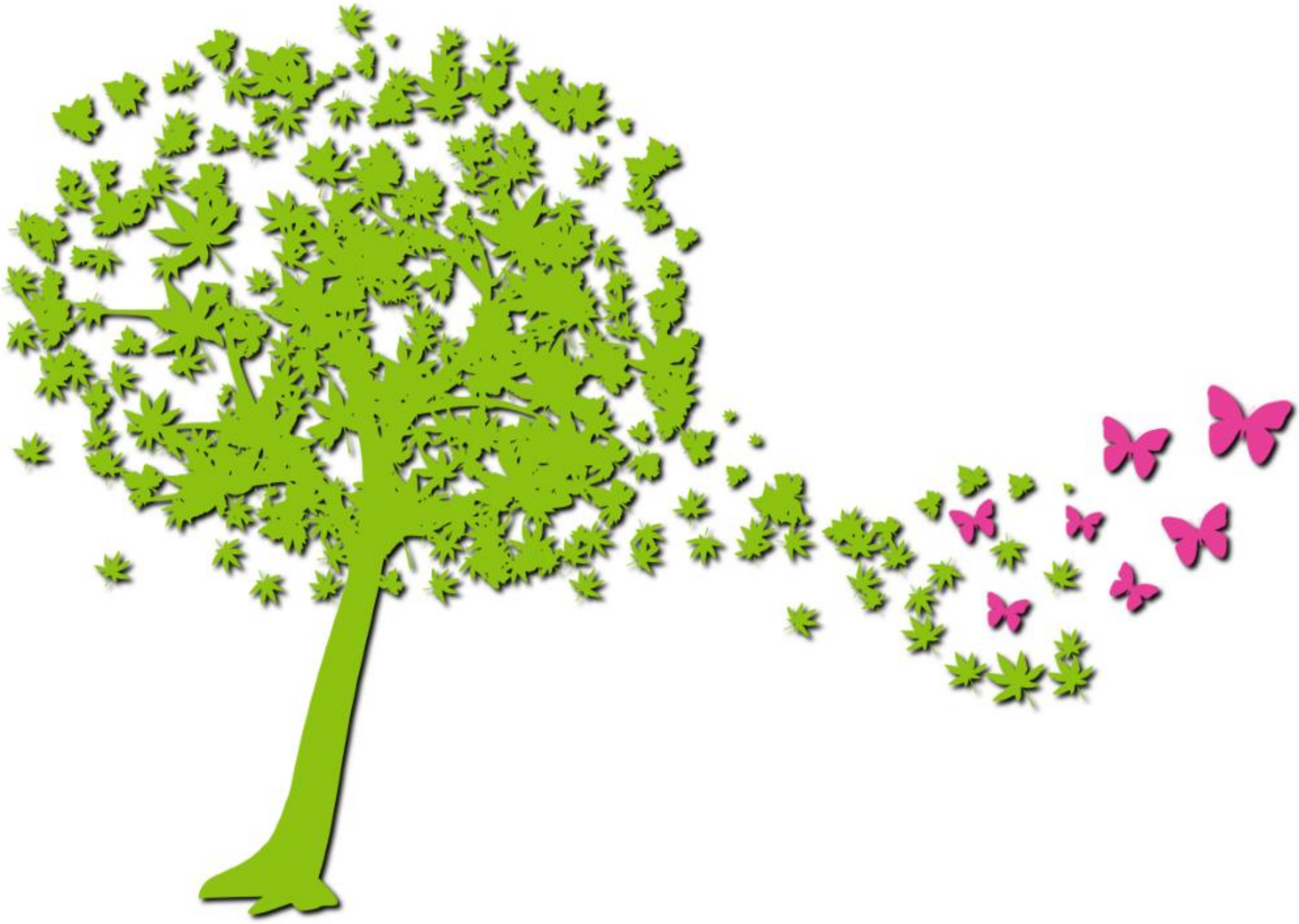
healthwatch
Oldham



Talking About Dying

A Review of Palliative and End of Life Care in Oldham

December 2019

What could we do better?

This report presents the feedback from over 180 people who took part in the Healthwatch Oldham End of Life Review.

The review shares the experiences of families and carers who have supported a family member through palliative and/or end of life care. It also provides an insight into what some Oldham residents think would be important to them at the end of life and how comfortable they feel talking about dying and sharing their wishes with family and friends.

We recognise that talking about death and bereavement can be very upsetting and we want to thank all the families, carers, partners and friends who took part in this end of life review. Their willingness to share very personal and emotional experiences will help others by informing the recommendations in this report and helping to shape end of life services across Oldham.

We would also like to thank the practitioners and organisations who completed the professional survey for their honesty and vital insight into the realities of providing care, and for taking the time to meet the Healthwatch Oldham team to explain how end of life services operate across Oldham.

Disclaimer: about our research

Please note that the stories within the report are subjective accounts by individuals given on the day they were interviewed, and do not represent the views of Healthwatch Oldham. Healthwatch Oldham carries out research in line with accredited guidelines set out in Healthwatch England's Research Framework. We aim to identify what matters most to people and use our findings to ensure that people's voices influence and improve the quality of local services.

If anyone has any queries relating to the content of this report, please contact a member of the Healthwatch Oldham team via info@healthwatcholdham.co.uk.

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Executive Summary

Background

Between July and December 2019 Healthwatch Oldham carried out a review of palliative and end of life (EOL) services. This was an opportunity for local people to share their experiences, thoughts and wishes to help inform best practice and shape local services.

Families and carers shared their stories of supporting a loved one at the end of their life. The review gathered the experiences of Oldham residents using Oldham services as well as a small number of residents who accessed palliative services in other parts of Greater Manchester. Through in-depth interviews we identified recurring themes and challenges faced by families as well as the key attitudes and types of care that make a good end of life experience. These findings have informed our recommendations.

We also recognise that people can be reluctant to discuss death and dying with family and friends. So, we invited the general public in Oldham to tell us what they thought would be important to them at the end of their life and what stops them talking about dying.

The review was chosen in response to the following:

- Oldham Carers' Partnership Board highlighting issues faced by carers supporting a loved one at the end of their life.
- Saddleworth District Centre Partnership highlighting a lack of community bereavement support.
- The NHS Advocacy Service receiving mixed feedback from families accessing palliative and EOL care and an increase in the number of Do Not Attempt Resuscitation (DNAR) complaints.
- Work by the Greater Manchester Health and Social Care Partnership to develop EOL commitments.

The review also recognises several new Oldham initiatives designed to improve palliative and end of life experiences for patients and families. Initiatives include the creation of five neighbourhood based integrated health and social care teams, the SWAN end of life service at the Royal Oldham Hospital and the Hospice at Home service provided by Dr. Kershaw's Hospice.

What is palliative and end of life care?

Palliative care is the diagnosis, treatment, care and support for people with a life limiting illnesses that cannot be cured. Palliative care can include help with day to day tasks, managing pain, aids and adaptations, emotional and psychological support, and support for carers and family. Some people can receive palliative care for several years.

In contrast end of life care involves care and support for people nearing the end of their life. This is an important part of palliative care and can include the final year of life but more often it relates to the final months or weeks. End of life care also involves talking about and planning for what people want and can expect as part of their end of life.

Palliative and EOL care are delivered by a range of different services and organisations across Oldham. These include hospital services, social workers, district nurses, GPs, hospice, care homes, private care agencies and voluntary sector services.

The review found that people going through palliative care regularly deal with at least four different services at any given time. So, we wanted to find out how well services are coordinated across different settings and how well they work together in the interests of the patient and their family. We also wanted to explore how well services respond to the changing needs of patients moving from palliative to end of life care and how they always ensure consistent high-quality care. The review is also designed to explore the experiences of carers both during their caring role and through bereavement support.

What we did

Between July and December 2019 Healthwatch Oldham carried out three different EOL surveys:

Survey 1: Healthwatch Oldham 100 - Talking about dying

We used the short Healthwatch Oldham 100 survey to ask the general public how comfortable they feel talking about dying and sharing their wishes with family and friends. We also asked what factors they felt would make a good death. Members of the public completed the questionnaire online or in person at one of our community events. A total of 131 people completed the short survey.

Survey 2: In depth Interviews - Supporting others through their end of life

In depth 1 to 1 interviews were carried out with families to gather their experiences of supporting a family member at the end of their life. The questionnaire was also available to complete online through our website. We appreciate that talking about death can be upsetting so information on a range of bereavement and counselling services was included with the questionnaires and as part of the interviews. The survey was advertised through Healthwatch Oldham e-bulletin, social media and promoted through the Oldham EOL Partnership. A total of 22 families took part in the survey.

Survey 3: End of life Survey - Questionnaire for professionals

The final survey was a short questionnaire sent out to professionals involved in the treatment or support of patients accessing palliative or end of life care. The professional survey was launched in September 2019 to allow time to analyse data from the first two public surveys and use any recurring themes as the basis for the questions. The aim was to seek the views of professionals on these themes and explore potential solutions. A total of 31 professionals completed the survey.

Key Findings

Families and carers shared many positive experiences about palliative and end of life care in Oldham, and 65% of respondents felt that the person they cared for had the best possible end of life.

When it works well care reflects the wishes of the patient and their family and is well coordinated across a range of settings including acute hospital services, GPs, community nursing teams and the hospice. Families who had a positive experience talked about professionals being patient and taking the time to talk, and staff providing care with empathy and compassion. Other key factors include effective symptom management and timely pain relief, and easy access to information and advice 24 hours a day. Whilst being in their preferred place to die was important, families understood when this was not in the interest of their loved one. Being surrounded by family or close friends at the end of life was the most important factor.

Families with a good experience of services tended to be those who were diagnosed early and did not have any other underlying health conditions to complicate the diagnosis or care pathway. It works well when all the care and emotional support for the patient and family are coordinated from one service such as the SWAN hospital service or Dr Kershaw’s Hospice, and where the needs of the carer are recognised and supported in a timely way.

60% of respondents said they would prefer to die in their own home and for many families this was a positive experience. Frustrations with care at home arise when families struggle to access timely treatment, information or support. Feedback highlighted the unreliable access to pain relief during evenings/weekends when fewer district nurses were available, resulting in one patient dying in pain.

Patients with two or more chronic conditions often had a poor EOL experience as a result of confused symptoms and being passed around different services without a main point of contact.

Perhaps the most telling feedback is the extent to which palliative and EOL services rely on the role of unpaid carers to coordinate and in some cases provide practical and personal care 24 hours a day. This role can be made more challenging with delays to EOL funding caused by complicated processes for Continuing Healthcare Funding (CHC funding) or disputes between services.

Coordinated Care:

When it works well there is good communication and central coordination of services across different settings with professionals working together to ensure continuity of patient-centred care. Examples included the GP, hospital or hospice each acting as a central coordinating point for multi-agency support.

Good coordination is underpinned by holistic care plans produced in a timely way to identify the practical, social and emotional needs of the patient and unpaid carer. When it works well care plans are shared with relevant services to ensure teams work together in line with the patient's wishes and actively engage with the family involved in the wider care of the person at end of life. Only 23% of families in the review were aware of a care plan for the person at the end of life.

50% of families were responsible for coordinating an average of 4 different services providing treatment and care to the person at the end of their life. Carers on their own often struggled with the pressure of this role especially where the person they cared for had more than one condition and it wasn't clear who to contact.

