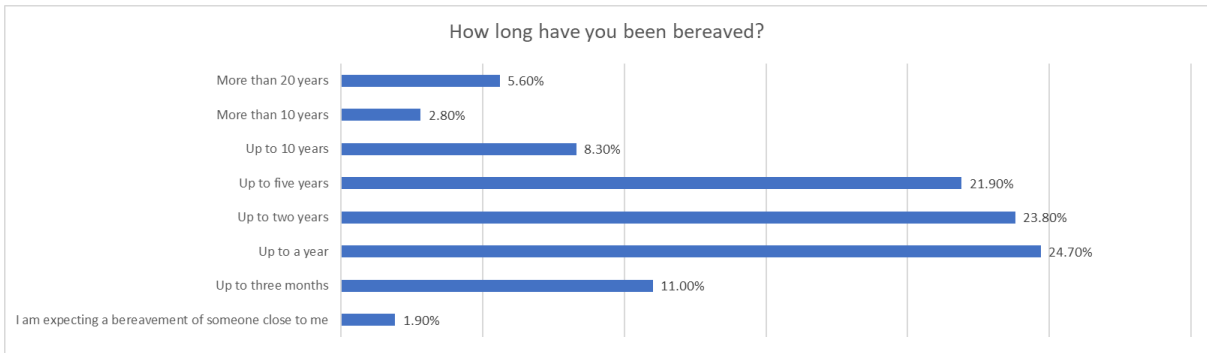
"Not make the bereaved person have to reach out to various places to try and get counselling, this should be done for them."

Who answered the survey?

Just over 100 people, **most of whom...**

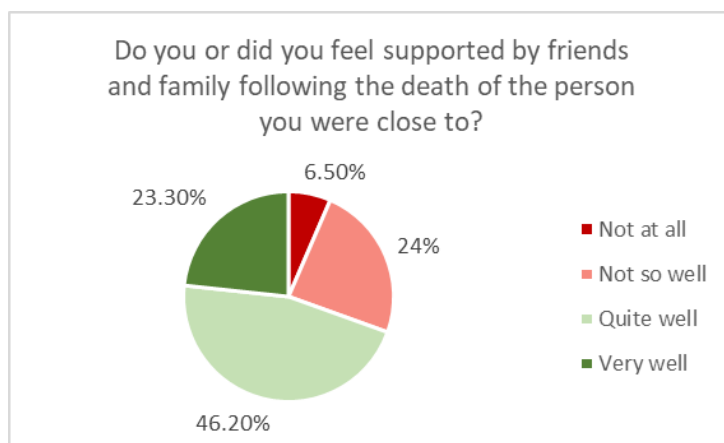
- had lost relatives and close family, some friends
- were bereaved in the last five years, some decades before
- 45–75yrs – some younger and older people
- female – small number of males/other
- were white British but also many different communities
- had especially distressing circumstances around loss – including suicide, accidents, death of a child
- were heterosexual, a few LGBTQ+
- Christian with a wide range of other individual faiths

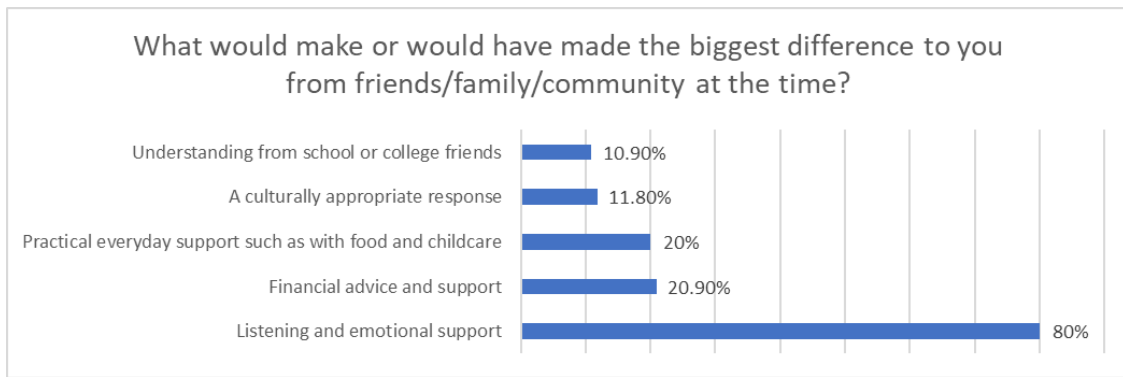




How well supported did people feel by friends and family?

Mostly of the respondents felt pretty well supported by friends and family. The key ask of friends and family is listening and emotional support – someone being there for you.





How well supported did people feel by professionals?

There was a mix of responses around the level of support from professionals:

