



People's experiences of palliative and end of life care

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healthwatch
Sheffield

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Introduction

Background

Healthwatch Sheffield helps adults, children and young people influence and improve how NHS and Social Care services are designed and run. We're completely independent and not part of the NHS or Sheffield City Council. We want to understand your experiences, and help your views to influence decision-makers in the city.

This report focuses on the experiences of people in Sheffield at the end of their lives, as well as their friends and relatives (who we might sometimes refer to as 'carers'). It sets out what they have told us about palliative and end of life care¹ in the city – this includes the support available for carers both while they are caring for someone, and after they have died.

There are many different services which people might use for support at this time. They include health services (e.g. hospitals, GPs, District Nurses and Pharmacists), social care (such as care at home to help with day to day life, or care homes for people who need a higher level of support) and also community groups, charities and faith organisations. The quality of people's experiences can be impacted not just by how they are treated within one individual service, but also by how these different services work together.

This work was done in the context of a city with a changing population. The data recently released from the 2021 Census shows that we have seen an increase in the number of residents in the older age groups in Sheffield, but also there has been a 4.7% increase in the number of residents from Black, Asian and minoritised ethnic communities, with residents in these groups now accounting for 20.9% of the population. Services need to be developed in a way which meet the needs of Sheffield's changing population.

¹ **Palliative care** is the active, holistic care of people with advanced progressive illness, involving the management of pain and other symptoms and the provision of psychological, social and spiritual support. Palliative care aims at ensuring the best possible quality of life for individuals at the end of their life or with advanced illness and their families.

End of Life Care refers specifically to care provided in the last phase of life. This is often defined as approximately the last year, but end of life care can also sometimes be used to refer to the last weeks or even days of life and, for carers, can include care into bereavement.

Why did we do this work?

Good palliative and end of life care is important for everyone; getting the right care and support at this time is vital. The Health and Care Act 2022 changed the way that health services are organised and planned in England – with this, came a responsibility for the new Integrated Care Boards (ICBs) to commission services which meet the needs of their population, and a specific responsibility to plan services for palliative and end of life care.²

Healthwatch Sheffield were commissioned by South Yorkshire Integrated Care Board (SY ICB) to help them understand people’s experiences at the end of life – both people needing care, and also their family members and relatives. They wanted to ensure that people’s views and experiences were able to influence the way that services are developed within Sheffield, and across South Yorkshire; what people have shared as part of this project has already contributed to the development of a South Yorkshire Strategy on Palliative and End of life care. As well as influencing the strategic approach to planning services, it is intended that the learning in this report can be used by individual services to help them develop and improve the way that they work with people at the end of life as well as their carers.³

What did we do?

There were two aspects to the work that we did.

1. Online survey⁴

We developed a digital survey to understand the experiences of:

- People currently using palliative or end of life care services
- Carers/family members of people currently using palliative or end of life services
- Bereaved carers – family members or relatives of someone that had died in the last 2 years⁵

² [Palliative and End of Life Care](#) – Statutory Guidance for Integrated Care Boards (ICBs)

³ A **carer** is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.

⁴ The survey questions are available on request.

⁵ 2 years was selected as the relevant timeframe because experiences during 2020/21 were heavily impacted by Covid-19 making some experiences ‘atypical’ in comparison to how services are working now

To develop this survey, we spoke to a range of relevant professionals who helped us consider what areas to explore. We also spoke with 2 bereaved carers whose stories helped us understand what needed to be included in our questions. Finally, when the survey had been drafted, we asked our volunteers for feedback on its content and accessibility.

Although we were commissioned to look at experiences in Sheffield, we took this opportunity to develop a survey which would be able to capture experiences across South Yorkshire. Experiences relating to other parts of South Yorkshire do not form part of this report, but the relevant anonymised responses have been shared with those who commission care in Rotherham, Barnsley and Doncaster.

This survey was widely promoted and shared in different ways:

- Social media – we paid for a Facebook advert, and partners across the city shared this widely
- Through services – staff in relevant services shared information about the project in different ways including; verbally, through leaflets and posters
- Through voluntary sector partners and networks (at meetings and via email)
- Through local Healthwatch in Doncaster, Barnsley and Rotherham
- Via radio – the ICB lead and a local GP talked about the work on BBC Radio Sheffield

Finally, although the survey was designed as an online tool, we also produced some paper copies. Some of these were left with organisations in community settings.

2. Conversations and Interviews in community settings

We recognise that for many people, a survey (particularly an online survey) will not be a suitable way to share their experiences. Barriers include data poverty, lack of digital skills, access to equipment, literacy, and language. To ensure we could include a wide range of views and experiences in this work, members of the Healthwatch Sheffield team went out to groups and community settings across the city, where they were able to hear from people in a variety of ways. This enabled us to hear different perspectives; it also enabled richer conversations where we could hear in depth about people's experiences. Broadly, this work included:

- **One to one interviews** – speaking with someone face to face, or on the phone to hear about their experiences. For these conversations we used a semi-structured interview approach⁶, with key areas to explore, but not a

⁶ The framework for these conversations is available on request.

set list of questions. People participating in a one to one interview received a thankyou voucher. Interviewees came to us through different routes, but primarily as a result of us promoting the project within voluntary sector groups and community settings.

- **Community conversations** – members of our team visited community groups, such as dementia cafes. In group settings they had shorter conversations with individuals – these conversations were linked to the areas explored in the fuller one to one interviews.

We recognised that particularly for this sensitive topic, many people would feel more comfortable speaking with someone that they had a trusted relationship with; therefore we paid two voluntary sector organisations to have group discussions and do one to one interviews on our behalf. These were the [Hadfield Institute](#) (who spoke mainly to people from the Yemeni and other Arab communities) and [SACMHA Health and Social Care](#) (who interviewed people from the African Caribbean Community). These organisations were able to conduct the work in a way that met the cultural and language needs of those taking part.

We extend our thanks to the Hadfield Institute, SACMHA Health and Social Care, and also to the many other community groups and organisations who supported this work. Organisations across the City played a key role by letting us to come and visit, talking to us about this project, connecting us with people, and sharing information on our behalf. Working together in this way means that more people in our city have had their say on this important topic.

The image on the front cover is called 'Transformation'. It is a piece created for the [Circle of Life exhibition](#) by artist Agata Pankowska in a collaborative visual arts workshop with ShipShape Community Hub. The workshops, run by Ignite Imaginations, aimed to explore how different communities in Sheffield celebrate the end of life.

Inspiration for the butterflies was drawn from their metaphorical link to death and the circle of life. "The caterpillar doesn't just grow wings, it fully dissolves in a cocoon and only then turns into a butterfly, but a theory is that it retains its memories in its new colourful form. And I find it very comforting"

Another piece from the same exhibition can be found on page 62.

[Ignite Imaginations](#) is Sheffield's visual arts organisation delivering creative activities in partnership with communities to unlock new experiences and skills.

"We want every person in Sheffield to have equitable access and opportunity to participate in visual arts experiences, which builds confidence, pride and reduces social isolation".

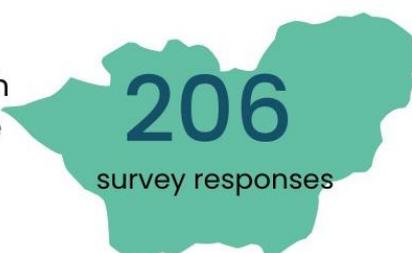
Who did we hear from?

As part of this work we spoke to people living in Sheffield through one to one interviews and group conversations.

We also ran a survey which covered all of South Yorkshire.

We spoke with 62 people through community conversations and one to one interviews

Across South Yorkshire we received:



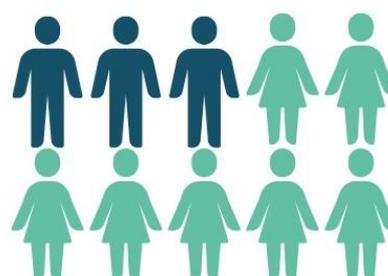
110 survey responses were about people living in Sheffield, or who used services in Sheffield e.g. hospitals

Who did we speak to through interviews and community conversations?

2 community organisations carried out interviews on our behalf – The Hadfield Institute and SACMHA. Many other voluntary and community sector groups supported us by helping to connect us with people they work with.

What is your ethnicity?	
White British	21
Arab	21
Pakistani	6
African Caribbean	5
East African	2
Other African	1
White European	1
Prefer not to say	1

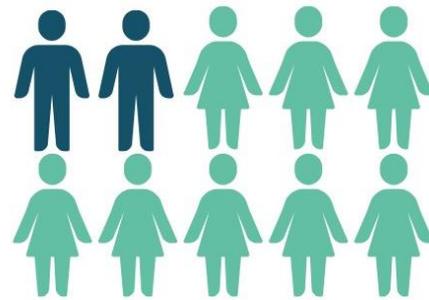
Conversations included care home residents, people receiving end of life care, and 2 people with learning disabilities



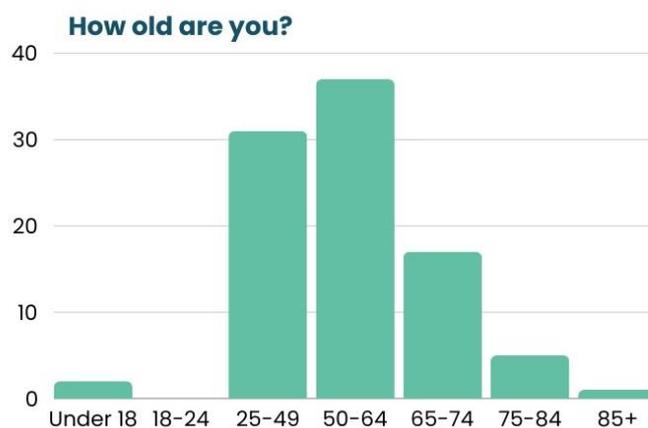
Around 70% of the people we spoke to in interviews and community conversations were women

Who shared their views about services in Sheffield through our survey?