Communication:

Feedback from families and professionals raised several communication issues.

When it works well professionals take the time to communicate clearly, explain medical terms and show compassion and empathy. Families said that the way the diagnosis was communicated and having time to talk to professionals was key to helping them deal with upsetting news. 53% of families in the review said that the diagnosis was handled sensitively.

Families get frustrated when they are asked to repeat their stories either to different services that should be working together or to different staff from the same service. Examples included poor communication by consultants within the hospital setting and between different district nurses looking after the same patient. Families felt this was due to poor record keeping on patient notes and lack of consistent care. However, some professionals said that asking a patient to share their story is often a way to get to know a family and help build a relationship.

Families who felt they had a poor experience included those who received upsetting information or a diagnosis in a public space and not knowing who to speak to for ongoing advice.

Professionals highlighted their own frustrations about the time wasted trying to track down information about patients and families due to different referral processes and different IT information systems.

Coexisting Conditions:

64% of people who took part in the review had more than one diagnosed health condition as part of their palliative and end of life care.

Patients with more than one condition often experienced different levels of care compared to those with a single terminal condition. Often this was due to confused symptoms which delayed the terminal diagnosis or complicated the care pathway. The delay is important as having a terminal diagnosis appears to be the key to a smooth transition from palliative to EOL services and treatment.

Families were frustrated where they struggled to manage conflicting symptoms and felt they were not being listened to. Examples include underlying conditions such as dementia, alcoholism and mental health delaying a terminal diagnosis and where the associated challenging behaviour impacted on the quality of care.

Timely and holistic care plans are needed that actively address each condition and proactively identify and address the management of any challenging behaviour as part of the EOL care.

Access and choice of care:

Families said they would welcome more flexibility of EOL services and easier access to EOL advice and support 24 hours a day.

45% of families who took part in the review experienced end of life care at home. Being able to die in their preferred place was often the key to a good end of life experience. However, families who had a poor end of life experience at home were those who struggled to access support, timely pain relief during the night, and where delayed end of life funding left carers providing all the care 24 hours a day without any other support. Families were also frustrated by the inflexibility of care packages which have fixed daytime visits and a limited night sitting service. Some carers wanted more support at night so they could get some sleep.

Professionals said that improved 24 hour access to hospice, district nurses and specialist palliative nurses would improve EOL care for patients and their families. Some families also wanted easier telephone access to the district nurses and Macmillan nurses.

Quality of Care:

Feedback from families highlights how the quality of EOL care varies across different settings. It also varies depending on the individual professionals working with the family.

For many the district nurses and GPs provided a lifeline and families shared examples of best practice about individuals and teams coordinated from the neighbourhood clusters. However, experiences were very mixed.

Families were frustrated by rushed visits where the district nurse focused on a single task and ignored any wider care issues for the patient or carer. Some district nurses were aware of this and shared their frustrations at the lack of time they can spend with families which means wider issues are often ignored because they don’t want to ‘open a can of worms’.

Families were also frustrated where GPs failed to engage with the family to support the person at the end of life. Often this was because the GP was not aware the person was at EOL. Feedback from professionals highlight the lack of palliative and EOL knowledge within primary care as an issue.

Preparing for EOL:

Macmillan 1-1 Support appeared to be the only service that **routinely** provided information and advice to help families prepare for the full range of legal and final medical stages of end of life.

Some professionals focused exclusively on the completion of Statements of Intent and DNACPR (Do Not Attempt CPR). Many families (77%) had a DNACPR in place however nearly half of these were completed without any discussion with the patient or family. Some families were frustrated to find out about it after the person had died. DNACPR guidance and practice varies and where it works well doctors follow the NHS England guidelines by taking the time to clearly explain their views and talk openly with the patient and family to answer any questions.

EOL Funding:

During the last three months of life 16 carers in our review provided over 12,000 hours of unpaid care; 7 of the carers provided care 24 hours a day.

This situation is often made worse as families struggle to access additional support due to delays with EOL funding. Families highlighted the complex processes for Fast Track CHC funding which caused significant delays to EOL care. Professionals making the applications often had to submit more than one application before being approved as they were not aware of the qualifying information such as the medical declarations and anticipatory medicine required for the application to be approved.

All this happens at an emotional time for the carer and in one case the delay resulted in the carer taking on unreasonable levels of personal care that impacted on their own health and wellbeing.

Role of unpaid Carers:

73% of carers who took part in the review felt that they were listened to by professionals and 55% felt they had enough information and support to help them in their caring role.

When it works well carers receive additional support from family, friends and services. Having a regular weekly break to socialise was important as well as having support from family to help make tough EOL decisions where the person being cared for does not have the capacity to make the decision.

The effects on a carer can be considerable both in terms of their physical and emotional wellbeing. Many struggle with the physical demands of lifting and moving the person they care for, often trying to prevent pressure sores. Some said they would welcome help from district nurses who visit regularly as well as access to training covering moving and handling, managing medication, and EOL symptom identification and management.

Bereavement support:

41% of carers who took part in the review were offered bereavement support.

The SWAN service at the Royal Oldham Hospital and Dr. Kershaw's Hospice already offer bereavement support to families using their end of life services. However, families outside of these services struggle to find any bereavement support within the community.

Carers providing care over a long period of time can struggle with loss of identity and role as well as grief following a bereavement. Many said they would welcome some follow up support. Carers and family members said that they would prefer to hear about bereavement support at the point of diagnosis or immediately following the death of their loved one.

Main Recommendations

Healthwatch Oldham's recommendations are based on the feedback and experiences of families, carers and professionals who took part in this review. The Oldham Health and Wellbeing Board will be responsible for reviewing and overseeing the delivery of the recommendations.

Where possible the following recommendations have been aligned with the Greater Manchester Health and Social Care Commitments. These commitments set out what individuals with palliative and end of life care needs can expect across Greater Manchester and provide a baseline to measure the quality of care provided in Oldham.

Recommendations:

1. **Coordinated Care –** Establish a **Lead Provider Model** for Oldham where EOL services are centrally coordinated across different settings and practitioners to ensure continuity of patient-centred care. Staff teams in the EOL hub should mirror and integrate with each of the 5 neighbourhood cluster teams and the local MDT would be responsible for assigning a key worker as the main point of contact for the EOL patient and their family. This model should include increased access to and usage of shared digital records between professionals to improve both continuity and quality of care.

2. **Timely Identification –** Ensure that patient reviews will actively prompt practitioners to identify people within or approaching the last year of life, particularly people with co-morbidities. This will help to ensure the smooth and timely transition from palliative to EOL care.

3. **Planning Care –** Provide training and consistent guidance on the production of holistic EOL Care Plans which include the identification and management of underlying health conditions, the preferred place of care and death, and consider the need for a Carers Assessment. Practitioners should encourage the individual to share their EOL wishes with their family, including thoughts on DNACPR, whilst respecting the wishes of individuals who do not want to discuss or plan for their EOL.

4. **Communication –** The Lead Provider Model should include mandatory EOL training for professionals across acute and neighbourhood settings covering all aspects of EOL communication, from delivering a terminal diagnosis to conversations during bereavement. The training should focus on managing sensitive issues with compassion, giving clear information to the dying person and their family about what to expect, and offering time for questions. The patient and family experience should be measured annually through carer/family feedback.

5. **Consistent Care –** Working closely with each neighbourhood cluster the Lead Provider Model should introduce measures, including an assigned EOL Key Worker, to limit the number of different people involved in the ongoing care of the patient.

6. **Hospice at Home –** For people who want to die at home the Lead Provider Model should ensure that EOL care is managed by the Hospice at Home Service and ensure reliable access to pain relief 24 hours a day.

7. **Information and Advice –** The Lead Provider Model, in partnership with the Macmillan 1 To 1 Service, should develop consistent information and advice resources across a range of EOL conditions to help families prepare for legal and financial issues, and any final medical wishes.

8. **Crisis Care –** Improve urgent care for EOL patients through a single point of access that provides 24 hour advice and the central coordination urgent care services including hospice admissions, DNs and specialist palliative care nurses. Promotional information should be available in a range of formats and languages to promote the service.

9. **Last Weeks of Life –** The Lead Provider Model should ensure timely access to EOL funding and work with Fast Track CHC systems to make the process more transparent and increase the number of trained staff able to complete successful applications.

10. **Care for the Last Days of Life –** Review the flexibility of funded care packages to allow more night sitting support for carers providing 24 hours care.

11. **Training –** The Lead Provider Model should coordinate and deliver mandatory training for professionals/GPs within neighbourhood clusters on the Mental Capacity Act and DNACPR. Training should ensure a consistent approach to DNACPR conversations by adopting a Serious Illness Conversation Guide and NHS England guidelines to ensure doctors in acute and primary care settings take the time to explain their views and talk openly with patients and families.

12. **Support Carers –** Oldham Carers Partnership Board is asked to consider how providers, including the voluntary and community sector, can increase support for carers to help manage their physical and emotional needs. Specific focus should be given to working carers, older carers and those caring on their own without wider family support.

13. **Bereavement Support –** Ensure that consistent access to bereavement support for carers/families is available regardless of where the person has died. Bereavement services should also include support to address social isolation, financial issues, selling property, legal advice and wellbeing and link into wider peer support and mainstream prevention services offered by the voluntary and community sector.