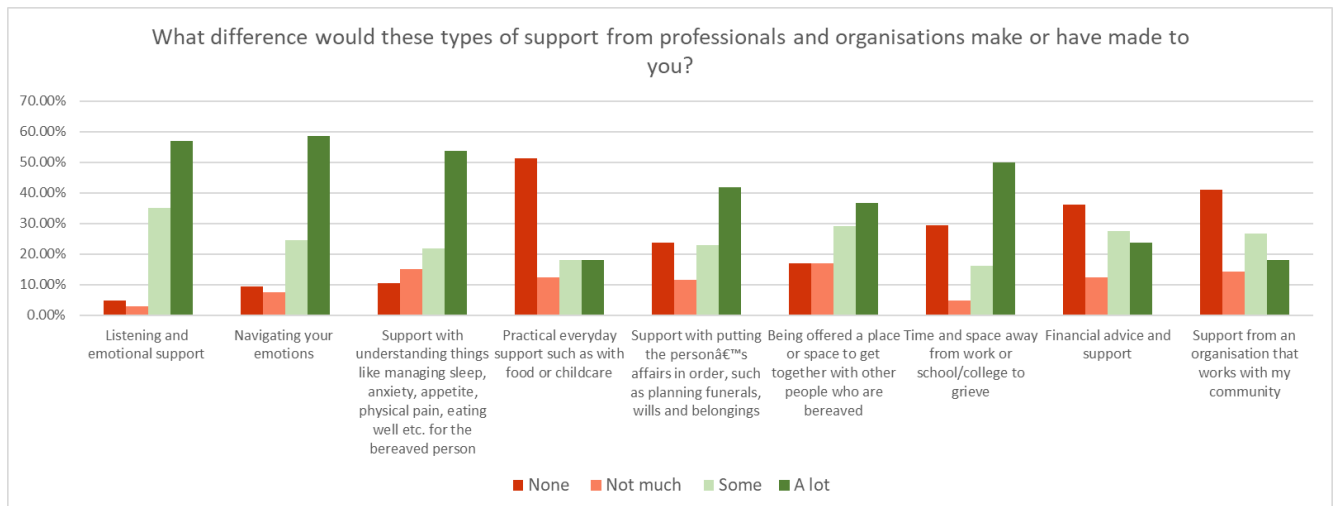
- funeral directors and community leaders offered best support
- secondary care support from hospices, hospitals and community nurses offered some good support to many
- primary care was generally not considered to have offered good support, and the same for care workers and teachers
- most people said they had no community grief counselling/support

What type of support helps most?

When asked what difference would these types of support from professionals and organisations make or have made to you, people cited a wide range of things and said the key things that would help a lot are:

- Time and space away from work or school/college to grieve
- Listening and emotional support – sometimes called grief or bereavement counselling
- Navigating your emotions – including stages of grief, reaching out for support, grief cafes, time in nature, rituals, faith etc
- Support with understanding things like managing sleep, anxiety, appetite, physical pain, eating well etc. for the bereaved person
- Support with putting the person's affairs in order, such as planning funerals, wills and belongings

“Actual bereavement counselling. I was offered talking therapies but that isn't really what I needed - I needed to talk about my complex feeling around the loss of my brother”



If there was some other kind of support that could or would have made a big difference to you around being bereaved, what would it be?

- I needed support immediately after the death in the hospital
- Emotional support and understanding of suicide
- Follow up from GP
- Some time off work
- Counselling, financial support
- Drop in help with the complex paperwork
- Follow up call to see if the person needed any support
- One to one counselling support - face to face
- Help with loneliness.
- Specific advice for managing major life change following bereavement
- Counselling that meets cultural and religious needs. Counselling available is not geared to my needs as a Muslim woman
- Financial support /advice

What particular needs should be considered?

When asked if there were particular needs that should be considered by professionals and organisations around your bereavement, there was a wide range of requests – from family caring responsibilities to mental health and faith/race/culture, plus many more.



This shows the great diversity of the demographics and the need to ensure the service is person-focused and definitely not one size fits all. Timing needs to be personalised too.

Information needs were broad across a number of subjects, most importantly how bereavement can affect you and your family’s emotions and mental well-being

“Very often counselling is offered far too soon. It can take years to be ready to deal with the complexities of grief. So, counselling should be made available at need, not necessarily just at the time of bereavement.”

What kind of service would be most helpful and where?

The survey gave some suggestions about the types of bereavement support that might potentially be developed, and asked people how helpful they felt they might be. The suggestions considered most helpful were the six sessions of one-to-one bereavement counselling for adults, and information about wider support available. However, this may reflect the demographic of the responders and further research is required for more diverse communities.

	A LOT	SOME	NOT MUCH	TOTAL
Six sessions of one-to-one bereavement counselling for adults	73.63% 67	19.78% 18	6.59% 6	91
Six sessions of child-appropriate bereavement support for children such as art therapy or play therapy	63.16% 24	26.32% 10	10.53% 4	38
Six sessions of family bereavement counselling	45.90% 28	36.07% 22	18.03% 11	61
Group activity sessions for young people	44.12% 15	44.12% 15	11.76% 4	34
Information about wider support available during and after the sessions	56.47% 48	40.00% 34	3.53% 3	85
Bi-memorial events offering young people the opportunity to remember a person they lost through a creative memorial event suitable for young people of all ages and cultures	37.78% 17	44.44% 20	17.78% 8	45

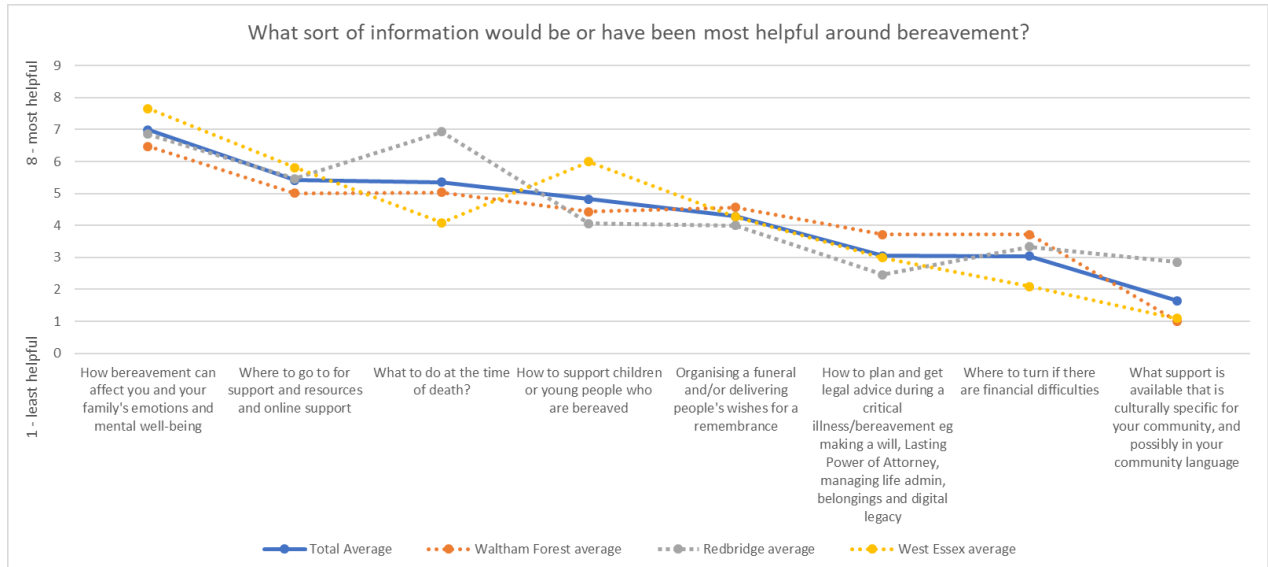
Most people wanted their support in person either in a hospital, community setting or outdoor.