Who are the survey respondents?	
I am currently receiving palliative or end of life care	2
I'm a relative or friend of someone currently having end of life or palliative care	20
I'm a relative or friend of someone who had palliative or end of life care and has now died (in the last 2 years)	88



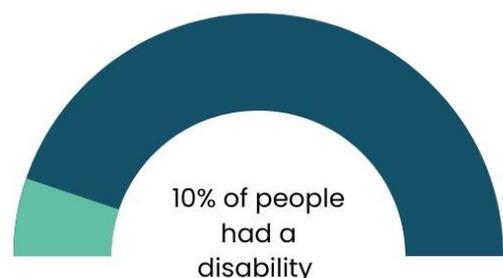
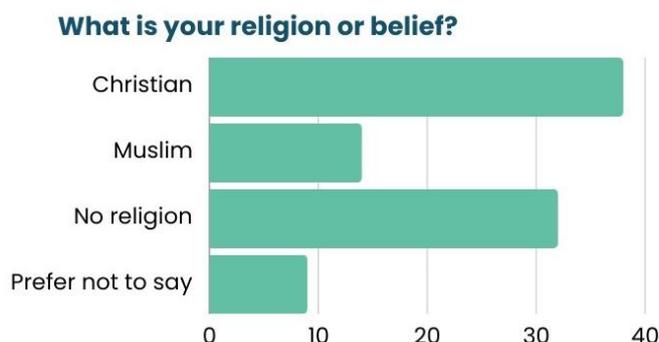
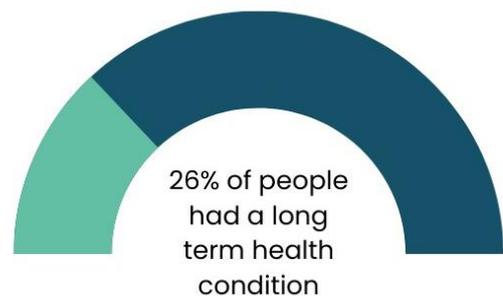
Just over 8 in 10 survey respondents (81%) were women



What is your ethnicity?	
White British	70
Arab	10
Asian/British Asian: Pakistani	4
Black/Black British: African	1
White: any other white background	2



41% of people (around 2 in 5) were carers



Findings

1. Experiences of health and care services

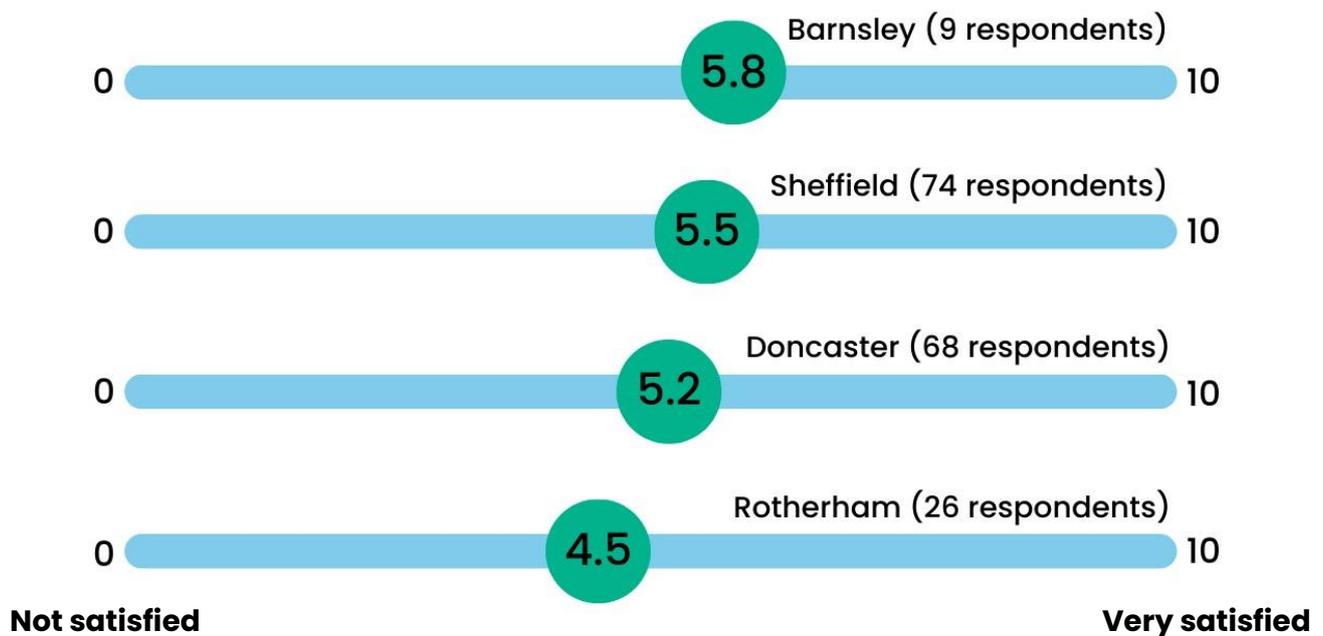
Overall satisfaction with care and support

We asked everyone who completed the survey how satisfied they were overall, with the care and support received by the person going through end of life care.

People's experience differs across South Yorkshire, with Barnsley coming out highest in satisfaction scores and Rotherham lowest. However, the number of respondents in Barnsley was low compared to the other areas.

People were asked to rate their satisfaction levels on a scale from 0 (not satisfied) to 10 (very satisfied). Average scores are presented below.

How satisfied are people with the care and support they/their friend or relative is receiving/received?



To understand experiences in relation to specific services, we asked people how satisfied they were with a wide range of health services that may have been used.

Within the Sheffield responses, 85 people told us their views on at least one health service – health services are listed below, starting with the service which received the highest percentage of ‘very satisfied’ or ‘satisfied’ responses, and ending with the service which received the lowest:

Health service	Number of people who used this service/ whose friend or relative used this service	Percentage who were ‘very satisfied’ or ‘satisfied’ with the care received
Yorkshire Ambulance Service*	65	73.8%
Hospice	34	73.5%
Community pharmacy	54	70.4%
District nurses	64	70.3%
Hospice community nurse	40	62.5%
Palliative care unit within a hospital	32	59.4%
Intensive home nursing	22	59.1%
GP surgery	78	51.3%
Patient Transport	32	50%
A&E	51	47.1%
Active Recovery	26	46.2%
Hospital	67	43.3%
NHS 111*	35	42.9%
Fast track Continuing Healthcare	28	39.3%

Services marked with an asterisk (*) operate across South Yorkshire, so we have also included the perspectives of other South Yorkshire residents who said they or their relative have received care in Sheffield, even though they don’t/didn’t live here.

Health service insights

We have combined a breakdown of satisfaction ratings per service type with analysis of free text responses throughout the survey, to provide further insights into people's views and experiences of each specific service.

However, it is important to acknowledge that people don't experience the services they use in isolation; their experiences often span across many different types of services, so how they work together and are coordinated has an impact on how people experience their care as a whole. Section 3 (page 46) contains what we heard about people's experiences across services.



We have also included what we heard through our one to one interviews and community conversations which are shown in the blue boxes like this.

Key



Yorkshire Ambulance Service and Patient Transport

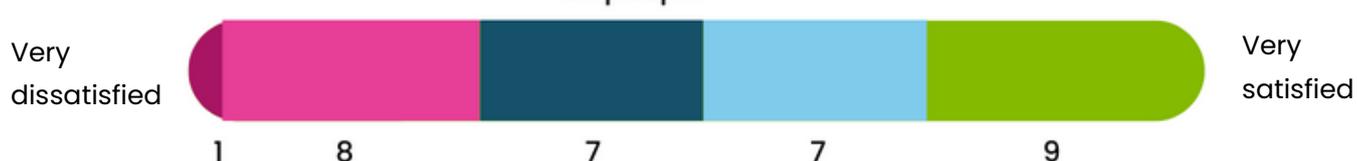
Yorkshire Ambulance Service

65 people



Patient Transport

32 people



The survey results showed 16 people (50%) were satisfied or very satisfied with patient transport, whilst the figure was much higher for Yorkshire Ambulance Service (YAS) at 73.8 %.