Detailed Findings

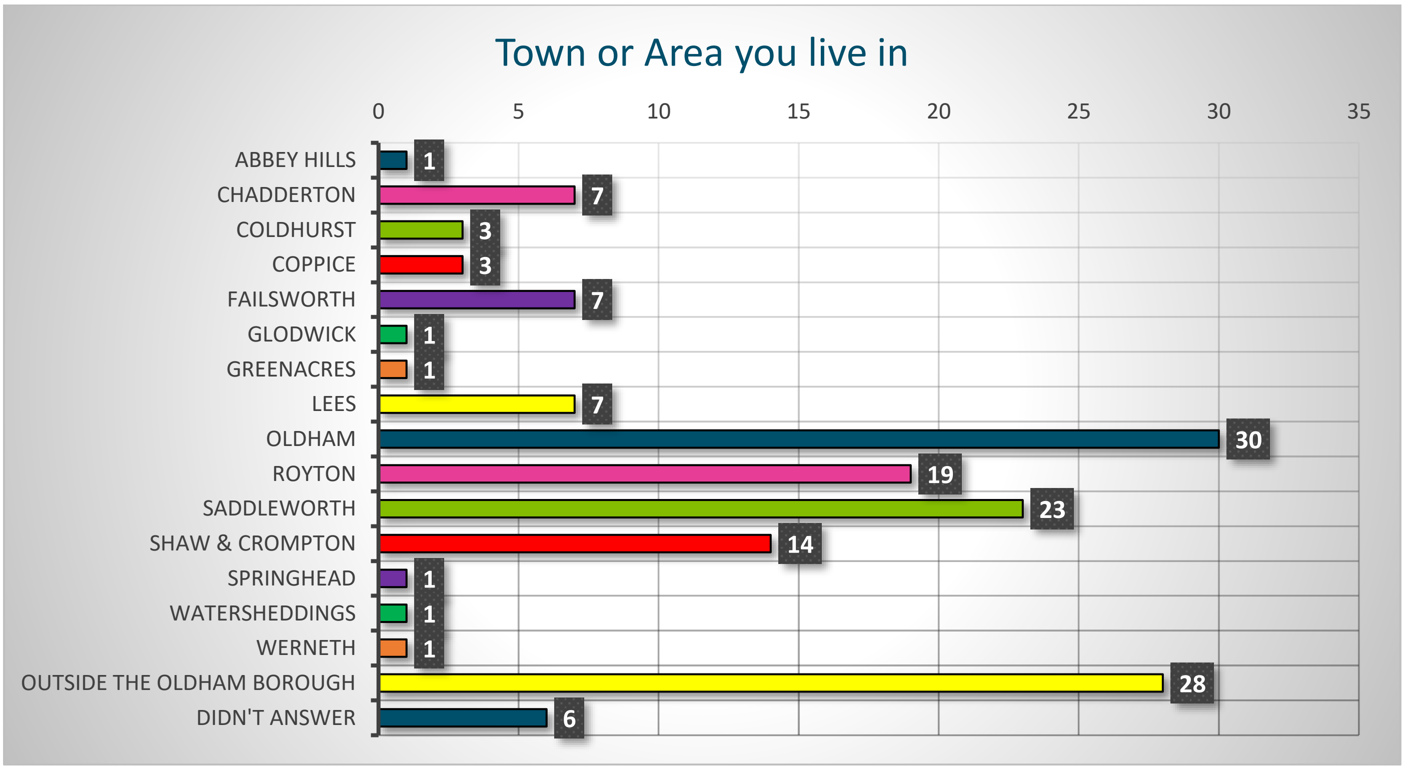
Profile of respondents

The following provides a profile of the 131 respondents who completed the Healthwatch Oldham 100 Survey plus the 22 families, carers or partners who took part in the more detailed end of life interviews.

A total of 153 people took part in the public survey, however not all the respondents completed all the questions. From the data we received we have been able to extract the following information.

Age Range	16-25	26-35	36-50	51-64	65+	Didn't Answer	TOTAL
Number of Responses	3	18	39	65	26	2	153

Gender	Male	Female	Transgender	Prefer not to Say	Didn't Answer	TOTAL
Number of Responses	26	121	1	1	4	153



Those who took part in the survey included Oldham residents using Oldham services; people living outside of Oldham using Oldham services; and family and carers living outside of the borough caring for someone at end of life living in Oldham.

Of the 153 people who took part in the surveys 69% (105) were White British or White Irish; 8% (12) were of black, Bangladeshi, Pakistani or Asian ethnicity and 24% (36) preferred not to answer this question.

Survey 1: Talking About Dying

The following infographic provides a summary of the feedback from 131 people who took part in our Healthwatch Oldham 100 survey. We asked members of the public what they thought would be important to them at the end of their life and how comfortable they feel talking about dying and sharing their wishes with family and friends.

Age Range	16-25	26-35	36-50	51-64	65+	Didn't Answer	TOTAL
Number of Responses	3	15	38	57	16	2	131

73%

Of people have spoken with their family and friends about death and end of life

59%

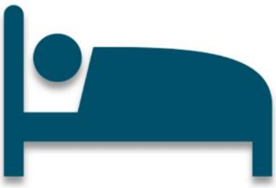
Of people say that their family and friends know their wishes

60%

Said that they would prefer to die at home

2%

Said that they would prefer to die in hospital



19%

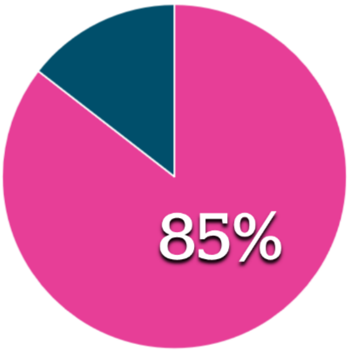
Said that they would prefer to die in a hospice

47%

Said that they knew they could write an End of Life Plan at any time

61%

Said that they would prefer to talk to family and friends to discuss and record their end of life wishes and plans



Of people stated they had experience of someone being on the end of life journey

62%

Of people stated that completing this survey has prompted them to think about making their own end of life plan

What's important to you about your care?

- To Be Pain Free
- Treated with respect
- Not to be a burden
- Not to die alone
- To have care when I need it
- To die where I want
- To have financial affairs in order

Most Important ↔ Important

What else is important to you?

- Chance to say bye to family and friends
- To know my family is cared for
- To be told I'm dying
- Have one point of contact to talk to
- To have one person to organise my care
- That my family are trained to care for me
- That my spiritual needs are met

Most Important ↔ Important

What stops you talking about death with your family?

Doesn't Feel It's The Right Time
Upsetting Others
Keep Putting It Off
Difficult Subject
Not Had Time
Morbid
Nothing
Denial
Taboo
Fear
Embarrassment
Not Ready
Nobody To Tell
Don't Want To Think About It

What stops you from telling your family your end of life wishes?

Don't Want To Cause Upset
I Don't Plan Ahead
Too Young To Understand What I Want
Nobody To Tell
They Know Some of My Wishes
Not Important
I Should Do
Fear
Complicated
Hasn't Come Up
Don't Want To
Not Thought About It
Not Made Decisions Yet
Too Young
Not Had Time
Hard To Talk
They Don't Take It Seriously
Feels Strange
Don't Know
All Arranged So No Need To
Deal With It When It Happens

Survey 2: In Depth End of Life Interviews

This section of the report shares the experiences of the 22 families, carers or partners who have supported a friend or family member through palliative and end of life services within the last 3 years. Of those who took part in the survey 55% (12) of the families supported someone within the last year.

The majority of those who carried out a caring role were female aged over 65 years whilst the most common age for the person at the end of their life was between 81 and 90 (9: 41%).

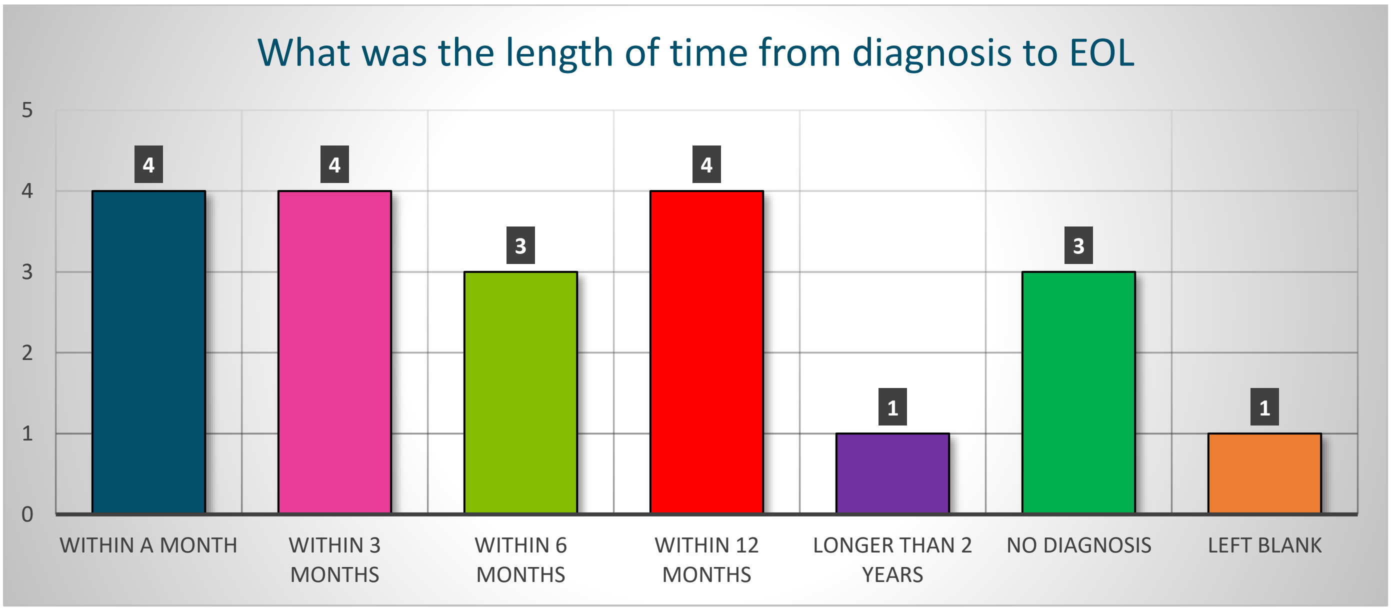
What was your relationship to the person that died?	
Husband/Wife	**7**
Partner	**2**
In-law relation	**1**
Grandmother	**1**
Adult Son/Daughter	**4**
Father/Mother	**7**

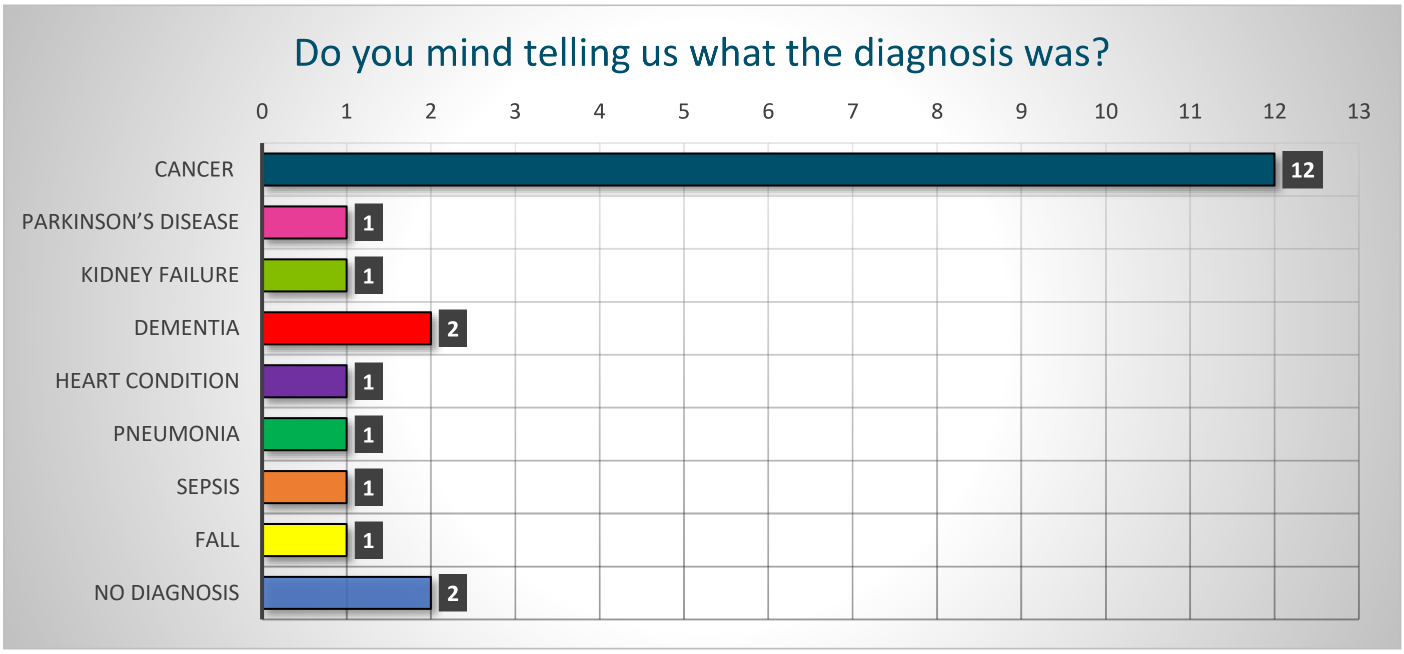
How old was your partner, relative or friend when they died?	
50 - 60	**1**
61 - 70	**4**
71 - 80	**5**
81 - 90	**9**
91 - 100	**3**

Identification

It is important that individuals approaching the last year of life should be identified as early as possible by professionals and the formal diagnosis and prognosis should be explained in an accessible and sensitive way. We asked families to tell us about the diagnosis of the person they cared for and how they were told.