Ten per cent wanted it digitally.

Most people wanted one to one support, followed by group and family support.

There was an equal split of timing preferences around day time or evenings.

What sort of information would have been most useful



When asked, other things that people said would have been or were useful

- The Margaret Centre at Whipps Cross provided excellent space and support prior to the person dying, and it was lovely to have this time.
- If we had remained in the hospital, or been moved back into the community, then we wouldn't have received the same level of support
- and I think this would have impacted on my grief.
- Community led sessions perhaps run by a local hospice
- Support and advice with taking over caring responsibilities for disabled family member
- It shouldn't be left to the bereaved person to have to reach out to various different bereavement places to get support.
A referral should be made straight away for them
- We worked with the Zig Zag service at Whipps Cross. I can't emphasise enough how important the Zig Zag team was to the whole family.
- Access to bereavement counselling from trained bereavement counsellors for 16 to 24 sessions as was offered by Psychological Support Service at Whipps Cross.
- The main support I have received is from a therapist that I paid for. I found I had to be quite active in seeking out help.
I initially spoke to a free counsellor over the phone but I found that quite distant
- Employers need to provide better bereavement leave, it shouldn't be discretionary it should be mandatory
- Consultant showing any empathy at all would have been better
- A place to meet with others in the same position
- Support long term
- More community-based support that could be accessed by the wider community that was affected by this child's death
- Help with after-death paperwork
- Talking to people who sent through the same thing. I have been supported by friends and family but at the end of the day none of them could really understand what I was going through
- Guidance on documentation

Appendix 3



End of life conversations with residents of Waltham Forest and Redbridge

Confidential Report for NHS North East London

PHASE 2 ENGAGEMENT
October 2023

Contact details:

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Introduction

Phase one of the Whipps Cross Catchment End of Life Programme engagement work, was carried out between July and September 2022 and focussed on investigating 'what does good end of life care look like?' We are now in Phase two, and this phase aims to gather further insight and information to determine which of the proposals and options, developed from Phase 1, most reflect the needs of our communities in Waltham Forest, Redbridge and West Essex, and ensure that the proposals put forward, provide services which are important to local people, and address issues currently experienced.

As part of the Phase two engagement work, Debbie Young, an independent consultant with experience of having open discussions about death and dying, was commissioned to have a number of one-to-one conversations with representatives from the local community.

This report outlines key findings from these conversations.

Findings from the conversations

The people who shared their experiences

Six local people shared their stories; three have a life limiting condition, one is caring for their teenage child with a life limiting condition and two were caring for their partners who had a life limiting condition and who have now died. Five were female and one was male.

Here are the people who so kindly shared their experiences. All names have been changed.

Arthur:

Arthur was diagnosed with Stage 3 pancreatic cancer in March 2023. He lives with this wife. He is supported by the Oncology Team at Barts Hospital, has some medical care from Whipps Cross Hospital and is supported by Waltham Forest Palliative Care Team.

Sharan:

Mabel was diagnosed with Pulmonary Fibrosis 25 years ago. Her health has significantly deteriorated in the last 6 months. She lives with her husband. She is under the care of UCLH. She is supported by Waltham Forest Palliative Care and District Nurse Teams.

Mary:

Mary was diagnosed with multiple myeloma and plasmacytoma in March 2022. She lives with her husband. She is supported by the Oncology Team at a Private Hospital, receives some medical care from Whipps Cross Hospital and is also supported by Waltham Forest Palliative Care and District Nursing Teams.

Nusrat:

Nusrat cares for her teenage son at home; he has a life limiting condition. Her adult daughter also lives at home. Her son has recently transitioned from children to adult services and now receives medical care from the Neurology

Hospital. He has two carers, 24 hours a day, provided by a care agency. He is also supported by Waltham Forest Palliative Care and District Nurse Team.

Alexandria:

Alexandria's husband died at home 3 months ago. He had lived with cancer for 2 years. He was receiving treatment at UCLH. At the time of his death he was receiving support from Waltham Forest Palliative Care and District Nurse teams, and had night sitters via a care agency.

Lynda:

Lynda's partner in Barts hospital died 3 years ago. He was diagnosed with bowel cancer in 2019 and died 11 months later. He was receiving treatment for his cancer at Barts Hospital. At the time of his death he was also receiving support from the Waltham Forest Palliative Care team. Their daughter was 3 years old at the time. Lynda is receiving bereavement support from Zig Zag Children's Service at Whipps Cross Hospital.

What the residents told us

The information that the residents shared will be presented in this report according to the questions asked in the interview schedule. For each question, key themes have been identified.