Positive comments often related to the service received when an ambulance had been called in an emergency situation, with a subsequent journey to A&E:

“They did all that could for my daughterat all time I was given all the respect required by all of the ambulance staff”

Although there were also examples where people found journeys by ambulance painful, and thought the support was **not as skilled** as it could be:

“A visit to A&E and the subsequent journey home were painful and traumatic... she stated she was never going back to A&E as a result”

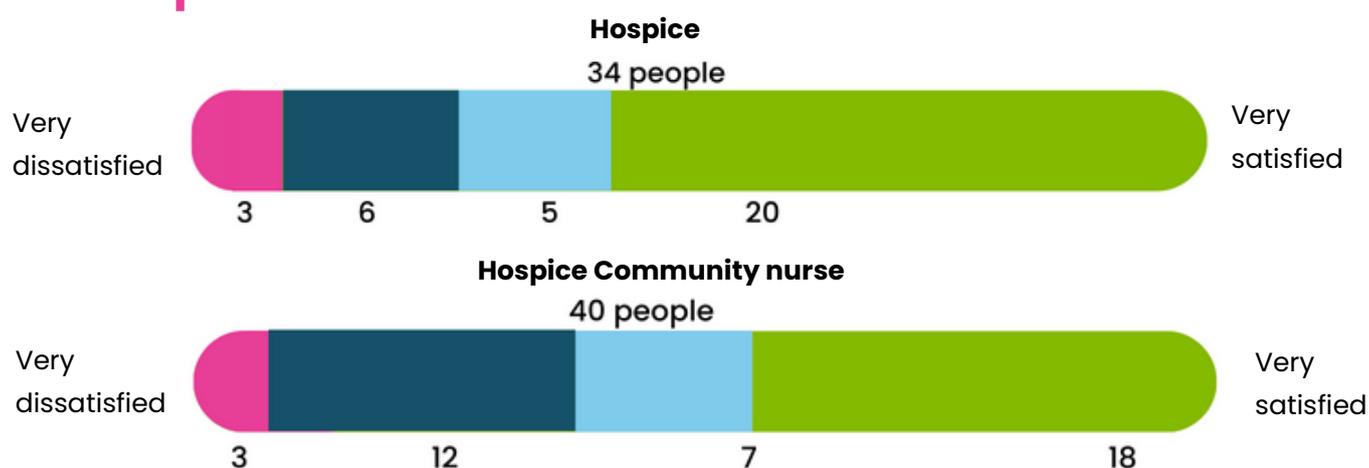
There were issues around hospitals **communicating** with and about patient transport. For patients travelling into Sheffield from out of area, we heard examples of people not being told by their local hospital about YAS provision. We heard that Weston Park Hospital gave this information, but patients still felt unsupported in the process, reporting that they had to book themselves each time:

“Left to find out things for ourselves at a very difficult time”

One experience involved a bereaved relative being caused distress when an ambulance came to pick up their father who had died for an appointment:

“The day after my father died the ambulance service turned up at my house to pick him up for an appointment that the hospital told me would be cancelled. They should not have come to my house as his home was in Sheffield and at this time he was in a care home (the hospital arranged this so they knew) a note was put through my door from the ambulance telling me how wrong it was to waste their time & how I should have informed them if we were not going to the appointment”

Hospice care



The survey results showed that 25 people (73.5%) were satisfied or very satisfied with hospice care, with 25 people (62.5%) rating their satisfaction of hospice community nursing that way too.

There was a lot of positive feedback about St Luke's Hospice, including:

- Person centred care, attentiveness
- The nice environment
- Good pain management
- Appreciation for the wellbeing and creative activities

"The care provided by St Luke's Hospice was excellent. I witnessed myself, how very happy my friend was with the outstanding care, support and treatment she received there and the lovely environment she was in. There was always a person centred, individualised, compassionate and comforting approach, which helped so much throughout such a difficult time"

The only negative experiences we heard related to **accessing** hospice care, for example delays with GPs which made it a long-winded process, and being unable to access a bed.

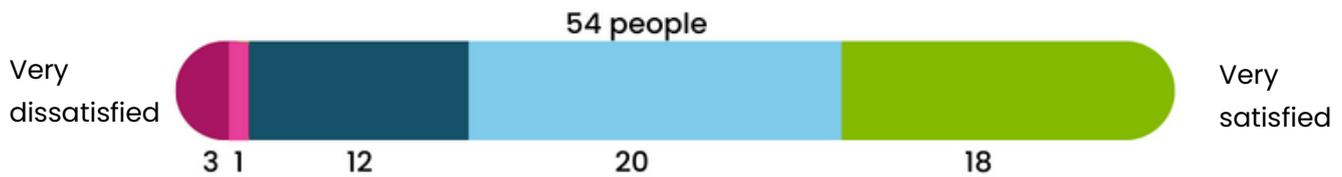


Hospice care is valuable for patients and their carers

Carers in our interviews described that they highly valued the support from St Luke's both in the community and within the hospice. This included support for the carer, as well as the person receiving care:

"We got a palliative care nurse from St Luke's arranged through the heart nurse. The palliative care nurse was really helpful. [My husband] eventually got a place at St Luke's hospice and died there 48 hours later. The care he received was incredible. They couldn't do enough for him. They looked after me too"

Community pharmacies and accessing medication



The survey results showed that 38 people (70.4%), were satisfied or very satisfied with the community pharmacy involved. However, we heard that medication shortages led to distress for one person and their carer:

“At times I was running round pharmacies to locate urgently required drugs, there was poor availability of items, there was a major issue between scripts being presented at the pharmacy and the pharmacy not holding or having warehouse problems. The community nurses were great but at times there was a long delay when pain relief medication was required and the nurses were busy and several priority patients were all requiring intervention at the same time. Distressing for the patient and carer”



Managing medication

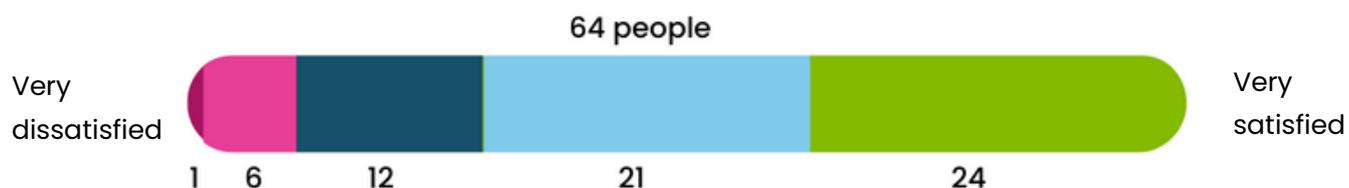
More broadly, managing medication can be complex and overwhelming both for people receiving end of life care, and their carers. People in the interviews told us that having the right information and support can help:

“Would like more information on the medication given – health professionals ‘blind you with science’ but it would be good to have a proper explanation of what each one was for”

“Medication given by pharmacy was so confusing – nobody explained what could be taken with what. Huge relief when palliative care nurse got involved and helped with this”

“The medication he was on was very complicated. I had to create a spreadsheet. He was on 17 tablets and I started to feel overwhelmed by it all”

District nursing



The survey results showed that 45 people (70.3%), were satisfied or very satisfied with the service from district nurses.

Most people described the care as positive once they received it, but some described **delays in access**, with services not being put in place in a timely way. Others also described that the service felt **understaffed** and **overstretched**.

“Any queries tend to be dealt with via phone calls. My friend tells me that the District Nurse will do everything possible to not visit her in person. She feels unsupported, does not know who to contact with queries relating to her failing health”

“It would have been helpful if the District Nurses could have come out to see her in good time, but they could only see her in 2 weeks and she died two days after this. She was not eating or drinking and in significant distress and it felt like the health service just didn’t care at all”

“GP/District Nursing teams in particular felt understaffed and unable to work quickly and efficiently in what was, effectively, the end of this woman’s life”

One person highlighted an issue with having the supplies that were needed:

“My friend spoke well of the District Nurses themselves, however unfortunately I know sometimes they did not always have the correct size or type of dressings with them that my friend required and alternative less suitable dressings had to be used, which would sometimes leave my friend feeling disappointed and frustrated, as it was more difficult for her to manage with these”

Many people described nurses who were **kind, very easy to talk to and helpful**; and commented on the **support that was provided to family carers**. The service was described as key in terms of enabling people to die at home.

“District nurses made it possible for her to have dignity and support at home for as long as needed”

“Community service once palliative very responsive. Patient live 2 weeks from diagnosis... Overall a positive experience, trust and guidance given to family carers who were able to enjoy the last week of the patients life with him in his home of 80 years”

“District nurses of which we saw a few all very easy to talk to and help”



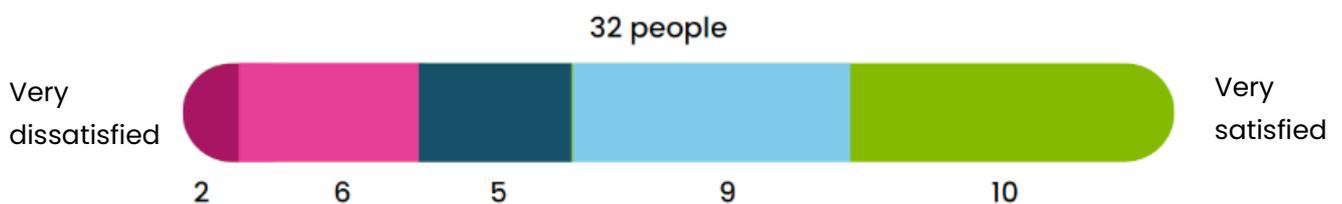
Specialist nursing roles

People in the interviews told us about specialist nurses who had provided valuable support and care; they described how condition specific roles such as COPD nurses, cancer nurses, and heart failure nurses provided continuity of care and expertise which had helped them. One person who was living with dementia told us that in other places, there were Admiral nurses who provided support to people with dementia, from diagnosis through to end of life. This is not available in Sheffield; the person who spoke about them would like to see that service here.