Of those who responded to the survey 36% (8) died within 3 months of their diagnosis and 68% (15) died within 12 months of their diagnosis.





Of those who responded 55% (12) had a terminal diagnosis of cancer and 64% (14) had more than one health condition to manage as part of their palliative and EOL care. The most common underlying health conditions were depression (36%: 8), diabetes and alcoholism. Where the patient had a dual diagnosis of a terminal condition plus dementia or a learning disability or alcoholism these underlying conditions often masked symptoms and delayed the early identification of end of life. Patients with these dual diagnoses also experienced different levels of care compared to those with only one diagnosed condition.

Families had mixed experiences about receiving a diagnosis. Of the 15 families/carers who responded to this question 53% (8) said the diagnosis was handled sensitively and they had a positive experience compared to 47% (7) who felt the news had not been handled sensitively and said there was nothing positive about the experience.

When it worked well professionals took the time to communicate clearly, explained medical terms and answered any questions the family had. Professionals also gave the diagnosis with compassion and empathy. Families who said they had a poor experience received a diagnosis in a public space where others could hear and others felt the diagnosis was treated as a routine conversation by professionals.

"My Grandma said she couldn't fault The Chrisities from the beginning, always happy with treatment and care. They told her the news compassionately and answered all her questions."

"No, nothing could have been done differently… there was one or two doctors and the Macmillan Nurse came in."

"We were both shocked about how he was told he had a terminal illness. The nurse/practitioner had his x-rays in front of her and her words to him were "well, what do you think is wrong with you?" to which he said "well obviously now, from your question, I think I have cancer". Cancer had never entered into our heads so of course it wasn't a good experience."

"The consultant was explaining it in medical terms…but X was quite direct and just said have I got cancer and he said yes."

"More empathy"

Whilst one family preferred to be left alone after the diagnosis overall those who were more positive about the experience said it was because they had professionals with them who they could talk to and felt well informed. Feedback from families show that the way the diagnosis is given is key to helping patients and families deal with upsetting news.

As the person caring for your family member or partner - what would have helped you at the point of diagnosis?

Many of the cases involved more than one member of the family contributing care and support and, in some cases, this provided vital support to the main carer within the family. Those who struggled tended to be family members who had the responsibility of making end of life decisions on their own. Many talked about the impact of caring on their own physical and mental wellbeing.

"I got all the support I needed from my two sons and their families."

"Felt supported by hospital staff and also MacMillan staff based in the hospital and in community."

"We were fully supported by the (SWAN) staff at Royal Oldham hospital. We were put in a side ward and made it our home for a week. We were visited by the end of life representative and could not have asked for anything more, even provided us with toiletries donated by a local guide group. My husband was attended by a family member 24/7 throughout the week and a put-u-up bed was provided."

"A phone call after to help me understand the process."

"Follow up support - not to be discharged with a bag of end of life medication."

"We had very little support throughout her illness and fell through the net. Just a single visit from Macmillan and NO follow up at all. Left completely on our own to struggle, with no support from anywhere…"

Treatment

For most of the families who responded treatment was not an option either because it was not appropriate, or because the diagnosis was made in the latter stages of end of life when it was too late for treatment to be effective. Of those who responded they said that the speed of treatment following diagnosis was what they expected.

> *"Spending the last few weeks of my partners life going from one hospital to another [was not good]. On reflection it was pretty futile but of course at the time we didn't realise how little time he had left."*

Care

Tell us about your experiences of end of life care

End of life care generally refers to the last year of life or more often the last few months or weeks. The 22 families told us about their experiences of end of life care in several different settings:

- Care at home
- In the hospice
- In a care home
- In hospital

When it works well people approaching end of life are offered a personalised assessment designed to capture their wishes and ensure a smooth transition between palliative and end of life care. The Care Plan is reviewed regularly to respond to any changing needs and also takes into account the wider support needs of carers. Only 5 (23%) families were aware of a Care Plan for the person at the end of life. However, this may be due to terminology as most families talked about having regular discussions with the GP, social workers or palliative nurses about the care they wanted, but this was not always presented as a formal Care Plan.

Palliative and EOL care is delivered by a range of services and organisations across Oldham and our survey found that people are often in contact with several services at any given time. So, we wanted to find out how well services are coordinated across different settings and how they work together in the interests of the patient and their family.

Families shared many positive experiences about the different health and social care services they came in to contact with. Often this was due to the attitude of an individual, so we have tried to capture the characteristics that make a particularly good or poor experience.

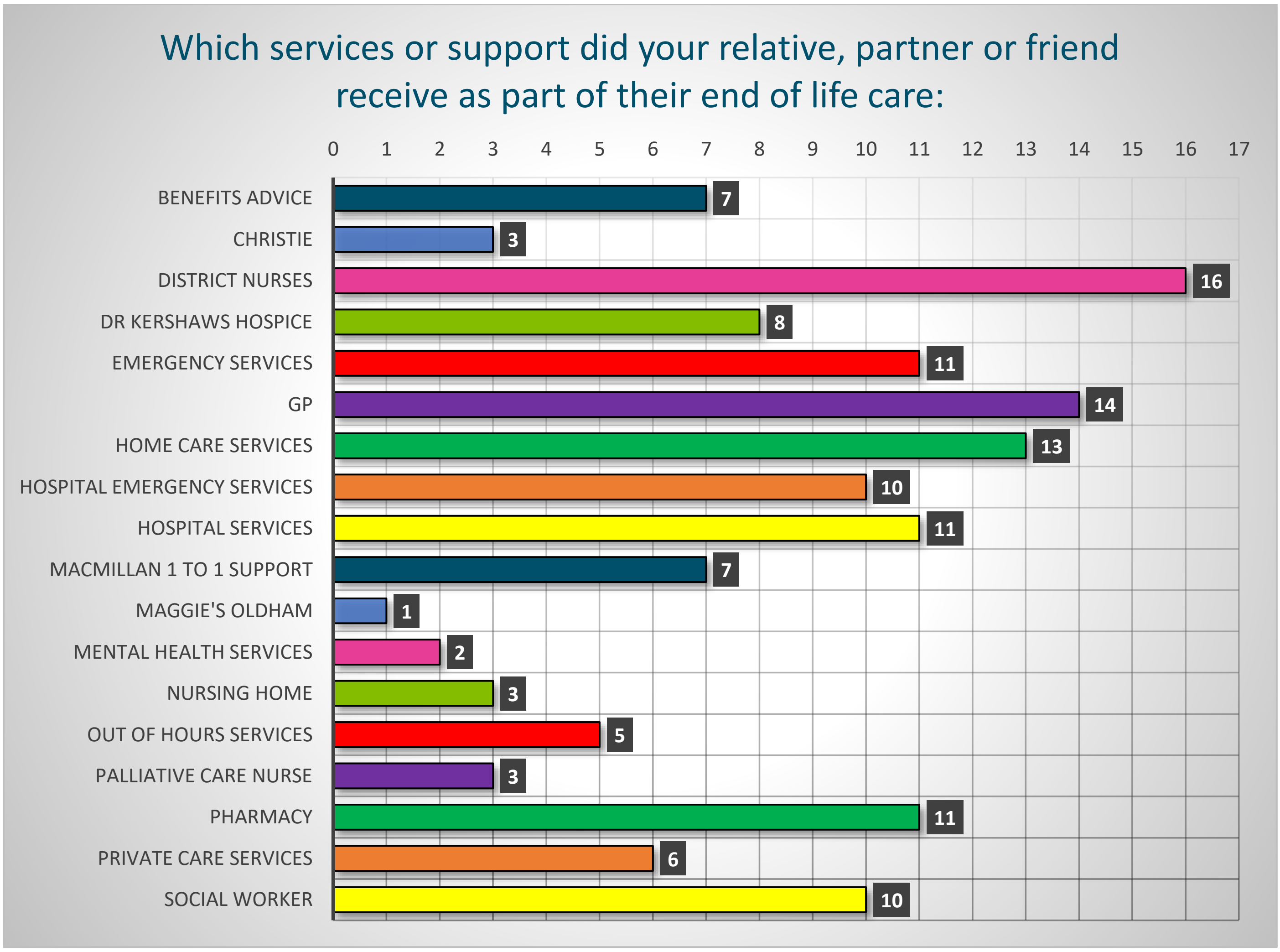
Where it works well there is clear communication and central coordination between generalist and specialist care services who are working in the interests of the patient and the family. This includes multi-disciplinary teams working together to address the practical, personal and emotional needs of the patient and their family or carer as well as providing consistent care regardless of any underlying health conditions or time of day.

> *"All the services Mum received were compassionate, efficient and supportive to the family as well as Mum. Always on the end of the phone and responded quickly in crisis."*

> *"All the different services worked well together. For example, the ROH advised the GP practice when Dad was being discharged and the GP would arrange for the District Nurse to come the following morning. There was really good communication and coordination between services."*

> *"There were so many support services helping X that sometimes I struggled with the pressure of coordinating all the different visits and services. My husband was able to help, and he became the main contact for services so I could concentrate on X."*

Tell us a bit about services



The following provides a snapshot of the care provided by these services:

Tell us a bit about the GP service

For many families the GP provided a lifeline and when it worked well the GP took time to listen to concerns, provided reassurance, communicated well, carried out thorough checks before prescribing medication and coordinated community services following discharge from hospital. In short, they actively engaged with the family in the care of the person at end of life.

Families were frustrated when the GP failed to engage with the family to support the person at end of life either because they were not aware that the person was at this stage or because they saw this as the responsibility of specialist services. Families and professionals recognise and value the central role played by GPs, and they want the GP to know which patients registered with their practice are at end of life and consider this when families contact for support.

"Dr x cared for me as much as he cared for my parents. If he was passing, he would bob in to see my parents then would phone with suggestions on what to do...He respected the way we wanted to do things as a family. I trusted him completely."

"When I was losing it as I was so exhausted, and my head was mush balancing full-time work with full time caring he would let me rant"

"The GP was really reassuring and provided quick and effective care and support for Dad throughout."

"As soon as I contacted him to let him know the District Nurses hadn't been out to change Mums dressings for a few days he straight away got in contact with the Community Matron who came straight out to see me"

"[The GP] said I could have something just to calm him, his Dementia… was really hard work…[the GP] prescribed Diazepam but didn't see him. I rang him again because he was in excruciating pain and he prescribed tramadol, then liquid Morphine without seeing him. [Daughter] requested that [the GP] come out to see him that day when she was here but [the GP] refused. It wouldn't have stopped the Dementia, but it might have stopped the stroke"

"Treatment and care from his original GP was appalling, so changed GP and received outstanding service, during treatment and beyond."