Question. What support have you, or the person you are caring for, received so far since your/their diagnosis? What support did the person you cared for receive from their diagnosis to their death?

This section of the interviews asked residents to outline the type of care services they had received, or are receiving, and to explore with them what was working well and any challenges they had experienced particularly around accessing these services.

What has worked well.

The main things that the participants described as working well were in relation to the **Palliative Care Team**:

- Half of the respondents had **been offered complimentary therapies (such as reflexology, reiki and massage) or the opportunity to join a support group to talk with people in a similar situation to themselves.** They all found these extremely helpful and enjoyable and were really pleased to have been offered them.
- Half of the respondents said the team were **reliable and on time and they would do what they said they would.** Two said that they responded quickly to calls and messages.

- Two people described how their nurses had **very quickly sorted out practical arrangements** i.e. equipment such as organising a bed, commode, blue badge, attendance allowance.
- One person talked about how the Palliative Care Nurse was **able to “cut through the bureaucratic red tape”** and sort out his medication with his GP (which he had been unable to do, due to difficulties getting through to his GP on the phone)
- One respondent commented how they had **helped her manage her pain control** and how they had discussed pain management options with her. This same person was very happy with the whole package of support that had been put in place for her:

“Well, providing all this equipment was wonderful and so quickly. I think that that was a great plus, we didn't expect that. The fact that [name of nurse] is at the end of the phone, I think is a sense of, not peace, but you know that you can rely on her to be there. You know that someone will answer the phone and answer your questions. And also, we wouldn't have thought about an urgent care plan. She suggested it. So that was a plus”.

Participant with a life limiting condition

Two of the six people commented that they thought **their GP** was ‘brilliant’ and one explained how, at the early stages of their diagnosis, their GP had been ringing them to check how they were.

All of these things were considered, by the participants, to be really important characteristics of good end of life care.

The main challenges:

Five of the six participants described a number of significant challenges they were facing – or had faced - accessing support from the services involved in end of life care.

The main challenges were:

- Uncoordinated services and poor communication within and between services – mentioned by 3 participants. Described by a 4th participant as “too much bureaucracy and bad administration” which leads to confusion between services and delays in patients getting what they need, specifically in relation to prescriptions and getting pain and end of life medication;
- Services unable to respond to, and cope with, the speed in which the dying person's condition deteriorated;
- Services being reactive and not proactive;
- Services “passing the buck” and “that’s not our job, it’s x, or y’s job”

- Inconsistent and unreliable care from some providers – including many examples of professionals not doing what they say they were going to do – people described ‘feeling let down’;
- Unavailability of out of hours end of life medication and difficulties accessing medication for symptom and pain control;
- Difficulties getting end of life symptoms managed;
- Lack of availability of a syringe driver at the very end of life;
- Decrease in quality and amount of support since transitioning from children services (Great Ormond Street Hospital) to adult services – “no one has been in touch since he has transitioned”;
- Lack of GP involvement in their care (highlighted by 3 participants)
- Difficulty getting appointments with GP - due to lack of available appointments, very long waits to speak with someone on the phone and difficulties getting past the “gatekeeper” i.e. reception.

All participants recognised that services were overstretched and most assumed they were short-staffed. However, these issues were, or had, significantly impacted on the care and support they were receiving, or had received, at the end of life.

Below are 3 specific examples, that highlight some of these challenges:

One participant, whose husband, had died described how her husband had been discharged from UCLH on a Saturday evening and she was told to call the local Palliative Care team as soon as possible so they could come to assess the situation. She phoned the Palliative Care Team early on the Sunday morning and when no one responded she left a message. When she realised her husband had deteriorated, she called again 1 hour later, and again there was no response. By late evening, she realised her husband was not responding well, so she called again and had no response. She cared for him overnight and tried again Monday morning. She said she left a desperate message. An hour later someone from the Team called back and she was told they wouldn't be able to assign him a nurse that day. Following a “*desperate conversation*”, a nurse arrived an hour later. They assessed the situation and realised her husband was dying. She was told it was too late for him to be moved to the Margaret Centre and she says she was reassured that he would have everything that he needed at home.

Some things were then put in place very quickly by the Palliative Care Team, District Nurse Team (who organised overnight sitters) and their GP (who prescribed the injectable medication, including morphine, which

needed to be given via a syringe driver, as her husband was no longer able to swallow. Everyone had left by midday.

By 5pm she hadn't heard anything further from any of the services so she called the District Nurses to ask when they would be coming to inject the morphine. She was told that they do not bring the medication and that she needed to contact her GP to get it. She called the GP and was told she needed to call her local pharmacy. When she called the local pharmacy, she was told they did not have any injectable morphine available that day and possibly not until the following day. She then phoned the Rapid Response Team to ask if they had any injectable morphine and was told that they did not. During the night, in desperation, she called St Joseph's Hospice to ask if they could supply the medication and was told she was out of area and they couldn't help.

At 8am the following morning the District Nurses arrived but they did not have a syringe driver as they had run out. She was told that someone would need to collect one from Chingford that day or tomorrow. By 10.30am, following numerous phone calls, she eventually managed to obtain the injectable morphine from the local pharmacy and the district nurse returned to administer this as an injection. They left at 11am. Her husband died at 12.30pm.

"I made 14 phone calls that morning by his bed trying to organise everything....to see who is doing what...why did he have to go through this? So senseless, so traumatic. It didn't have to be like this".