“[The heart failure nurse] came and took his blood pressure. We could ask questions, we could ring her and leave a message and she would always get back to us, she was really supportive and helpful, she became like a friend”

Palliative care

Palliative care unit within a hospital



The survey results showed that 19 people (59.4%) were satisfied or very satisfied with the Palliative Care Unit at the hospital.

Positive aspects of care included **supportive staff**, and being given **good information** about what to expect from the progression of the illness:

“The hospital palliative care staff were kind and supportive”

“A lot was discussed with the hospital palliative care consultant explaining how things would be as the disease got worse – this was very helpful”

Where people shared negative experiences or concerns these related to:

- Shift changes leading to a **delay in pain relief**
- Difficulties getting an **onward referral for community palliative care**
- Care feeling **rushed** due to delays in diagnosis
- **Access** – including not being offered a transfer from other wards
- Lack of respect for **individual choice** and need

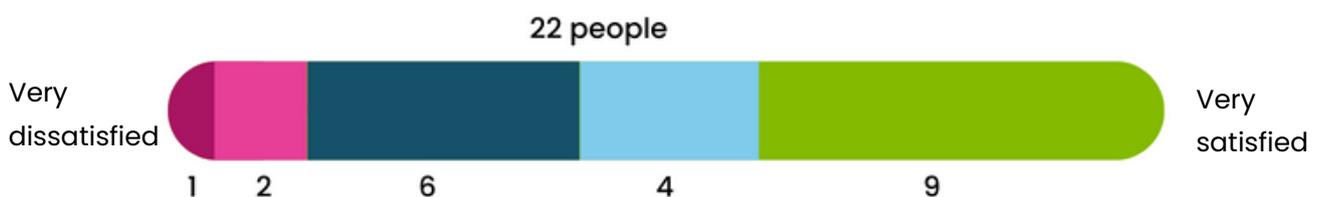
“Care in northern general was good and palliative care was really good. However, because of the initial difficulty of gaining a diagnosis this made all the care going forward very rushed and daunting...it therefore took a month to find out what was happening and only after persistent chasing up”

“Pain relief was agreed by Palliative care doctor earlier in the day. But was delayed when my father needed it as a new medical team had come on duty and they had to check with person in charge. This took over an hour to get the ok during which time my father was in great pain”

“There was a massive difference between care received at home and care in palliative care, the care at home was great, not so in hospital, not great at respecting choice and individual need, not great at getting to the bottom of symptoms and managing pain. Not great at getting on top of care needed”

“The Palliative care at Northern General was excellent, maybe more resources needs to be given to this unit as I had to ask for Palliative care and initially didn't feel confident there would be room for a transfer from a ward”

Intensive Home Nursing



The survey results showed that 13 people (59.1%) were satisfied or very satisfied with the Intensive Home Nursing service.

Intensive Home Nursing Service provides care for patients who are approaching the last days to weeks of their life and wish to die in their own home. They provide a responsive 7-day and night service to patients registered with a Sheffield GP 365 day a year. The service provides varying levels of care depending on the needs of the individual.

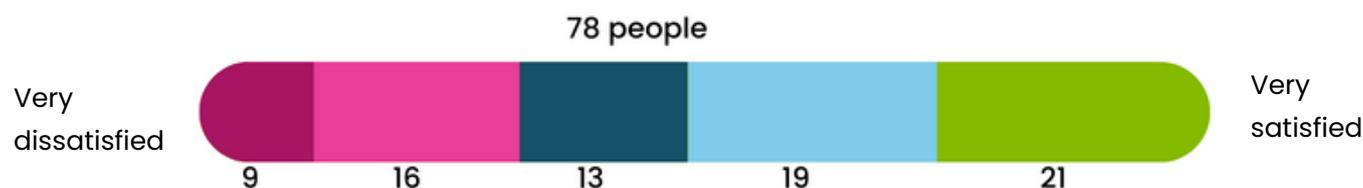
Several positive stories were shared about the “fantastic” support provided; enabling people to die at home, and giving support to carers, with the night sitting service being particularly valued:

“Received 3 daily visits with 2 nurses + night sitters frequently from the Intensive Home nursing team. This allowed my husband to stay at home. Knowing I could phone for help or advice 24/7 was a tremendous help. The level of support has been above & beyond anything I could have hoped for. I can't believe so few people know about it!”

One negative response highlighted the **gaps** in this service and the pressure this placed on family:

“Not enough intensive home nursing, carers 4x per day leaves gaps between visits, lots of emphasis on family to care between gaps and advocate for patient”

GP surgeries



The survey results showed that 40 people (51.3%), were either satisfied or very satisfied with care and support that the person dying received from their GP.

Through the surveys, interviews and community conversations, people reported mixed experiences around the quality of care and responsiveness from the GP surgery.

Positives included:

- GPs working **flexibly** (e.g. doing home visits)
- GPs working in a **joined-up** way with other services (e.g. CHC)
- GPs doing **timely** referrals (e.g. referrals to fastrack CHC)
- Seeing **a GP who was known**/familiar to the family led to people feeling better supported
- People being given **time to talk** things through

“Always willing to do home visits when going to the surgery became difficult”

“Excellent service from gp, very supportive & joined up”

Negatives included:

- **Lack of pro-active support** – e.g. not checking in with people who they are aware are end of life
- **Failing to recognise serious symptoms** – also not monitoring conditions which needed regular/annual checks
- **Not being able to see their own GP** – including being repeatedly sent to ‘the hub’ rather than their own surgery
- **Difficult to access** – specific issues relating to access included the negative impact on family carers who are often already stretched for time, and the difficulties caused when social care staff were unable to contact the GP on behalf of the person they were supporting
- **Not giving timely support** or making timely referrals (e.g. to hospice or continuing healthcare)
- **Poor communication with hospital**

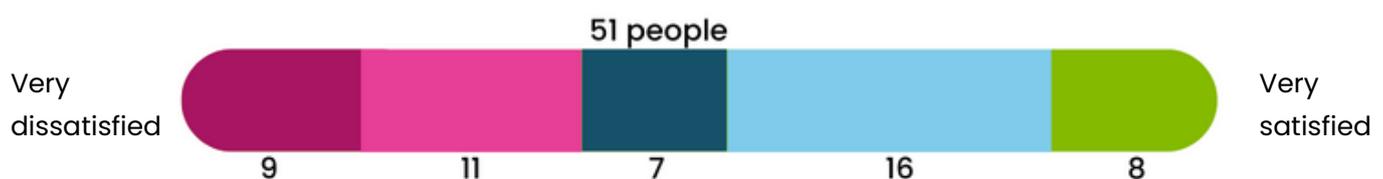
“The Drs at the medical practice weren’t very proactive. They responded to concerns, but it was all driven by my mum, aged in her late 70s, and exhausted. Felt there should have been more monitoring of drugs prescribed”

“GP care was awful, could never reach them. Left hand didn’t know what the right was doing. Hospital letters never appeared to reach them! Constant battle with them”

“The carers only have short timeslots and they can’t get through to the GP surgery and give up calling saying “we’ll see how you are at next visit”

“Mum needed antibiotics and S rang the GP early in the morning. The GP said they would phone back but they never did. I’ve been number 25 in the queue. 56 mins waiting and then no appointments”

Accident and Emergency (A&E)



The survey results showed that less than half of the people who spoke to us about A&E (24 people, or 47.1%) were satisfied or very satisfied. Some people highlighted A&E as one of the most negative elements of their experience. Concerns included:

- **Long waiting times** in A&E made worse by the **environment** and the lack of a peaceful, comfortable waiting area
- Concern about **exposure to illness** such as Covid when spending long times in a busy waiting room
- **Basic needs not being met** – e.g. lack of food, not being able to get to the toilet

“As a terminal patient and a wheelchair user I felt that it could have been easily remedied had there being a quiet area, with comfortable seating. Obviously in these difficult times this would not have changed the length of time I waited but it would have made it a little more bearable. Future planning to improve the care of palliative patients who arrive at A&E should take into account that many are suffering from the underlying effects of their treatment and have complex care needs, as well as the immediate reason for attending A&E. Twelve hours plus waiting could be vital in the lives of terminal patients cases and maybe some of their last. When a palliative patient presents at A&E they should at the very least be allotted a named nurse at the triage stage who can make sure they are

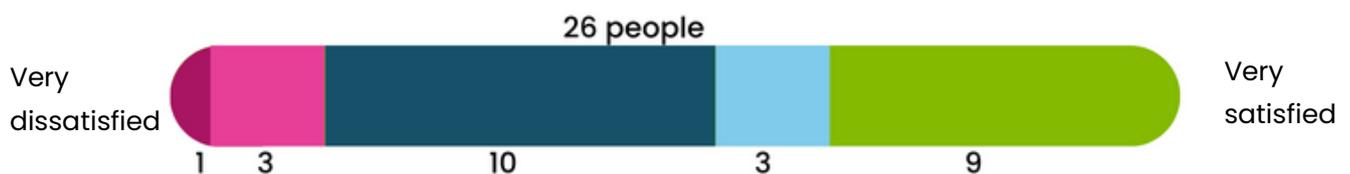
comfortable and initial tests completed in a timely manner. It's not much to ask for when reaching this stage in your life"

"Being left in A&E whilst awaiting to go on the ward impacted on health and therefore caused deterioration. Left in a wheelchair for 12 hours is not good for someone with parkinsons and lung cancer. Was not made to feel comfortable and well as emotionally impacting on their wellbeing. If he had not been in a&e for this amount of time for something that was only a minor issue it may not have escalated to palliative care within the hospital"

One person described being kept well informed and treated with compassion by staff when their daughter died:

"At regular intervals A&E staff checked in with me to see if I was OK. This continued until 2 doctors arrived and in the best way possible in the circumstances delivered the news that my daughter had died"

Active Recovery



The survey results showed 12 people (46.2%), were satisfied or very satisfied with the Active Recovery service.