"At the beginning the GP wasn't that helpful as X had a history of drinking so they just put it down to that. Once diagnosed with Cancer the GP was good."

Tell us a bit about the pharmacy service

Overall families expressed satisfaction with the pharmacy service and valued their knowledge and advice about medication and the fact that some individuals ‘went the extra mile’. However, some families were frustrated with the lack of privacy and were not comfortable discussing sensitive issues such as incontinence, in a public space.

> *“The delivery person was marvellous, if I was at work or not there he knew to leave things in the kitchen, he would shout up to my parents to say he had dropped the products off, and would switch the kettle on for them.”*

> *“Helpful with volume of medication.”*

> *“Services could be explained to carers in a quiet environment not at public counter.”*

Case Study 1: Bert’s Story

Bert started with horrendous headaches. The GP said he needed sugar in his body, and we should just give him sugary drinks, he didn’t prick his finger to check. Bert was in bed with terrible pain so wouldn’t eat or drink, he just wanted tablets. I took him to A&E at the Royal Oldham Hospital who said they would keep him in for an MRI scan. That night he was worried about dying so he wouldn’t close his eyes and talked to keep himself awake. Staff saw him as a nuisance and wanted to get rid of him, so they sent him home the following morning without the scan saying there was nothing wrong with him. They never asked me. He had a stroke later that day at home. Bert then had to manage the effects of a stroke, vascular dementia and Non Hodgkinson’s Lymphoma.

The District Nurse said she would ring every Wednesday. The first Wednesday she didn’t ring nor the second, so I rang her and said he’s got pressure sores. She organised some barrier cream but never asked if he needed a wash, how I was managing, or how I was getting him to the toilet. She was there five minutes. The last two or three weeks were difficult. He started falling because he was in so much pain and I was trying to pick him up off the floor. It got so he was unable to move himself at all, he forgot how to sit on the toilet.

It wasn’t until he got to Dr Kershaw’s that it changed. They were wonderful. Initially he went in for 2 weeks and they sorted his medication and shaved him. He wouldn’t let me shave him. Within two days of being in the hospice he was clean shaven because they were giving him the right medication and pain relief – Morphine tablets at first for two days but then he couldn’t swallow them, so they put him on a shunt. He slept a lot, but he was comfortable. They were wonderful; they kept him clean, kept him pain free, they had music going for him. In the morning the nurse would say “We’ve been watching Homes Under the Hammer; we’re not going to buy a ‘doer upper’ are we Bert?” She took away all the embarrassment out of the situation and looked after me, checking I had eaten. All of them are fabulous.

Tell us a bit about Hospital In-patient Services

Most of the feedback involved Oldham residents being treated at the Royal Oldham Hospital (ROH) and just a few being treated at other hospitals across Manchester.

Families spoke highly about the SWAN end of life service at the ROH. The service uses a swan symbol next to the patient's bed to represent end of life and allows relatives open visiting around the clock. The swan also acts as a reminder to staff to be extra caring and to pay extra attention to relatives and friends whose loved ones are in the last stages of life.

However, people without an EOL diagnosis accessing palliative care on a general ward had mixed experiences. Families were frustrated when they had to repeat their information several times to different doctors on the same ward and where they experienced long delays when they were told they were about to be discharged home.

Some families also praised the ambulance service which took them into hospital both for their speed of response and ability to remain calm under pressure.

"The ROH was good with the communication and information about Dad. Even though they were always busy they made time to talk. We were always able to speak to senior nursing staff and they always gave us plenty of notice about hospital discharge. I was impressed that they would not let Dad go home until the adaptions at home were in place - they were very efficient."

"The care at North Manchester Hospital Critical Care Ward was absolutely amazing and could not have been better, apart from one doctor telling us they were terminating treatment on the Tuesday night, so we prepared for withdrawal of the ventilator and then he changed his mind about 9pm and said he wanted to wait until the following day for the other doctors to confirm. He sent the nurses to tell us."

"The attention from the (ROH SWAN) medical staff was second to none. My husband was treated with the utmost respect, and attention to cleanliness and comfort were unquestionable."

"I really can't fault the care and attention Dad received. We had a follow up call from the ROH to check how Dad was doing and the hospital Dieticians helped when he was struggling to swallow, and District Nurses constantly checked for pressure sores."

"Mum was deteriorating rapidly…we left drink but the following day it had not been touched because the table was moved away from her."

"Very matter of fact - like it was just one more in whole lot of other people."

“Nurses were over stretched on all the wards but on the female medical ward a Polish cleaner was fetching things for patients, really helpful. Need more staff and to be more caring - too many agency staff.”

“One time after she had been sent home a taxi driver came with a bag of medication sent by the hospital. We had to ask the DN if she knew what it was.”

Tell us a bit about the District Nursing service

The feedback about the District Nursing service was very mixed. When it worked well the district nurse (DN) provided holistic support for the patient and the family or carer, ensured regular contact, and was easy to access regardless of the time of day. The DN Team in Oldham’s South Cluster were praised for allocating the same nurses to one family ensuring continuity of care and a trusting relationship.

The key concern for families providing EOL care at home was the uncertain access to pain relief particularly through the night when there were fewer nurses available. Families were also frustrated if they felt the DN focused on a single task for the patient and did not take into account the wider needs of the family or consider how the carer was coping with the physical and emotional demands of their caring role.

“Nothing was too much trouble.”

“The DNs were really lovely. They healed his leg ulcers, offered constant care and wrote copious notes so that the family knew exactly what was happening. The outcome was perfect. We could ring them at any time to discuss his care.”

“They had a great manner with Dad and he enjoyed chatting with them. They were extremely competent and personable. Dad didn't have the same Nurse each time but there were some regular ones.”

“Absolutely wonderful, so caring. One day before leaving gave personal number for family to contact.”

“x and x provided excellent care. Without their support the situation would have been practically intolerable, as there was no support from the GP other than to complete the Statement of Intent.”

"We had 17 different District Nurses over a period of 12 to 14 weeks, they were all from different teams I felt we were an inconvenience to them, the odd one was nice. Their note keeping was appalling and each time they came I had to say the same story. They would not turn my father as he did not have pressure sores, so I had to do this to prevent them from developing."

"It would help to know when the nurse is coming, however I appreciate this can be difficult, I couldn't take her out some days as no allocated time bracket maybe am or pm slots could be offered."

"The DN came to change the dressings on my Mums legs as she had Lymphedema…DN also attended my father but they would not attend to my mother when they dealt with Dad even though Mums dressings were leaking. I was told I had to wait for the team that dealt with my Mum. There was a lot of politics between teams which they discussed in front of myself and my parents."

"At night we had to phone up for pathway medication (pain relief). We phoned at night as she was screaming in pain, but they only have one DN on at night and they were in Saddleworth and couldn't get there so she died screaming in pain."

"Need easier access on phone systems."

Tell us a bit about Doctor Kershaw's Hospice

Feedback about Dr Kershaw's Hospice was overwhelmingly positive. Families praised the quality of care, empathy and compassion shown by the staff for the patient, carer and wider family.

Families also valued their focus on maintaining the patient's tidy appearance and dignity and recognising what is important to them. Hospice staff also ensured timely and effective pain relief.

"The 24-hour telephone helpline was really good."

"Open visiting, Parking spaces (free), lovely caring staff, local to where our family lives, good environment."

"(Dr Kershaw's) palliative care carers would sit with Mum and spend time with her whereas the carers before only had a 15-minute slot."

"After Christies told Dad that he only had days to live the Helping Hands service started the following day and the support he received was phenomenal. I was spending all my time washing him and taking him to the toilet, but their support meant I could spend time talking and reading to him"

"Keep on with the Hospice at Home as they specialise in EOL care and know what they are doing."

"More beds to be available to have more capacity. When X passed, she was in a ward with curtains separating the cubicles, when it looked like she was getting near to dying the nurse offered to move X we said no as she looked comfy and peaceful. After she passed away we then wished we had said yes as there was a young patient opposite who had seen someone die a few days before, we held in our sobs, not crying as much as we could until she was moved, we hadn't realised we would also want to talk to her."

Tell us about any other end of life services

Many Oldham families shared positive experiences of the Macmillan 1 – 1 Support Service. Families praised their role in the coordination of services and the time spent with families discussing, explaining and helping to plan everything to do with the end of life care and support for those with cancer. However, there were mixed experiences about accessing the Macmillan nurses.

There was also praise for the specialist palliative nurses and social work team based within the Oldham Community Health Service.

“The Palliative nurse visited her every week; he was always on the end of the phone.”

“Nearer the end Macmillan pulled out all stops and got place in [nursing] home then admitted quickly to Dr Kershaw's. They also organised transport.”

“[Palliative nurse] is like a whirlwind she’s the person you need when something goes wrong, she organised the Hospice... What a busy lady her phone did not stop going all the time… She was wonderful; I can’t speak highly enough of her. They need more of her.”

“The Social Worker sorted out Direct Payments these were organised through an appointed Social Care broker - who I dealt with and was lovely, but the pay roll was often wrong.”

“[Following a fall] support services immediately came to help us. The OCAT assessment prompted a host of practical solutions including a keypad, emergency helpline, equipment and adaptations such as chair, railings, access step etc and involved Age UK Oldham.”

“The Macmillan nurse only really got involved nearer the end. One day she asked, “where do you want to go for EOL?” then left and was on holiday for a week. Tried to contact her for an idea of timescale for EOL - this was a difficult long week. No contact then until nearer the end.”

“I couldn’t get hold of the Macmillan nurse. I kept leaving them voicemails and they never contacted me.”

“Dad was under Christies Hospital. By April he couldn’t use cutlery, wash himself or get to the bathroom. We (daughters) provided all the personal and emotional care and were not aware we could get aids and adaptations or help. There was no connection between Christies and the GP.”

Case Study 2: Mary's Story

I cared for Mary 24/7. She had psychiatric behaviour caused by alcoholism. She could be violent, verbally abusive, and was banned from driving as she crashed the car. In the last 18 months there was a gradual decline. She would not accept responsibility for her own behaviour and had several falls over time breaking her wrist, neck and collarbone.

It was difficult to pull out from her behaviour what was psychiatric and what was Dementia. She didn't have a formal diagnosis although everyone accepted that she had Dementia, the problem was the alcoholism which clouded things. She became incontinent, unable to get to the toilet, and her mobility was restricted.

Twice a day I paid for a carer to come in. Some of the carers were good and tried to talk to Mary but usually they were rushed and under pressure. They were due to arrive at 10.30 but often arrived at 11.30 am. There was quite a rotation of staff, so I didn't know who was coming, just had to sit and wait. They were supposed to get her up and wash and dress her, but she was aggressive, and they got fed up fighting with her so didn't do it. So, I was left to do all the washing and personal care on my own.

The community matron and hospital social worker were both very good.

Tell us a bit about care at home services

Many families caring for a loved one at home relied on home care services coming in each day. These were paid for by the patient/family, social care or Continuing Health Care (CHC) Funding or through a combination of funding. Some families struggled with complex 'Fast Track' funding processes that resulted in unnecessary delays to home care services during the final weeks of life. Other families found the system very inflexible with CHC funding up to 4 visits during the day and a maximum of 3 night sitting services per week. For carers caring 24 hours a day some said they would prefer fewer daytime visits in favour of the night service so they could get some sleep.