Another participant, whose partner had died, described feeling as though they had "*fallen through a gap*" and how she had made desperate calls to Macmillan Cancer Support because "*we were just flailing in the wind*". Her partner had been assigned an Oncology Nurse at Barts Hospital but this nurse was not responding to any calls or emails and they felt none of the health professionals were being open about her partner's prognosis yet he was obviously deteriorating. Macmillan told her to call their GP to start the process of being assigned a Palliative Care Nurse. When she contacted her GP, she was told that this wasn't needed as her partner wasn't "*at that stage yet*". She pushed for palliative care support, and in the end was allocated a Palliative Care Nurse. Her partner died 2 months later in hospital. She felt that everything had been left far too late.

One participant, with a life limiting condition, described the care from the Palliative Care Team as "*inconsistent*". She had felt acutely let down when a nurse had cancelled her appointment at the last minute and told her she

would re-schedule and then did not. This was particularly upsetting as she had been feeling very low and had specific things she had told the nurse she needed to talk about. She says she doesn't see anyone from the team in person very often and they only call every few weeks. In the short time she has been supported by the service she has seen 3-4 different nurses.

"It's just not like what I thought it would be like, I thought I would have the same nurse to build a bond with but I've had about 3-4".

What would make a difference:

1. A service that can respond to the needs of a dying patient, at any time of the day, including evening and weekends.
2. End of life medication that is available 24 hours a day.
3. A service that answers the phone and that you can rely on to be there.
4. A family liaison person who can co-ordinate your end of life care – who will be your first point of call – at the end of life and for a period of time after the death (see bereavement questions on page 27).

Question: What support have you, as a carer, received?

This section of the interview explored whether those who had had a caring role, had received a carers assessment, where their support had come from, and what support would have made the biggest difference.

Did you receive a carer's assessment?

- None of the participants had received a carer's assessment.

Where has support come from?

- Most of the participants support appears to have come from their family and friends.
- Two of the three participants, with a caring role, had been offered counselling. One had declined as they did not feel that would be helpful to them. The other required counselling to deal with the fact that her partner was dying. However, by the time the counselling was offered to her, her partner had already died. The third participant, with a caring role, had organised their own counselling.
- One participant found support through Facebook support groups i.e. cancer support groups and another accessed support through a charity related to the medical condition of the person they were caring for.

What support would have made the biggest difference?

The sense I got from all of the participants was that the thing that would make, or would have made, the biggest difference was;

- **A reliable, consistent service that you can depend on** – that is there when you need it – with staff who are compassionate and who are able to talk openly and honestly about what is happening and what they should expect at the end of life.

The participant, who is caring for their child with a life limiting condition, had three very specific needs:

- Help with household tasks (financially and practically) as they do not get any financial support.
- Help to get a better wheelchair for her son as his current one is not fit for purpose. They have contacted a charity to try and get a grant as they have not received any support from the Council.
- Privacy for her teenage son. He is cared for in the living room.

Question: How has communication been with services so far?

This section of the interviews asked residents:

- whether they felt staff had been approachable and easy to talk to,
- if they had been provided with suitable/appropriate information, advice and guidance about their situation, and
- if they felt that they knew where to go to access information they need regarding their life limiting condition.

What has worked well:

- One of the six participants was extremely positive about how staff had communicated with her and how approachable they had been. They described them as:
 - Positive
 - Had a sense of humour
 - Been knowledgeable
- This participant had also been given a brochure by the Palliative Care Team with addresses and phone numbers of who to contact and information about how the team worked. She found this really helpful.
- The other five participants, had generally found communication difficult, but were able to give a few examples of specific staff (like their GP, a Palliative Care Nurse, a Counsellor and Ziz Zag counsellor) who had been helpful and approachable (“lovely”, “positive”, “friendly”).

The main challenges:

Five of the six participants described a number of significant challenges they faced in relation to communication with services. The main challenges were:

- **Not being told, or been given any information about, what to expect as they, or the person they were caring for, becomes more unwell and is dying** (discussed by four out of six participants) – e.g. information about the different stages they might go through, how to cope with these, and who to contact if they need support. This was something they all wanted.

“I just want someone to explain to me the different stages I’m going to go through”. Participant with a life limiting condition

- **Health care professionals not using the word ‘dying’ when talking with them about their situation and using euphemisms instead** (described by four of the six participants). Euphemisms used were: “*disease progression*”, “*becoming restless – final stages*”, “*when they stop breathing*”. Two participants described how this had caused confusion about their prognosis or meant that they were in denial about the reality of the

situation. Both participants described how they had had to Google to understand what these words meant and what was happening. A couple of participants questioned whether staff had received any training to have these conversations.

- **Not being given any information about their prognosis, or the prognosis of the person they were caring for** (described by three of the six participants). This links to the point above – these people described just wanting a sense of timescale:
 - *“I don’t like to be shielded for my own good.....that’s one of the things; you want control. I want to know exactly where I am with my cancer progression, as they call it. How many, approximately good months or weeks do I have, so I can make the most of them and that’s it”*. Participant with a life limiting condition.
 - *“No-one was really explaining what was happening, what I could expect. You know, we continued to have hope, you know, but it was false hope.....So it’s almost like no one wants to say they’re dying, but they know how these things end...”*.
 - Participant whose partner had a life limiting condition & who has died.
- **Difficulties and frustrations communicating with the District Nursing Service** (described by two participants). The participants used the phrases “they were totally lost” and “they seem to be like, lost”. Because they had been referred to service, the participants had expected to be ‘known’ when they called asking for advice/support. But when they had called, the person answering the phone didn’t seem to be aware of who they were or their current situation.
- **Lack of compassion from some health care professionals**, this seemed to be mainly in relation to the district nursing service – *“they don’t seem to give a hoot”* and *“the funeral people were much more respectful towards his dead body, than the district nurses were to his live body”*
 - *“And I wish they did some education about empathy and respect of the dying people and their families. I think that would be useful, because you know, these are very difficult times....and it only happens once in their life and is not something you can improve on later, and you feel a bit degraded really”*.
 - Participant whose partner had a life limiting condition & who has died.