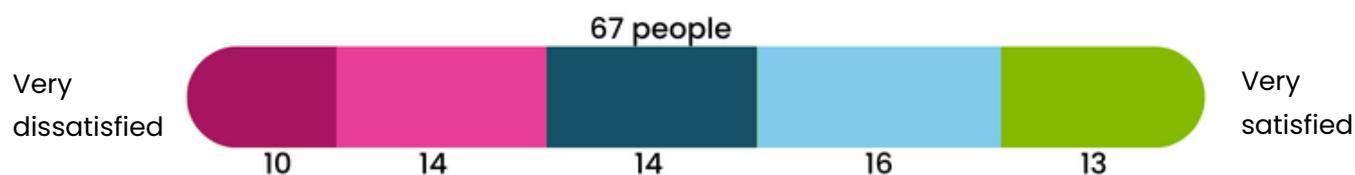
Active Recovery is a joint service provided by Health and Social Services which supports discharge and prevents avoidable hospital admission by –

- Rapidly Responding to individual needs
- Assessing the needs of individuals
- Providing support and reablement
- Available 7 days a week for a short period

One relative felt that that the service helped their relative's health but they still had unmet needs with regards to domestic tasks:

"When she finally got home, the first time she was with active recovery who were good for health, but couldn't do any household stuff she required. She also got frustrated she never saw the same face twice but there is a clear gap when noone can buy shopping etc or run a Hoover over, and she wasn't allowed anyone else at that time to fill those gaps"

Hospital



The survey results showed 29 people (43.3%) were satisfied or very satisfied with care and support from the hospitals.

Positive descriptions of care in hospital focussed on areas such as:

- **Caring** and **respectful** staff
- Being given **time to stay with the body** of the person who had died. This came out strongly in both the survey and the interview responses
- Good experiences of oncology care in outpatients – including **continuity of support** from consultants overseeing care

“We were not rushed in the hospital after our friend died. Her children were allowed to stay with their mother’s body for several hours”

People also described negative experiences. The main issues identified were around poor communication, unsuitable environment, care and access, visiting, and poor experiences after a relative of friend has died.

Poor communication

- **Poor communication with other services** –including at discharge, leading to delays getting care in place, and delays getting home
- People not being informed clearly about their **end of life diagnosis**
- **Lack of adjustment to meet people’s needs** – for example lack of adjustment for autistic patients
- **Lack of responsiveness** – including patients having to chase for diagnosis
- **Lack of follow up** and communication after a diagnosis
- People feeling **not listened to** or understood
- Family feeling **excluded** from the decision-making process and **not being kept informed**
- Looking at records but **not talking to patients** – leading to poor decision making because of incomplete/wrong information

“Coming from working class roots and being on the autism spectrum means that she finds it difficult to put her case forward and other people misinterpret her as coping or not needing help. I worry about her because she may suffer needlessly

because she does not communicate her issues, problems, needs in a coherent way”

“She left hospital and was prescribed end of life drugs with no communication either with my mum or myself. It was a huge shock when I opened the drugs when we returned home”

“The second spell [in hospital] was characterised by poor communication and a delay in getting care in place to allow her to return home. This meant that her stay in hospital was longer than it should have been, which led to a deterioration in her health and morale”

Environment

- **Lack of privacy** – not being allocated a private room
- **Space** – the size of the space makes a difference. Larger bays or larger rooms make visiting a more positive experience
- **Lack of peaceful space** – including staff on ward chatting/not appearing mindful of the family and dying patient on the ward
- **Noisy environment** preventing sleep and recovery after treatment

“The continually hectic, noisy and chaotic environment was less than conducive to my friend's wellbeing and recovery whilst particularly unwell and receiving treatment, this was particularly an issue throughout the night and led to my friend being deprived of the sleep and rest she needed which was so crucial to her recovery”

“DYING isn't enough to get you a side room or family time”

“They shoved her onto a busy ward to die with a curtain round her while I listened to nurses talking about holidays and house prices”



Communication and bedside manner

People told us examples of both good and bad communication within the hospital. Some people described the way they were given information as “blunt” or “matter of fact” and they did not like this style. One person also told us that their parent had been on an older person's ward where they were spoken to “like kids”. She found this upsetting and disrespectful.

Others described how staff spoke to them sensitively and appropriately, and this helped them at a difficult time:

“I took comfort in the sympathetic wording that was used”

Access and care

- **Basic care needs not always being met** as an inpatient, with an impact on quality of life, e.g. the loss of glasses or hearing aids causing isolation, or difficulty getting to the toilet
- **Lack of responsiveness on wards**
- Excellent **person centred care** in Weston Park Hospital contrasted with poor experiences in general hospital services after completion of initial treatment – including finding it **harder to access urgent care** when unwell
- Being **moved from one ward to another** was disorientating and confusing
- **Reluctance to facilitate a move home** for 'hospice at home' care because of lack of certainty whether person was at end of life – resulting in their death in hospital

"Spent the last 3 nights of my husband's life in a chair beside him as before this he used to cry and say please don't leave me. When I buzz at night they don't come. Truly heart-breaking"

"Weston Park Cancer Hospital has a person centred approach, with specialist nurse support. Whilst undergoing treatment they will admit you immediately as soon as you feel unwell. Once twelve weeks post treatment this ends and care reverts to normal N.H.S. which is a completely opposite proposition"



Hospital Discharge

We heard from several people in the interviews about the difficulties they experienced when their relative was discharged from hospital – these included:

- Lack of information and communication about **planned date** of discharge
- Delay and confusion around the provision of **essential items** which would be needed at home – for example Fortisips, an appropriate mattress
- **No clear route to access help** should the situation deteriorate at home. Several people described how this was made more problematic by the weekend

Visiting

- **Not enough notice** given to some families to allow them to travel to their dying relative
- **Not being allowed to visit with a child**, meaning no family visits were possible at all due to lack of childcare

- **Covid** impacted some experiences negatively, but some people shared that despite Covid restrictions the hospital made it possible for them to visit. It was not always clear to people why restrictions had been applied/what the restrictions were



The impact of differing visiting rules

In interviews, we heard from some families that they had been able to visit at all hours; they appreciated the opportunity this gave them to be with their relative. Other people told us that they had encountered restrictive visiting hours on wards, making it much harder for all the family to spend time with the person. In particular, we heard how this meant that family from outside of Sheffield could not visit because it wasn't possible for them to get there at the right time.

Experiences after the person has died

- We heard about people being able to **spend time with the body** after death, and how important this was to them. We also heard from people who felt rushed, and the negative impact this had
- **Impact of the weekend** – a death on the day before a bank holiday weekend meant that the family weren't contacted by the morgue for several days
- **Bereavement office** – didn't get in touch for several days, leaving people feeling unsupported

"I would have liked to have stayed longer after death but felt rushed. When we came out of the room the sister didn't wait until we had gone before she locked the door, this was distressing to us because my daughter always liked the door open, even in death you should be compassionate"

"We were then taken to the relative's room and told we could stay in there and take our time. We weren't rushed and the nurses were very kind to us"



Getting a death certificate

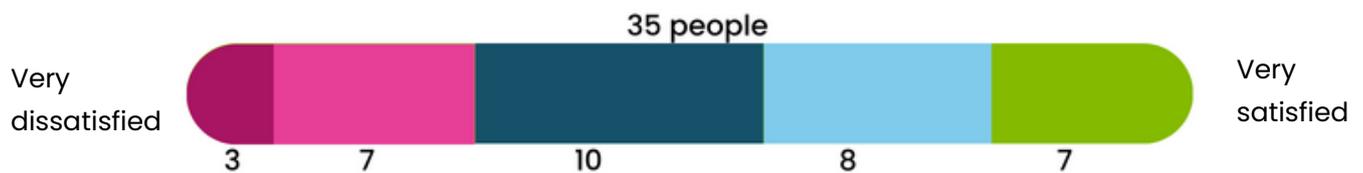
We heard from 2 Muslim families whose relatives had died shortly after discharge from hospital, and the important role hospital consultants played in helping them to obtain a death certificate on the weekend:

"The hospital told us that she might as well go home. She was discharged on a Friday at 8pm. We were worried that she might need help over the weekend.

We asked who we should contact. The hospital said care was now with the GP and to contact our out of hours GP if we needed support over the weekend. In the Muslim culture you need to bury your dead quickly. Nan died the Saturday night; we phoned the GP and they said go back to hospital. The consultant at the hospital sorted out the death certificate and we managed to bury her on Sunday.”