When it worked well the person at end of life was supported by the same care workers and there was time to chat and build a good relationship. Families were frustrated where there was a high turnover of care staff, rushed visits and poor time keeping.

Reliable, usually the same care workers arrived at time they said they would, professional, intelligent. Had a conversation with Mum and my Dad, Mum 'approved of them' which gave me some much-needed respite."

"We were charged 50/50 – we paid half and they (social care) paid the other half for Safe Hands as we needed 2 carers for palliative care."

"Could not plan anything as uncertainty of when care staff would arrive."

"No one was familiar with the process for Fast Track CHC funding. It took from July to September for funding to be approved during which time I struggled alone with what help I was able to get from the goodwill of neighbours"

Can you tell us about any experiences of being transferred between services? (e.g. from home to hospital during palliative and EOL care)

Feedback from families about the ambulance transport was overwhelmingly positive. When it worked well families could accompany the family member in the ambulance and there was good communication between services and the family. Families were frustrated with long delays or where hospital transport was not provided, and the family were left to make alternative arrangements.

> *"I would like to commend the transfer of care team for making it possible and hassle-free to bring Mum home to die. They arranged district nurses and CHC funding very quickly."*

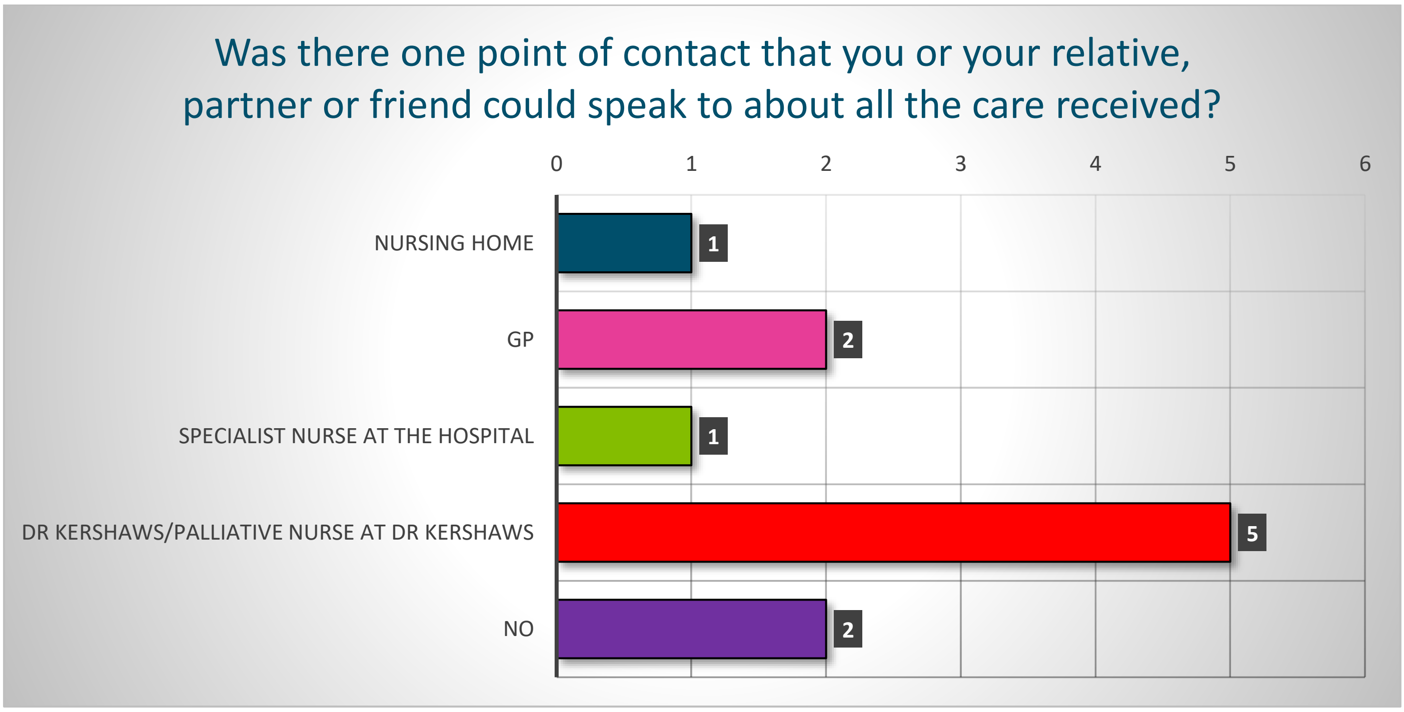
> *"The ambulance service was good; they made her laugh and made her comfortable."*

> *"When Mum was taken to hospital paramedics were good with her, well-spoken and polite, they said she was sprightly which she liked."*

> *"Transferred to NMGH from Oldham due to no bed after 22 hours in A&E."*

Single point of contact

50% of the families (11) who took part in the survey coordinated the care services. Carers without wider family support struggled to coordinate all the different services and treatments, and those caring for someone with a dual diagnosis struggled to find a single point of contact who could offer holistic advice.



To add to the confusion some services have a designated phone number whilst others have a single point of access which means going through more than one person. When it worked well care following hospital discharge was coordinated across acute hospital and community services by the Royal Oldham Hospital, Dr. Kershaw's Hospice or the GP.

> *"It was [coordinated by the] Macmillan Nurse, District Nurse and secretary at Christies. Doctor at Chrisities phoned her at home several times - she was amazed by this and felt really special! Not sure if one point of contact would have made any difference."*

> *"Having one contactable person who was fully aware of all treatments and information would have improved communication rather than just me as his carer and wife on countless calls."*

> *"Too much duplication and numerous people/services coming out and form filling. There should be one person and one team who coordinate through a single point of contact, better systems in place for sharing information."*

Preparation

Were you given any legal or medical information to help prepare for end of life?

Few of the families who took part in the review received information or advice to help prepare for the legal and/or final medical stages of end of life. For many, discussions about the preferred place of care, preferred place to die and final medical wishes were initiated and managed within the extended family. The real challenge was for family members caring on their own who lacked any wider support. Some said there were times when they needed expert advice to help make difficult decisions.

> *"Father got Sepsis and was very poorly. [I was] left with the option to try treatment but didn't want Father to be worse…I struggled to cope with the ethics of the decision which I had to make alone in a short space of time."*

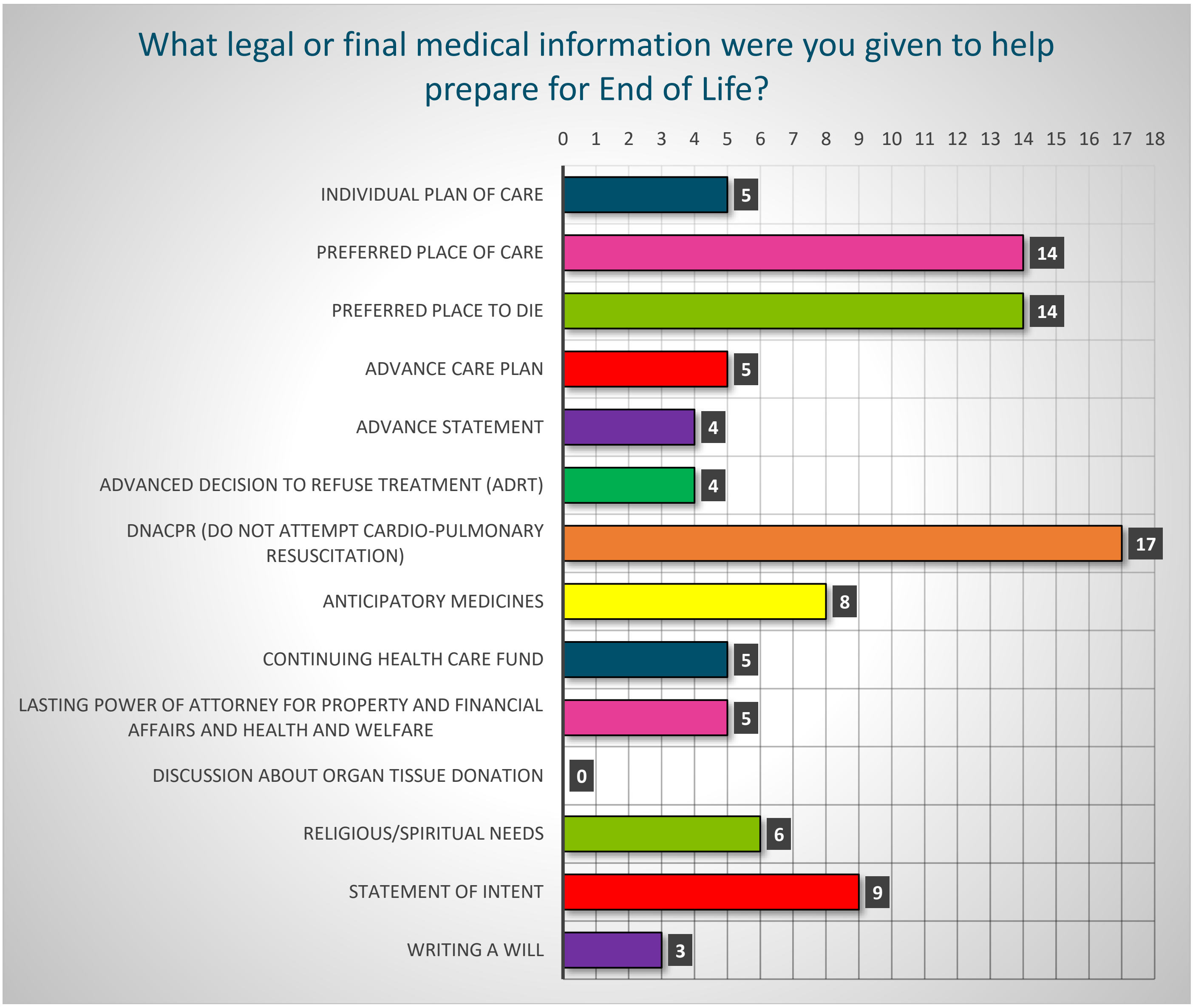
Of the families who responded 17 (77%) said that all the legal documentation was in place prior to death so they could start making the funeral arrangements. However, the most contentious issues related to DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation) and Statements of Intent.

The DNACPR is a legal document that needs to be signed by the doctor during end of life and added to the patient's medical records. The issue appears to be about communication and consistency of practice. NHS guidelines state that the decision to be resuscitated rests with the patient and the doctor, provided the patient has the capacity to make the decision. However, some doctors see this as a clinical decision. This has led to confusion for families and of the 15 (68%) DNACPRs in place 6 families said that these were not discussed with the patient or family and many were upset to find out about the decision after the person had died.

Where it works well doctors take the time to explain the DNACPR and avoid medical jargon, talk openly with patients and families about their views, and answer any questions. As a result, families feel involved in the process and understand the implications. This is where it is important to have a timely discussion about end of life care and make family members aware of any wishes not to be resuscitated.