What would make a difference:

- **Guidance, or a flowchart, about what might happen at the different stages of end of life** (including after the death), how to cope/manage these (e.g.

managing pain and symptoms, access to medication and equipment), which service is responsible for helping with this and how to contact them.

- **Information about the dying process** – offered verbally and in written format. Recognising that not everyone wishes to know, or have this information, but available for those who do.
- **Discussions about their prognosis in simple language.** Again, for those who wish to know this.
- **A list /register of palliative care patients** (or equivalent) that is shared with key services in the borough so that when you contact a service (e.g. GP practice or District Nurses) they are aware that you, or the person you are caring for, is end of life and can respond quickly and efficiently.
- **Staff who have been trained to have open conversations** about death and dying.

Question: Do you feel like your current care is personalised to you or the person you are caring for/cared for?

This section of the interviews asked residents:

- Have professionals providing care to you informed you/discussed with you and the people close to you the options available to you/ the person you are caring/cared for?
- Do you, or the person you are caring for/cared for, have a plan for preferred place of death and the things that are/were most important to you/them?
- Is support offered to you/them appropriate for you/them? E.g. cultural/faith requirements.
- What could be done, or could have been done to make your/their care more personalised to your/their specific situation?

This participants responses to these questions have been divided into two parts.

- Part 1. Personalised care; and
- Part 2. Plans for preferred place of death and end of life wishes.

Part 1. Personalised Care

Reasons why care has felt personalised:

One participant felt that her current care was personalised and she described a number of reasons why she felt this:

- Has an Urgent Care Plan in place
 - This was offered, and brought up by the Palliative Care Nurse, very early on
 - CPR has been discussed
 - Spiritual needs have been discussed
 - The participant has her own copy of this plan.
- Her Palliative Care Nurse has told her she can call her anytime and they check in with her regularly.
- The Palliative Care Nurse has also arranged for her to have a massage as she knows this is something she enjoys.
- Her GP rang fairly frequently at the start to see how she was doing.

Reasons why care has not felt personalised:

Five of the six participants didn't feel that their care was, or had been, personalised.

One of the participants said that they “didn’t expect it to be” as the NHS is supporting far too many people to be able to get involved in the “*minutiae of each individual person*”.

The main reasons given, for why they didn’t feel that their care was personalised were:

- Care and support **focuses on the practical aspects** (organising equipment, pain control, medication, treatment etc) **but not the emotional/mental health side of care** (discussed by 3 participants). See the box below for further details.
- **No-one has talked with them about what will happen** as they become more unwell and when they die.
- **Feeling like they are on a tick list:**

“You feel like you’re on a tick list...you don’t feel like you’re a person a lot of the time. You’re just someone to get... that’s her done & out of the way with”. Participant living with a life limiting condition.
- The **services are so overstretched**. There are too many patients.
- Lack of respect shown towards the dying person.
- **Treating the dying person as a ‘patient’** to be clinically treated, rather than supporting them to die.

Below are 3 specific examples (with quotes), that highlight some of these reasons why participants did not feel care was, or had been, personalised

One of the participants explained how she just needs someone to explain to her the different stages that she’s going to go through, as her health deteriorates, so she knows what to expect.

“I’m really struggling now. Mentally I always thought I was very strong, which I do believe I still am, to some extent. But, when that day, when that girl [palliative care nurse] never came back, you know, the one who was coming, she said, she’s coming to talk to me and I had all my questions ready and when she didn’t and I just got the phone call, I just got really upset. So I thought I was gonna get some answers today. And yeah, and I just felt really sort of upset that they, they couldn’t be bothered to try and get somebody else. But then if they’re short staffed and, you know, they haven’t got anybody else spare. It’s just that nothing, nothing was said at all.....

.....I just thought I’m gonna have to deal with it on my own – the mental side of it. I mean, I’ve got a very good backup like, my family, really good. And [name of husband] he’s good as well, but I can’t talk to him about

certain things because he gets upset, and I can't talk to my sons for the same reason.

... it's just different to how I thought it would be. You know, I thought that palliative care, I thought I would get more mental help than anything. Because it's a hard thing to come to terms with, you know, that you're, you're going to be leaving this planet. It really is. And, you know, I suppose it's hard for them as well, because they probably don't know what to fully say. Do they have training for it?"

Another participant, whose husband had died, explained that the Hospital Palliative Care Consultant had offered her husband counselling when he was told his cancer was incurable, but at that stage he didn't feel that he needed it and declined the offer. However, in the last month of his life, as his health deteriorated, and his ability to do basic daily activities decreased, the need to talk became quite pressing but unfortunately, the counselling then took a long time to organise and only became available after he had died.

"My husband actually asked for, he needed some mental health support in the last month of his life. They offered him some when he was told that his illness isn't curable. And this was through Macmillan and they found it but he didn't need help them. So they will check every three months or whatever. And he'll say no, I don't need it. But in the last month, he needed it. But it took a long time to get it going. And when it was supposed to start, he ended up in hospital. And then he couldn't do it in hospital because every 15 minutes somebody coming to measure something and go to check something else. And then I received an email to his email address after he died. And that therapist was very happy that she managed to reinstall all his sessions that he lost but I said well, it's too late, he needed mental health support in his last month, when he was feeling really low. The only one who touched on it was this Palliative Care Consultant".

Another participant, whose partner had died, explained, how she, herself, had needed emotional support:

"It's probably just a complete lack of resource and reactive care, because, for me, you know, and maybe because he was young, they wanted to sort of keep the hope going, I don't really know, I think it was more that there was just no one around, no one available to be that kind of, you know, they saw him very much as a patient. And, you know, and they were dealing with the treatment, and it was all very clinical, and, but the emotional side of it was a bit lost".