“We rang the GP Saturday night and was asked to call in the morning (Sunday). It was very stressful. I was awake all night. Sunday morning we rang the nurses and then said a GP needed to sign the death certificate. The nurses came to our home but the GP didn’t. We (family) went to the hospital to find the consultant. The consultant was on annual leave. We emailed her and she came out and signed the death certificate. Mum was buried on the Sunday”

NHS 111



The survey results showed that 15 people (42.9%) were satisfied or very satisfied with 111.

Only one person described their experience of using the service. A terminally ill person who uses a wheelchair had called 111 and was directed to take themselves to A&E:

“Calling 111 who asked if I could find someone to take me to A&E as there was no ambulance available”

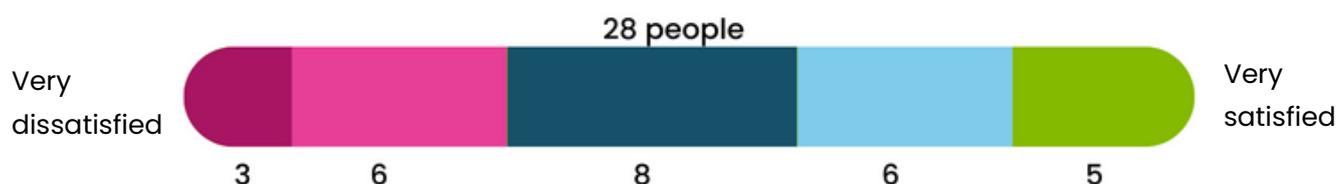


Feeling dismissed by services

We heard about the experience of Amina, a woman in her 40s who had English as a second language. Her family felt that her concerns were dismissed by the GP and 111 when she became suddenly unwell (with no previous diagnosis of a serious health condition). She collapsed a few days later and died in hospital:

“3 calls to GP, told no appointment and to just rest. One call to 111 and was told symptoms were normal....”

Fast track Continuing Healthcare



The survey results showed that only 11 people out of 28 (39.3%) were satisfied or very satisfied with the fast track Continuing Healthcare (CHC).

NHS Continuing Healthcare (NHS CHC) is a package of care for adults aged 18 or over which is arranged and funded solely by the NHS.

When an individual's health is rapidly deteriorating – and when they are considered to be approaching the end of their life – they may be eligible for fast-tracked NHS Continuing Healthcare.

People described **delays** in accessing fast track CHC – these included delays with being referred, delays with care being put in place, and also delays in payments being made:

“Fastrack service – very slow to get care to go home – I know it can be procured much more quickly in surrounding areas, Sheffield takes a very long time when people don't have long they don't want to waste it in hospital”

“No CHC fast track referral done by hospital despite being told 3-4 months prognosis”

“CHC fast-tracked swiftly but funding still not paid after 5 months”

Social care and community organisations

The survey asked people about other services that had given them support, outside of the NHS. 44 survey respondents told us about at least one social care service or community organisation – these are listed below, starting with the service which received the highest percentage of ‘very satisfied’ or ‘satisfied’ responses, and ending with the service which received the lowest:

Social care service or community organisation	Number of people whose friend or relative used this service	Percentage who were ‘very satisfied’ or ‘satisfied’ with the care received
Community organisations/ charities	27	92.6%
Faith organisation	18	77.8%
Care homes	13	69.2%
Home care services	38	68.4%
Advocate	5	60%
Social worker	22	50%
Respite care	9	44.4%

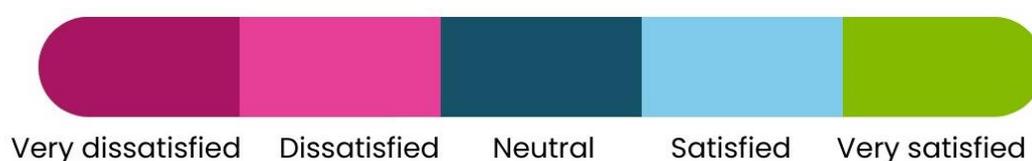
We have combined a breakdown of satisfaction ratings per service type with analysis of free text responses throughout the survey, to provide further insights into people’s views and experiences of each specific service.

However, it is important to acknowledge that people don’t experience the services they use in isolation; their experiences often span across many different types of services, so how they work together and are coordinated has an impact on how people experience their care as a whole. Section 3 (page 46) contains what we heard about people’s experiences across services.

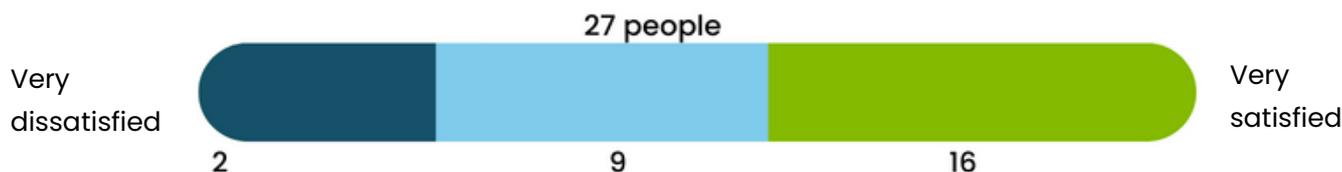


We have also included what we heard through our one to one interviews and community conversations which are shown in the blue boxes like this.

Key



Community organisations/charities



The survey results showed that 25 people out of 27 (92.6%) said they were satisfied or very satisfied with community organisations and charities, with no dissatisfaction ratings received in this category – the remaining 2 people said they felt ‘neutral’.

People valued these organisations’ compassion, wellbeing activities, advocacy, language support, and useful information.

“The support we had from our Community groups was instrumental – empathy, advocacy. language support”

“The only people who even tried to help me were Sheffield Carers Services and I will be forever grateful for them just speaking to me kindly at that time. No one in the health service were helpful at all and I found Sheffield carers service proactively when I was desperately trying to get my mum out of hospital when she was clinically well enough to go home but being held hostage waiting for adult social care to provide care at home”



Community groups offer valuable support in a range of ways

People in the interviews described how community groups had supported them in different ways, at different stages of their experience.

In some cases, people who had joined these groups when their friend or relative was alive, later benefitted from their support after bereavement. We spoke to a bereaved carer at a dementia group:

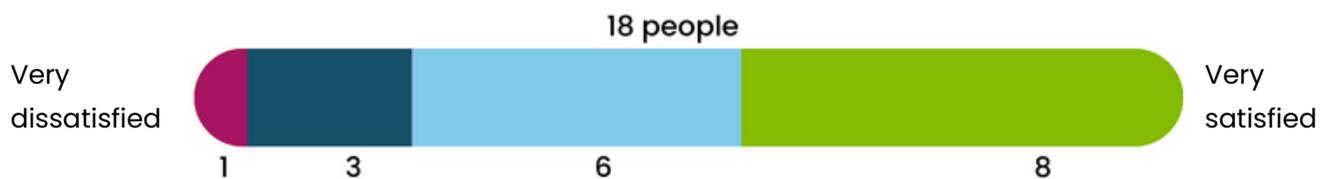
“Memory café [Parson Cross Forum] has been a life saver. We were made to feel really welcome. It was friendly, warm. I started to bring my wife. All my life I’ve tried to get my wife to dance, but she never would. She looked forward to coming to the café. We came three times a week... She was relaxed here [café] and made friends. She even started dancing”.

“We have a network of friends and the staff are very good... Even if you go for a walk to get out of the house, it’s still just you. We’ve been on coach trips with friends from the café and I’m still part of the group now my wife as passed away”

For some people, the support provided by community groups gave them more than just social support. People from communities marginalised by race (including those with English as a second language and migrants to the UK), relied heavily on community groups to help them to navigate health and care services, as well as the processes after death of a friend/family member. We heard how volunteers and staff in voluntary sector organisations are doing this work, often with no or very little funding to support them. They play a vital role in helping people link to statutory health and social care services.

“The communication with social services went smoothly because SACMHA took care of it”

Faith organisations



The survey results showed that 14 out of 18 people (77.8%) were satisfied or very satisfied with a faith organisation.

Although people of different faiths completed the survey, all the additional comments we received related to Christianity. They were all positive:

“Our local priest was equally fantastic and helped immensely with the spiritual process”

“Church community and close family all very supportive”



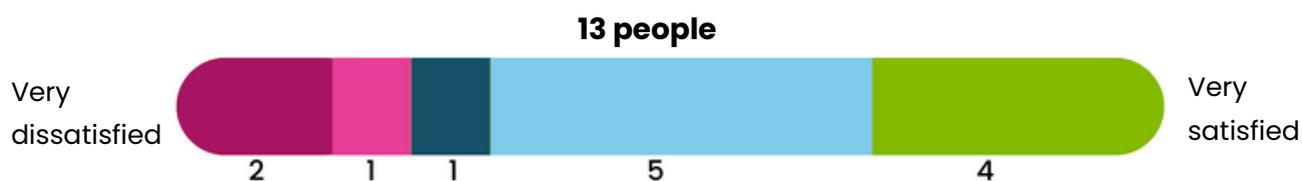
In our interviews we heard about the different roles that faith organisations played in supporting people.

Support during illness – for example church groups that were accessible and supportive for people living with dementia; this inclusive approach made it possible for people to continue to be part of the church community.