> *"Dad couldn't understand why he was being refused CPR when he had just been resuscitated...they used a lot of medical terms which he didn't understand until we explained it to him"*

> *"Dr on the ward completed DNACPR with no discussion even though it was challenged by us."*

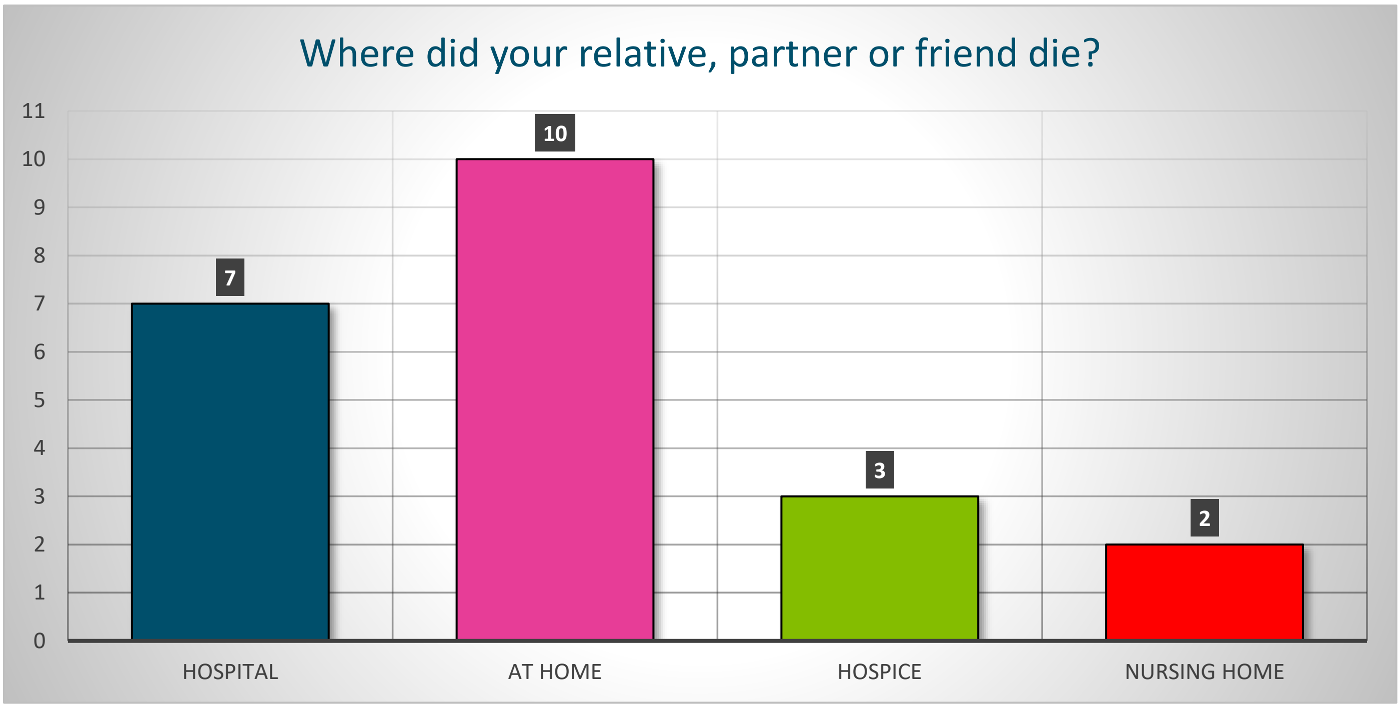


Families praised the Macmillan 1 - 1 Service who provided information on all these issues. Often professionals focus on the completion of DNACPR and Statements of Intent as these are required to secure some end of life services and access Fast Track Continuing Health Care Funding. There needs to be an equal focus on supporting families with EOL planning information.

> *"A locum had to come out and visit my father, I was then told by the GP practice that there was a letter waiting to be collected addressed to my father I opened it for him and found it was a Statement of Intent. We had not been told that he was that close to dying and seeing it in a letter was a shock."*

> *"Despite Mum lodging a statement that she did not wish to discuss any end of life plans but simply take each day at a time, the GP was extremely insistent on putting an EOL plan, Statement of Intent and DNAR form in place. I was left with the distinct impression that completion of this paperwork was a key priority…I appreciate this is a useful reference point for medical professionals… I feel very strongly that completion of paperwork should never take priority over care and treatment…and should accommodate an individual's wishes."*

Death



Of the 22 people who took part in the survey 14 (64%) died in their preferred place of death. For those who could not die in their preferred place this was usually because the person was too ill to be moved from the hospital or hospice back home.

> *"Initially we were hoping to get my husband back to the care home for end of life but were advised that was perhaps not a good idea."*

> *"Wanted to die at home but had to be admitted to hospital as unwell so she died where she was at the time."*

Do you feel that your relative, partner or friend had the best end of life that they could have wished for?

👎 7 People answered NO

👍 13 People answered YES

Families who felt it was a poor end of life experience listed issues such as inadequate or timely pain relief and the lack of care and attention by nursing staff.

Families who felt it was a good experience for the person at the end of life valued the fact that they were pain free, had family and close friends around, nursing staff who were caring and considerate, and the person dying with dignity. Being able to die in their preferred place, often at home, was also important but families understood when this was not in the interest of the person at end of life. Some families also valued the opportunity to sit with their loved ones after death.

> *"During her last days we couldn't have asked for anymore for her care, we as a family were supported and I was able to comb her hair and keep her looking good, she was a smart lady and I know this would have been important, the nurses encouraged this."*

> *"At home, with children and grandchildren and beloved dog, able to listen to her own music, friends able to say goodbye easily."*

> *"Staff did everything to ensure my Dad was comfortable and pain free. He was surrounded by family and they gave us as much time as we needed with him afterwards. We were given handprints, a lock of hair and my Dad was given two teddys by the nurse and when he died he kept one with him at all times, even right up until he was cremated and I keep the other one with me now so he didn't feel he was on his own."*

“He was well cared for and had his family around him. Whilst we realised he was at EOL, over the last few weeks he had rallied and the morning he died he was very positive and looking forward to a family visit. He just drifted away.”

“Very busy staff didn't have the time.”

“Staff were too busy and left us to it.”

“He was in pain and the DN couldn't come out till shift changeover.”

Caring for someone at end of life

Did you feel you had a choice about taking on this caring role?

👎 13 People answered NO

👍 7 People answered YES

Of those who responded 13 (59%) were caring for their spouse/partner or adult child.

“I didn't have to take on the care and support for Dad, but it was something I wanted to do.”

“As soon as we became aware, we discussed everything and I gave up everything - job, life etc to care full time for him.”

“I did it willingly as she was my wife.”

“Mum wanted to die at home, and no-one else could sort it out.”

Did you have enough information and support to help you in your caring role?

👎 10 People answered NO

👍 12 People answered YES

When it worked well the main carer received support from wider family and friends. Families also praised the information and support provided by the Macmillan nurses, Dr. Kershaws, care home staff and palliative nurses. Only 2 families received any training to help them manage their caring role and 6 families said training to ‘move a person safely’ and to understand and recognise EOL symptoms would have been helpful.

“The doctors at ROH explained what was happening and what to expect. This information was given privately to the family (without Dad). The doctors spoke with sensitivity and respect.”

“Felt supported in my carer role by all services.”

“Supported by my family.”

“Dr Kershaw's looked after me even at weekends when the café was closed, the girl who cooked the meals came round and said can I get you anything for your lunch…they used to say have you had something to eat today? Even though they were busy.”

“Family used to sit with him when I went to the hairdressers, and I had a friend who came every Saturday, she came and chatted and that made me feel normal because there was no conversation.”

“Just to have been listened to would have been nice.”

“In the beginning I got a lady to sit with him, but she only came once. I wanted him to mix with people I didn’t want him to be in here (at home) wanted him to spread his wings a bit… I just wanted him to feel he didn’t need me all the time.”

Were you told that the person you were caring for was in the final stage of end of life?

6 People answered NO

14 People answered YES

As the person providing care, did you feel that your views were listened to?

6 People answered NO

16 People answered YES

Can you estimate how many hours of unpaid care YOU provided on a weekly basis during the last 3 months?

Of the 16 carers who responded to this question over 12,400 hours of unpaid care was provided over the final 3 months of life for the person they cared for. Caring roles ranged from 7 carers providing care 24 hours a day every day; carers juggling daily care with a full-time job; and carers who visited the person they had been caring for in the hospice or hospital during the last weeks of life.

Spreading the hours equally across the 16 carers is the equivalent of each carer providing 9 hours of unpaid care every day over a 3-month period.

Is there anything that would have helped you in your caring role?

"looking back, I would like to have told myself - look after yourself, give yourself space…"

"Knowing how hard it would be emotionally."

Case Study 3: Gwen's Story

Mum was 90 and had breast cancer and COPD. The District nursing team in the cluster were excellent and built a good relationship with Mum.

Our first challenge was applying for fast track CHC funding. Mum lodged a statement to say that she did not wish to discuss end of life plans and wanted to take each day at a time. However, having an EOL plan, Statement of Intent and DNAPR in place were essential requirements for CHC funding so I reluctantly agreed to them against my Mum's wishes in order to get some help with her care. The Macmillan nurse put in the funding application, but it was rejected because there wasn't enough information. This led to a 6-week delay during which time I was caring for my terminally ill mother without any help. There were also issues with the stairlift which should have taken 2 weeks but eventually took 6 weeks. I wanted to spend time with Mum not battle bureaucracy.

Our biggest issues related to oral pain relief for Mum. A couple of days before she died Mum took oral medicine for pain relief but was having difficulty swallowing it. The district nurse (DN) was satisfied she was drinking other liquids ok but said she would raise it with the GP. She also advised me to monitor her swallowing closely and discontinue all liquids if she showed signs of being unable to swallow.

I later received a call from the GP practice nurse saying the GP wanted to discontinue all my mother's oral medications due to risk of choking and that everything now needed to be given through a syringe driver. I asked what I should do if mum asked for a drink as she was still able to drink other liquids but I was told not to and if I did they would not be able to issue a death certificate and the case would be raised with the coroner. Over the next 24 hours there were conflicting messages as the DN observed Mum and wanted her to continue to drink whilst she was able. The GP delayed coming out until the following day and then agreed with the DN.

I was also challenged by social care services about Mum's pressure sores and was threatened with this being raised as a safeguarding issue. In the end I bought a pressure pad designed to heal grade 4 pressure sores as the new bed the social worker suggested would make it hard for me to care for Mum through the night as I slept alongside her. The threat of being reported to the coroner's office and for safeguarding issues were really upsetting especially at such a difficult time for me where I was pretty much caring for Mum 24 hours a day. I wanted time with the person I was caring for, and for them to be comfortable and pain free.

After Death

Were you offered any bereavement support?

👎 13 People answered NO

👍 9 People answered YES

How and when would you prefer to receive information about bereavement support?

Some carers highlighted the impact of caring on their own health and wellbeing and how this affected them beyond the death of the person they cared for. Others struggled with a loss of identity.

Of the 12 carers who responded to this question the majority said they would want to know about bereavement support at the point of diagnosis or immediately following the death of the person they have cared for. Carers were split in their views about how they would want the information with 7 (58%) preferring a personal telephone call or email with information whilst 5 (42%) said they would prefer a leaflet so they could read it when they felt that the time was right for them.

"I think it would help people to know that bereavement can take many different forms. For me I am still managing the aftereffects of the worry and responsibility of caring for Dad."