This participant explained that when she did eventually manage to arrange for the Palliative Care Team to be involved in her partner's care, they offered her counselling to help her prepare for his death. But by the time she got contacted about the counselling, her partner had already died.

Part 2: Plans for preferred place of death and end of life wishes

What has worked well.

- All of the participants had had some level of conversation about preferred place death with a health professional. However the depth of these conversations varied.

What has not been so good:

- **Most of the end of life discussions had been quite limited.** Discussions appear to have focused mainly on – where do you want to be? Two participants said they had had discussions about CPR and what interventions they would or would not want. The majority of the participants said there hadn't been any conversations about the things that are most important to them at the end of their life.
- **Most of the participants did not know where their preferred place of death had been recorded or who this information was shared with.** Only one person said they had a physical copy of their Urgent Care Plan where her wishes were recorded. All other participants did not have a copy of any plan – Urgent or end of life care.
- One of the participants, with a life limiting condition, had a very strong opinion about something she does not wish to happen to her, based on what she saw happen to her sister. She said that she had told a Palliative Care Nurse about this and that she had written this down, but the participant did not know where this was recorded and who this information had been shared with. She was extremely concerned that if she was taken to hospital they wouldn't know her wishes:
- *“I'm absolutely terrified, because I think they will do the same to me. You know, when I get iller. Sometimes you get into hospital and your wishes go out of the window don't they”.*
- **Most end of life discussions appear to have only taken place once,** at the start of the care and support, and have not been revisited, particularly when health has deteriorated.
- **Five of the six participants said they had not been asked about any specific cultural or faith requirements.**

What could, or could have been done, to make care more personalised:

The participants suggested a few specific things that would improve care and end of life care planning:

- **Mental health support** for the person with a life limiting condition and their carer/s.

- Health professionals having **open conversations about what they can expect as their condition deteriorates** and how they might cope with this.

Question: What characteristics are important to you regarding the care received/provided and where it is received/provided.

This section of the interviews asked participants:

- Would you rather receive your care at home or away from home? OR would the person you cared for or are caring for, prefer to be cared for at home or away from home? Why?
- Thinking about things like the environment, visitation rights, how easy it is to access etc.
- How do you think this may differ as time progresses?

The participant's responses to these questions have been divided into two parts:

- Part 1. Preferred place of care and death and how this might change as time progresses;
- Part 2: Characteristics that are important regarding the care received/provided and where it is received/provided.

Part 1. Preferred place of care and death and how this might change as time progresses.

Table 1 on page 21 sets out the participants preferred place of care and death, and the reason for this. The third column outlines how they think this choice might change as their health deteriorates and when they are dying.

- It is important to note that most of the participants had reported that they had experienced unreliable and inconsistent care. For this reason, home was their preferred place of care/death as they felt they would have more control over the care they would receive.
- However, most participants were very conscious that as their health deteriorates, family members/loved ones who will be responsible for caring for them, may not be able to do this meaning they will need to move to another setting.
- Participants were then very keen that whatever this setting was, it was as much like 'home' as possible.

Part 2: Characteristics that are important regarding the care received/provided and where it is received/provided.

Table 2 on pages 23-24 outlines the characteristics that participants felt were most important in relation to the care that is provided at the end of life, and where this care is provided.

These characteristics are divided into:

- The location – based in the borough or out of the borough
- The environment i.e. the setting
- The people – who provide the care and what they would like these people to be like.

Important points raised by the participants:

- **Whatever the setting is, participants would like this to be as much like 'home' as possible** e.g. 24hour visiting/access, family members are able to be totally involved in the person's care, being able to stay overnight, a non- medical setting so no beeping noises or interventions.
- **Good transport links and easy access to the setting were almost more important than whether it was in or out of borough.** There were lots of comments that Whipps Cross Hospital being difficult to travel to depending on where you live in the borough.
- **The setting needs to be age appropriate and family friendly** i.e. for teenagers and for families who have young children.
- **The people providing the care need to be knowledgeable about end of life care and have been trained to talk openly about death and dying.**
- **The people providing the care need to be reliable and be able to provide a sense of safety and security.**

Table 1. Preferred place of care/death			
Participant	Preferred place of care/death	Why?	How might/did this change as time progresses/progressed
Arthur	1 st choice – Home 2 nd choice - Hospice	“I don’t want to die in hospital”	Arthur would prefer to die at home but he doesn’t think his wife will be able to deal with it so he is aware that he may need to move to a hospice environment at some point
Mabel	1 st choice – Home 2 nd choice – Margaret Centre	I will have my home comforts, my family around, 1:1 care (from my family), full attention. “I feel safer” “I don’t want to die in the main hospital”. Mabel witnessed her mother dying in hospital and saw how she wasn’t able to call for help when she needed to. She doesn’t want to experience this.	Mabel wishes to stay at home as long as possible if her husband can manage this.
Mary	1 st choice – Home 2 nd choice – Hospital or hospice		Mary wishes to stay at home as long as possible but is aware that she may need to move into hospital or hospice if those around her are suffering in any way.
Nusrat	Home	She believes her son experienced poor care/neglect when he was in hospice for respite care. It is therefore difficult for her to trust others to care for her son.	Nusrat will take her son to hospital if his health deteriorates and she can’t manage him at home. “It is hard to watch your son die”. However, it

			needs to be a setting/environment that is appropriate for a teenager – not with older people.
Alexandria	No preference	Her husband didn't mind where he died as long as he received the appropriate care	Her husband was asked if he had a preference when he was at UCLH and they were reassured that if he went home to die he would have everything in place that he needed. Based on this information he decided to go home. His care from this point was chaotic, uncoordinated and he didn't have what he needed when he was dying. His wife describes his death as "traumatic".
Lynda	1 st choice - Margaret Centre	They had a 3-year old daughter so they felt it wasn't appropriate for her partner to die at home	Her partner was being cared for at Barts Hospital. He was told he couldn't move to the Margaret Centre as there were no beds available. He was provided with a hospital bed at home so he could die at home. Lynda says they weren't given any options and this was how it had to be. He died in hospital before he could come home.