Practical support around the death and funerals – “The mosque has a death committee who pays for food and consumables that you need for the burial. The family has to pay first and then claim it back from the death committee [...] The mosque bought an old pub to use. Families can use the building for the day of the burial”

Bereavement support – checking in with people to see how they are after the loss of the family member or friend.

Care homes



Survey results showed that 9 out of 13 people (69.2%) who had experience of care homes were satisfied or very satisfied with the experience. There was general praise for care homes:

“Great end of life care home”

Negative feedback included:

- Concerns about **staffing levels**
- Concerns about **quality of staff**
- Lack of **person-centred care**

“The nursing home treated her like a number rather than a patient”

“Not enough staff and not enough quality staff – too many sit around”

“More work needs to be done for people without friends and family in care homes at end of life”



We spoke to a **care home manager** who told us how they approach the subject of end of life care when people move in. This includes talking with them about preferences for care and treatment, and where they would like to die. They also ask for other information to help them to make death personal to the individual – for example what music they would like, and any other particular preferences such as scents to spray in the room

Enabling visits from family was important – they allow 24 hour visiting, and have a spare room for family members to stay. If a resident has no relatives, staff prioritise spending time with them at end of life, bringing in additional support from night time nursing service when it becomes appropriate.

They described that some people were not able to die in the home, despite it being their preference – reasons for this included disagreements within families about what was best, for example during a medical emergencies where a decision is needed about emergency admission to hospital. In some cases, residents have been unable to return to the home after a hospital admission because their health needs have increased, and it is decided that it's not possible for them to be cared for in a residential home setting. This can be

confusing and upsetting for people who are not able to return to their home to die.

The manager also described that they used to be able to get supplies of mouth swabs from the District nurses, but these were no longer available. The home was now buying them instead, but this was a significant cost to them.

Anna and Maria's Story* – good support in a care home

Anna was in her 90s when she died in a care home in Sheffield. She was from Eastern Europe but had lived in the UK for more than 50 years; her religion was a key part of her life. Anna had dementia and had been in a care home for a number of years before she died. We spoke to her daughter, Maria – she told us about the care her mother had received in the last few months of her life.

Maria was happy with care that her mum had been receiving in the care home (which was dual registered nursing and residential) – she told us she was settled there. When we asked whether there had been conversations about end of life care, Maria told us that years ago (following the dementia diagnosis) their GP had had a conversation with Anna about end of life care. A review of this conversation happened at a later stage as well, when her mum said that she wanted to die in her care home.

When Anna's health deteriorated, Maria was satisfied with the care and support from both the GP and care home – she was also happy with the way they communicated with her and kept her informed.

"Mum's GP was very good with me. I asked if mum was dying and he explained the situation very well and very clearly, for which I am thankful"

"Care home rang me end of Oct, to say mum had deteriorated. They made the decision that she was no longer going to have any more food or drink. Just swabs, as she was beyond the point of recovery"

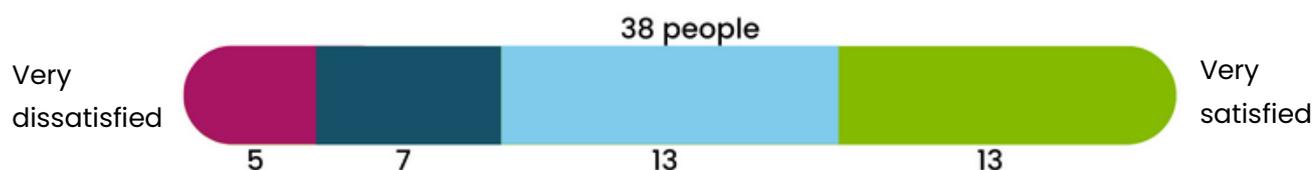
Maria agreed with that decision. We asked about how Anna's pain was managed:

"[Palliative care] nurses administered morphine, other times they didn't give her enough and she was in pain"

She died in the care home, as was her wish. Maria was happy that they were able to uphold a cultural tradition which was very important to them – an embroidered cloth was hung around the door. Their religious community helped with the funeral arrangements.

**Names have been changed*

Home care services



The survey results showed that 26 out of 38 people (68.4%), were satisfied or very satisfied with home care services.

Getting a care package in place

People told us about **delays** in getting care packages in place, including discharge from hospital. We heard that discharge was too slow and setting up a package took a long time – one person told us that their care package was cancelled 48 hours after hospital admission and this later prevented a timely discharge:

“The waiting list system before discharge is dangerous to patients who need to go home in a timely fashion – no one seemed to care at all that this was not happening and the phrase ‘care crisis’ was bandied about constantly but every time I tried to speak to any operative they were always on annual leave or off sick. Complete lack of all urgency to improve services”

“Every time she was in hospital for more than 48 hours her care package stopped. Yet I was told she would be in hospital more often than not in her final months. Well if she has a need to be admitted for 3 days every 3 weeks, but it takes 3 weeks to reorganise her care package, you are sentencing her to remaining in hospital until death”

“Robbed her of about 2 weeks of her last 5 months simply because they couldn’t get their act together to provide homecare”

A family with a child that has a life limiting illness told us:

“We have a PA from social services who comes and takes my son out. This is good and I had to fight for 8 hours of care”



Barriers to getting the right care

In group discussions with the Hadfield Institute, people described how **information** about social care was not easily available, or pro-actively shared with them. They also highlighted the **strain that was placed on family carers** as a result.

People were not aware of services and help available for their family members, or them as carers; they described that if they did not look it up or ask for it, it was not offered to them. The lack of support alongside increasing care needs put strain on their day to day life and impacted on the family setting.

Those that did access support felt that care packages didn't always take into account the other commitments of carers and the timeline for assessment of care needs was often too late.

In the **one to one interviews**, we heard examples of families choosing to provide care themselves because they didn't feel confident that agencies/other support services could offer culturally appropriate care.

Quality of care

People described a range of concerns around the quality of home care. These included:

- Rushed visits
- Variable standard of care amongst different care workers
- Issues around medication
- Language barriers
- The type of food being prepared.
- Carers not identifying when the person was unwell
- Carers not providing appropriate care for people with dementia
- Inaccurate record keeping

“Double the time is needed for someone in the last months of life not rushing in and out”

“She is using a private care agency which is a Sheffield Council preferred care provider, but the staff (and management) do not have a good command of English and to date, they have not enabled my friend to have access to her online medicine/drug records or care records. My friend does not know which drugs she is being prescribed or dosed with”

“She was not asked about her needs by social care. The social services accepted what she said and would leave. Sometimes left her starving at home”



Length of care calls

While many people described rushed care, in the interviews we heard an example of good care from someone that was able to pay privately and organise care themselves – longer timeslots helped the carers to provide better care

“The carers are fantastic... they are private, we pay for them. I ask them to leave the washing for me to do. They charge by the hour so you can't book ½ hour slots. They are attentive to mum's needs, they give her all her meds and Saturday is shower day.... They even bring food and things in for mum that they think she'll like. They are tuned into her needs”



Consistency of care

We heard stories that described how getting the right care in place was hard; often people had tried more than one agency before finding one that worked for them. This included difficulties finding companies that could meet specific needs such as female-only carers, or working with someone that was displaying aggressive behaviour due to dementia. In some cases care packages broke down and families had to step in to provide care themselves:

“Two companies withdrew care. Mum could be violent and we needed female carers for personal care”



Carers being able to offer appropriate support in relation to death and end of life

People described both positive and negative experiences of how carers had worked with their family and approached the subject of death and grief. One person described how supportive the carers were when their family member died:

“They went absolutely above and beyond. She died at home and the carers stayed with her body for many hours later until the death certificate was done – they came to funeral and have stayed in touch since”

In contrast, we heard how some people felt carers lacked awareness of how to talk about death:

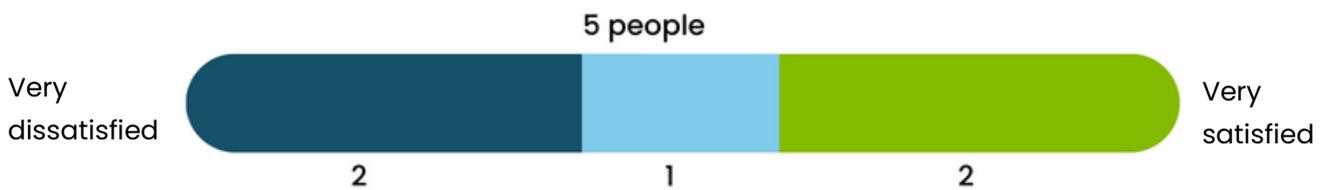
“The carers walked and shouted ‘What's all this talk about dying? You're not going to die. If you die I'll bring you back to life and kill you again for dying’ Mum was confused and asked what the carer meant, and the carer repeated it. I couldn't believe she was saying this”



Culturally appropriate care

We heard about the importance of culturally appropriate care at home. In some cases, families chose to provide care themselves to ensure this because they weren't confident that care agencies could meet the need. But we also heard examples of how social care had supported this. SACMHA shared an example about a team of carers, where one carer of African Caribbean heritage was able to support others on the team to provide the right care. Direct payments were also highlighted as a valuable tool to enable families to choose carers themselves; support from a voluntary sector organisation to help put this in place and manage it was also key.