"When Dad died, I felt sad but comforted by the fact that he was so well looked after and because he managed to live at home until the last. So, at that time I didn't feel bereaved in that sense."

"As soon as he passed every service stopped, no support whatsoever given to me or family. Had to seek it ourselves."

"My young daughter is worried that I might die after seeing what has happened to her grandad, so I would really like to get some family bereavement counselling."

Is there anything else you would like to tell us?

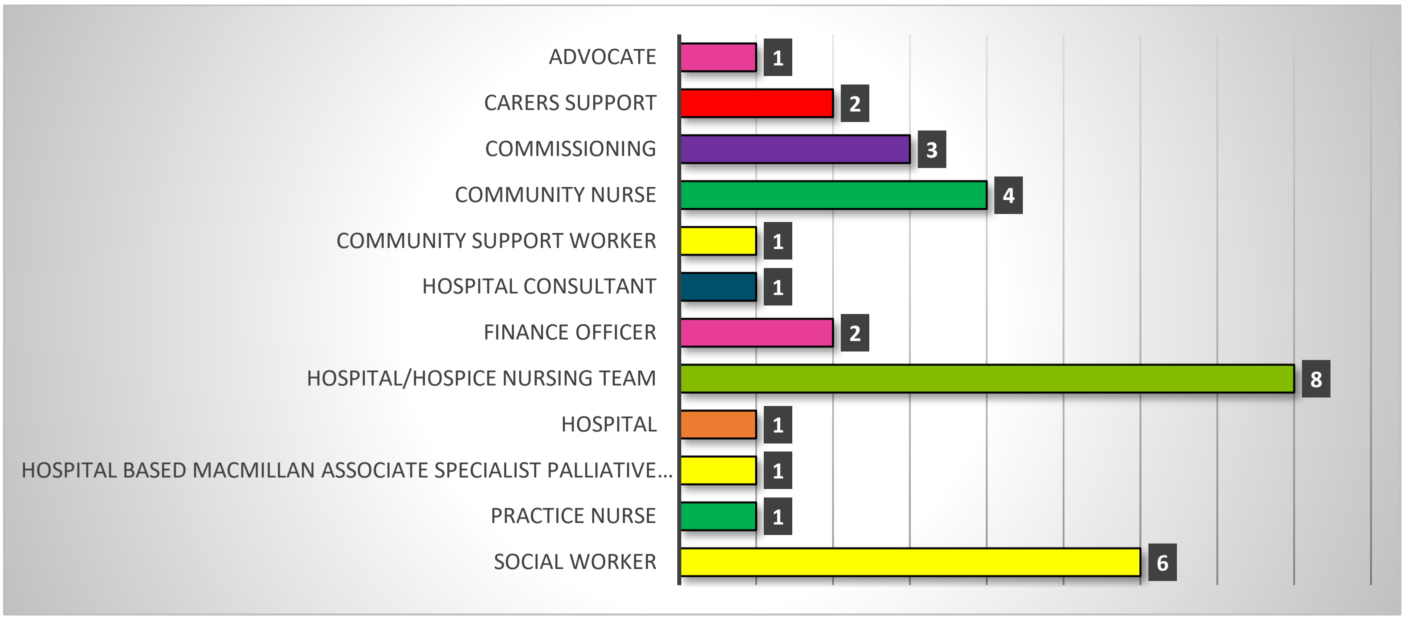
"We are so lucky to have the NHS service."

Anything else you feel is important about end of life?

Survey 3: End of Life Professionals Survey

Profile of respondents

The questionnaire was completed by 31 professionals employed in the following roles:



What do you think is important to the patient and family at end of life?

Based on their experience we asked a range of professionals to list the three most important things for patients and their family at end of life:

- That care is provided with empathy and compassion
- Professionals take the time to talk to families and provide relevant information and advice
- Offer timely care and support that responds to the needs of the patient
- Where possible ensure end of life care respects the patient’s wishes
- Smooth transition between services
- Provide emotional and practical support for family members providing care

Some comments:

“Support is arranged quickly to enable the patient to be in their preferred place of care/death without issues regarding funding”

“The feeling that someone genuinely cares about them and their loved one”

“Be sympathetic to all parties, show consideration dealing with difficult/confrontational issues that may occur.”

"Give them your time… make them feel like you are not rushing or just visiting to perform a task"

"Work across different boundaries, join dots that statutory sectors are not encouraged to."

What do you think would improve the experience for patients and their families?

We asked Professionals to list the three things that they felt would improve the experience of patients and their families:

- Better mental health support for end of life patients
- Earlier discussions with families about end of life care planning
- Timely and flexible approach to end of life funding for care packages
- Increased choice and availability of care
- Consistency of staff working with the patient and family
- Twenty-Four-hour access to hospice, district nurses and specialist palliative care
- Designated worker responsible for coordinating care
- Improved recording and information sharing to avoid repeating the same information
- Bereavement support

Some comments:

"Have as few professionals involved as possible with different agendas and work streams"

"Give patients and families control"

"Night sits need to be available to help families; they are saving the NHS thousands by caring for them at home, but more support is needed."

"Easy access to seven-day week working for Specialist Palliative Care and access to Consultants in palliative medical advice."

"Staff having more time to spend with families."

"Continuity of the same professionals involved in providing care, not a different District Nurse every visit."

"Increased choice of care-night support, care at home, care home admission, hospice admission etc."

"Actual collaborative MDT (Multi-Disciplinary Teams) working. Not just saying this happens."

What are the barriers that prevent this from happening?

Professionals highlighted the following barriers:

- Resource constraints and staffing levels
- Lack of time to spend with families
- Unrealistic expectations by families for the preferred place of death
- Lack of palliative knowledge in primary care
- Limited understanding of the Mental Capacity Act
- Challenging processes to access NHS Continuing Health Care
- Cultural and system differences between care providers

Some comments:

"People are scared to have the conversation and don't want to 'open a can of worms' because of lack of time, or confidence and knowing what else might be done."

"DN's are over stretched and simply do not have adequate time to spend with palliative care patients. Care agencies do not have the resources to provide sufficient night sits, the period of time when family care is most likely to break down. Burnout leads to reduced ability to genuinely care for patients."

"Limited resources may mean that access isn't always as available when it is needed – particularly when this is at nights and weekends and there are reduced staffing levels."

"The district nursing service… remain the key coordinator of the care… however, not all district nurses are comfortable with end of life care or have the knowledge and skills to be able to provide high quality end of life care."

"Services are being delivered by a number of different groups of staff from different organisations. This leaves care being delivered in a disconnected way and families are often unsure which professional/service to contact when."

"In this economic climate it is unrealistic to assume families can take unlimited time off to care for their loved one… The 'normal' 4 calls a day does not fit in with most situations… and a personal health budget is not offered to patient funded on fast track which could be used to fund care package as required."

What would help to address these barriers?

Professionals suggested the following solutions:

- Do more to support the physical and mental wellbeing of existing staff
- Reduce the case load of staff to allow more time to spend with families
- Establish a clear EOL care pathway for Oldham and clearer referral processes
- Better systems for sharing patient records and information
- Single point of access available 24 hours a day across district nurse service, specialist palliative care nurses and hospice
- Commission/offer more night sitting support for families
- Extend the Hospice at Home Service to cover 24 hours and consider its potential as a key coordinator of EOL care
- Programme of EOL training for neighbourhood integrated health and social care teams
- Local Authority to encourage incentives for care homes who specialise in EOL care

Some families said that having one trusted professional to coordinate all the EOL care would be valuable. What would be the challenges for your organisation?

Professionals suggested the following:

- Good suggestion but would be problematic to cover part time working, leave and/or sickness
- Could end up with an over reliance on one member of staff
- This relies on a good relationship between the family and the named coordinator
- May need to have 2 or 3 named contacts to manage this

Some comments:

"I suggest… that cluster GP's regularly have all patients with a palliative diagnosis made known to them. The palliative care nurse would monitor the patient's condition by liaising with the district nurse and GP and they could coordinate their care. They would also be a main point of contact for the patients and they would not have to go through the single point of access."

"Having more than one professional provides different views/opinions, if this was just one individual, may not have different ideas etc, may do the same thing for every patient."

"There are certain services and resources which are only available to certain professionals i.e. fast track can only be completed by a health professional, equipment can only be ordered by DNs, OT or hospital. Also accessing care home or care at home can only be commissioned by social care professionals. There may be one professional coordinating this, but it will still mean that the service user will have to go through various assessment processes."

Some families said that EOL communication between healthcare teams is not as good as it could be, and many had to repeat their stories. How could this be improved?

Professionals suggested the following solutions:

- Joint access by services to a central information system
- Adopt a common assessment form which can be used by all professionals
- Better communication at the cluster level with more regular MDT meetings
- Clearly defined communication pathway for EOL
- Some services feel there is already good communication in place so important to highlight where it is working well

Some comments:

"This is difficult as each service uses the assessment of a new patient as part of the process of building a therapeutic relationship. I would suggest that any referrals to other services should be fully completed with ALL the requested information… getting to know about the patient as a person, their fears, wants, needs, like and dislikes rather than diagnosis, prognosis etc."

> *“Need for electronic records to be shared with patients consent and within the confines of clinical governance.”*

> *“All parties need to have access to the same IT facilities e.g. We use Mosiac, Health Workers use Paris. The two systems are not compatible and important information could be lost/not available because of this.”*

Some families said they would have benefited from bereavement support. What services or support do you think should be available to families following the death of the person being cared for?

Feedback from professionals highlight the existing bereavement support available through Dr. Kershaws and the SWAN bereavement nurses at the ROH. These services are routinely offered to families of patients within their service. Families supported by other EOL services can struggle to find bereavement support within the local community.

Professionals suggest the following solutions:

- Bereavement support should offer a safe space to talk
- Counselling should be flexible so people can access when the time is right for them
- Support should include information about practical issues such as finance, managing and selling property, legal advice etc.
- Self-help guides could be produced about support after a Bereavement

Some comments:

> *“I think there should be a number of opportunities e.g. phone number, 1-1 support, groups, ‘death cafes’”*

> *“There are no clearly defined bereavement support services to refer people to and no services to refer those at risk of complicated grief prior to bereavement… bereaved patients will receive one visit but are then left to their own devices and the support of their GP. There is simply not enough time to care for both patients and bereaved relatives.”*

Is there anything else you would like to tell us about EOL services in Oldham?

> *“Services often stop when the person dies but it’s important to flag up a potential safeguarding issue with the GP if a vulnerable adult is left living on their own following the death of a partner or parent.”*

“I feel the support at night for the patient and families is a big issue, when they ask for this support it should be available without them having to be involved with all the ‘backroom wrangling’ that goes on between the Social Worker and the CCG.”

“Services have come such a long way and excellent care is available. However, for those patients that choose to die at home this care can often expose the family to high levels of stress… dealing with issues they do not fully understand and/or cannot physically manage.

There are a raft of professionals who will attend to support but the reality of this is that these are short visits (due to other demands on their time) and it may take time to be able to attend (particularly at nights and weekends) – this may leave relatives feeling stressed and unsupported.

There ais also an assumption in EOL care pathways that all patients want to die at home – this may not be the case and services need to be developed that allow for choice and have resources to accommodate this.”