Table 2. Characteristics that are important regarding the care received/provided and the location it is received/provided in.

1. The location the care is provided in	Number of participants	Why this is important
In Waltham Forest	5	<ul style="list-style-type: none"> - My wife doesn't drive, as long as there is easy access to public transport - But easily reachable by public transport, good transport links, ideally tube as the bus can take too long. Easier & quicker to get to UCLH than Whipps Cross - Make it easier with young children – even Whipps Cross is tricky to get to.
Out of borough	0	
It doesn't matter	1	- As long as isn't not too far away,
2. The environment	Number of participants	Why this is important
24hr access - visiting	4	<ul style="list-style-type: none"> - At the end I think I will be frightened and want someone with me at all time, - This is what it would be like at home – friends and family can visit, - Someone from the family can always be with him, - "Good for me so I could monitor him, good for the nurses so I could help with care and alert them to any changes" - Not too many restrictions – there should be flexibility when someone is dying – you should just be able to stay there
Calm, quiet and peaceful	3	- No annoying beeping machines, alarms or snoring!
Type of room		
Own/single room	3	

Shared room	1	- I don't want to be in a room on my own – I'm a mixing kind of person
Good quality food	3	
Outside garden/space	3	
A view – not staring at a horrible wall	2	- View for the carer and for the patient
Not medicalised – stop procedures and monitoring (including BP), give care – “let him die”	2	- Give good end of life care
The room has enough space for a wheelchair and all the medical equipment and be able to move around	1	
Clean & bright	1	
Access to music or radio	1	
To be able to be 100% involved in the person's care	1	- To be involved in the person's care like you would be able to be at home
A bed for the carer & ensuite bathroom	1	- I Had this at UCLH and it worked really well – “lovely rooms with lovely views”
A Community room	1	- To meet other people
Comfortable seating	1	- Because of the pain I experience
Consider families with young children	1	- A hospital setting isn't appropriate
Age appropriate – for a teenager	1	- It's not appropriate for a teenager to be with older people
3. The People who provide the care	Number of participants	Why this is important
Knowledgeable and open	3	- Be trained to care for dying people and be knowledgeable about what happens to dying people - Be able to have open and direct conversations about what is happening and what will happen next

Be reliable Be able to provide a sense of safety and security, some feeling that you are being looked after and that they know what they are doing and be able to project that to family/carers so they can rely on the staff and feel able to trust them	3	<ul style="list-style-type: none"> - Knowing that the team that are looking after me would come quickly and be caring - Need to give medication on time - To respond when you call the buzzer
Have humanity & empathy, and treat people with dignity	2	<ul style="list-style-type: none"> - "Some people were nice and some were mechanical" - Help me get to the toilet when I need to and not wet myself
Be cheerful	2	
Be efficient	1	
Be positive	1	•
Be able to listen to what you have to say	1	

Question: Did you feel supported by professionals in the lead up to the death of the person you were close to?

This section of the interview was specifically for those participants who had cared for somebody with a life limiting condition who had now died.

This section asked participants about the type of support that would have been most useful in the lead up to the person's death e.g. listening and emotional support, practical and everyday support, support with putting the person's affairs in order and space away from work.

Did you feel supported in the lead up to the death?

- Neither of the participants had felt supported by any service in the lead up to their partner's death.
- They described their partner's death as "uncoordinated" and "handled badly" and this had ultimately affected their grief.

"It was so disappointing at so many stages; the diagnosis, the treatment, and ultimately the death was handled so weirdly, and badly you know, and it just ended up leaving us all with you know, I've since had to have like trauma counselling. I mean it was always going to be a traumatic experience, but the way it ended was just such a shame".

The type of support that would have been most useful:

- Emotional support to help come to terms with the fact that their partner was dying – as discussed in a previous section on page 16.

Question: What sort of information would have been most useful to you after [name of person] died?

This section of the interview asked participants who had cared for somebody with a life limiting condition and who had now died about the type of information that would have been most useful to them after the death e.g. how bereavement can affect wellbeing, where to go for support, what to do at the time of death, where to turn if there are financial difficulties.

Key issues:

- Both participants were surprised that support from the Palliative Care Team ended at the death. They had expected that there would have been some support or follow up after the death. Once their partner had died, all support from every service had stopped.
- Both participants had found their own (bereavement) support. This included listening to Podcasts, joining Facebook support groups (i.e.

Widowed And Young (WAY) and Macmillan), and organising their own grief counselling.

- One participant explained how she didn't think that counselling/talking therapies would have been helpful in the very early stages of grief as she was just totally in shock and she wasn't able to do anything apart from just 'exist'. Counselling was something that had been more useful to her, in the months/years after the death

Information and support that would have been helpful:

- **Someone 'checking-in' with the bereaved carer during the first few months after the death.** This could be by someone like a Family Liaison/Care Co-ordinator (as described on page 9) or someone from the Palliative Care Team.
- **Grief counselling provided by skilled and trained staff** (rather than peer support provided by volunteers). This should not be time limited i.e. able to access this at any stage after a bereavement (including years later) and is not limited to a particular number of sessions.
- **An information booklet about local and national bereavement services that have been quality checked.** The quality check is important as there were concerns that there are a lot of services offering bereavement support (of varying quality) and that people are very vulnerable at this time.