Advocacy services



In the survey responses, only 5 people reported having used Advocacy services. 3 of these (60%) were satisfied or very satisfied with advocacy support.

An advocate is an independent professional who supports someone to have their say and know their rights. Advocates can support people with things like the process of getting social care, and making complaints about NHS services.

No respondents provided further comment on formal advocacy services, but one person commented that community groups had helped with advocacy:

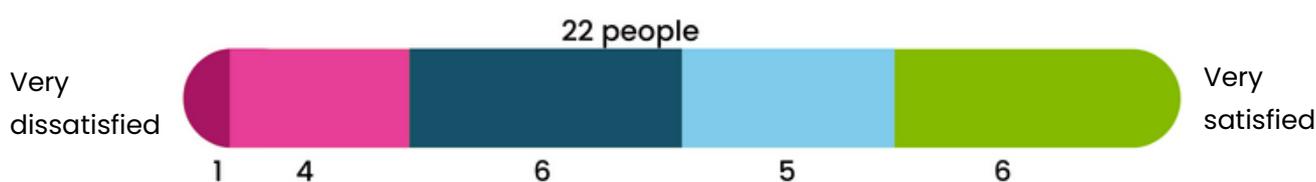
“The support we had from our Community groups was instrumental - empathy, advocacy, language support”

Some people felt that experiences would have been improved through advocacy:

“I think that my friends lack of access to timely and relevant information is due to the fact that she has no close family to advocate for her, or on her behalf. She lives alone, is bedridden and not able to exercise any real control over her care”

“I think if people have an advocate they will get better support but too many people fall through the gaps”

Social workers



Survey results showed that half (11) of the people that rated their satisfaction of the social worker involved in the person’s care were satisfied or very satisfied.

People appreciated the support received, including **support after the person had died:**

“It was welcomed when social services acknowledged the death and communicated support”

“Persons from adult social care have been supportive and my daughters social worker and a senior manager did attend my daughters cremation”

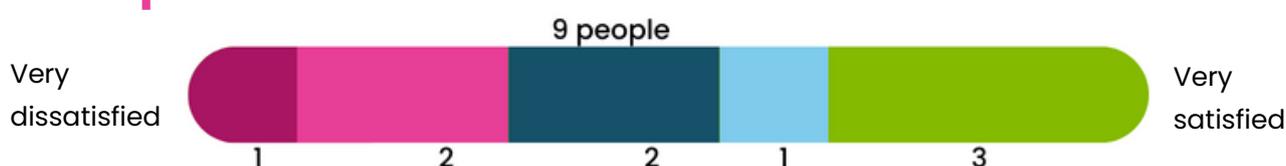
One person felt the social worker involved **struggled to help coordinate care:**

“She had a good social worker, but it seemed the social worker also didn’t know how to get the health systems to work together. Her social worker only worked part time and this may have impacted on how much she was able to chase services”

A relative thought a social worker would have helped them **navigate the system:**

“Lack of social worker, would have been helpful in navigating the complex care system, often unclear who to contact about what, which when you’re dealing with a close relative’s decline just adds more stress and complexity to an already difficult situation”

Respite care



Only 9 survey respondents reported using respite services; 4 of these (44.4%) said they were satisfied or very satisfied with the respite care.

Respite care is short-term care for people who need extra support following an operation or illness, or temporary care while their regular carer takes a break. It may be extra care provided for the person at home (for example by a care agency) but more often it will be short term stay in a residential or nursing home.

One person shared a positive experience about the help received through hospice based respite:

“The hospice respite care was the only organisation that helped everyone else either was too stretched or just didn’t help!”

We heard many instances of family and friends describing being in need of a break, but not being able to get one.

Someone commented that “allocation of respite still seems hard to come by”.

“Provision of more respite care is a needed improvement”

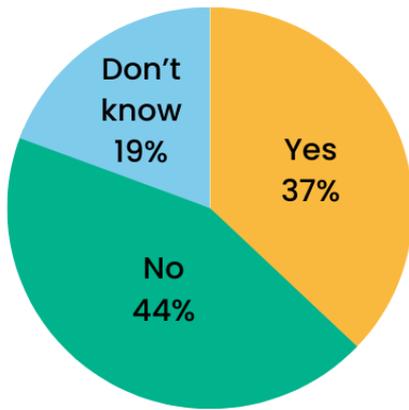


Difficulties accessing respite care

One of the people we interviewed, Jane, was exhausted after the care for her mum broke down. It was suggested that the family could use respite, but due to their social worker going on leave, the family were told a duty worker would need to get in touch to arrange this. They didn’t hear from anyone, meaning respite wasn’t arranged and the family continued to provide the care themselves.

2. Advance care plans

Do you/does your friend or relative/did your friend or relative have an Advance Care Plan?



We asked everyone who responded to the survey whether they or their friend/relative had an advance care plan. 186 people across South Yorkshire answered this question.

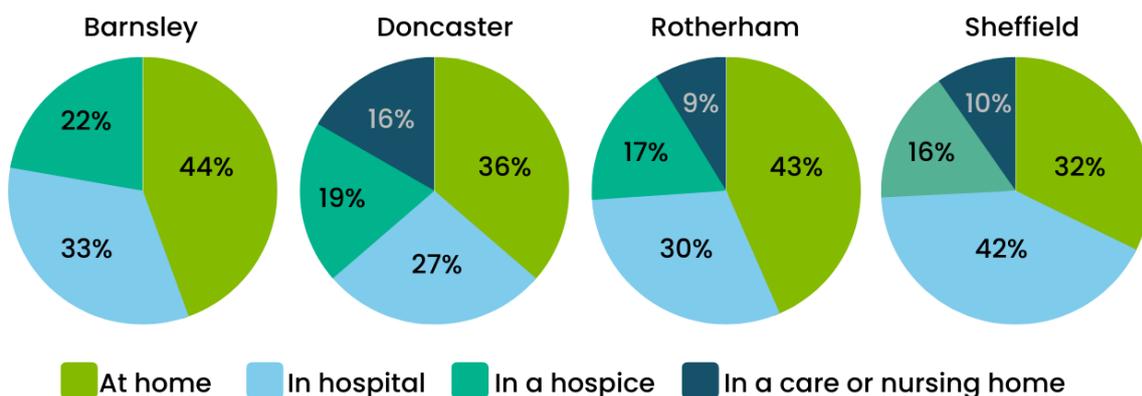
Results are fairly evenly split between those who did and did not have an advance care plan.

This does vary quite widely across the region, though, with Sheffield having the lowest percentage of people with an advance care plan in place:



Where did your friend or relative die?

We asked people who had been bereaved in the last 2 years where their friend or relative had died. We received 161 responses to this question (6 from Barnsley, 67 from Doncaster, 23 from Rotherham and 62 from Sheffield).

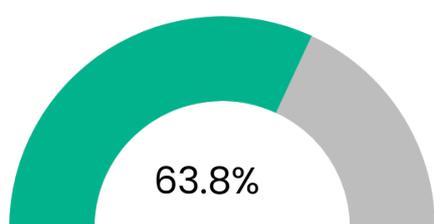


We heard from people whose friends and relatives died in a variety of settings, which were relatively consistent across South Yorkshire, though there are some differences. Compared to South Yorkshire as a whole:

- More people in Doncaster died in a care home
- More people in Barnsley and Rotherham died at home
- More people in Sheffield died in hospital

We didn't hear from anyone in Barnsley whose friend or relative died in a care home, however the number of survey responses is lower than the other areas.

Were people asked where they wanted to die?



44 out of the 69 people who answered this question (63.8%) said that the person who is/was dying had been asked about their preferred place of death.

“Husband had advance care plan. We both thought it was a good idea as he was able to state his final wishes of how and where he

wanted to spend his last days as he did not want to die at home”

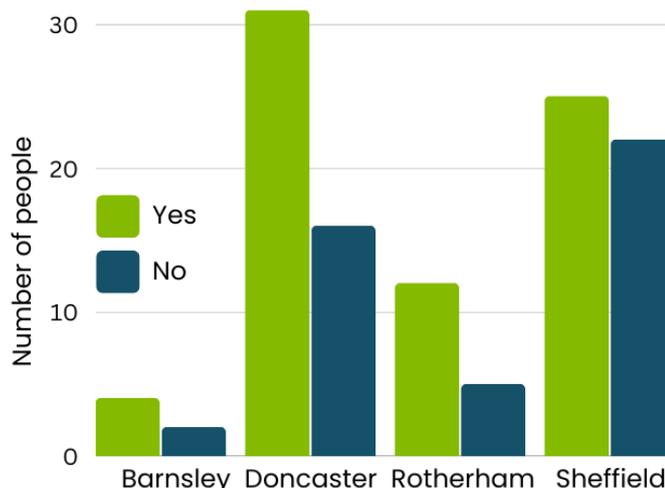
“No options discussed about place of death although we were involved in the decision to stop treatment”

Is this where they wanted to die?

Just over 1 in 4 people (27%) told us they didn't know where their relative or friend wanted to die, that the person couldn't express their view, or that the person didn't have a view.

Where people did know their friend or relative's wishes, we heard that just over 3 in 5 people (61%) were able to die in the place that they chose.

Barnsley, Doncaster and Rotherham have fairly consistent rates, at 67%, 66%, and 71% respectively. It was lower in Sheffield, at 60%.



Did your friend or relative die where they wanted to?

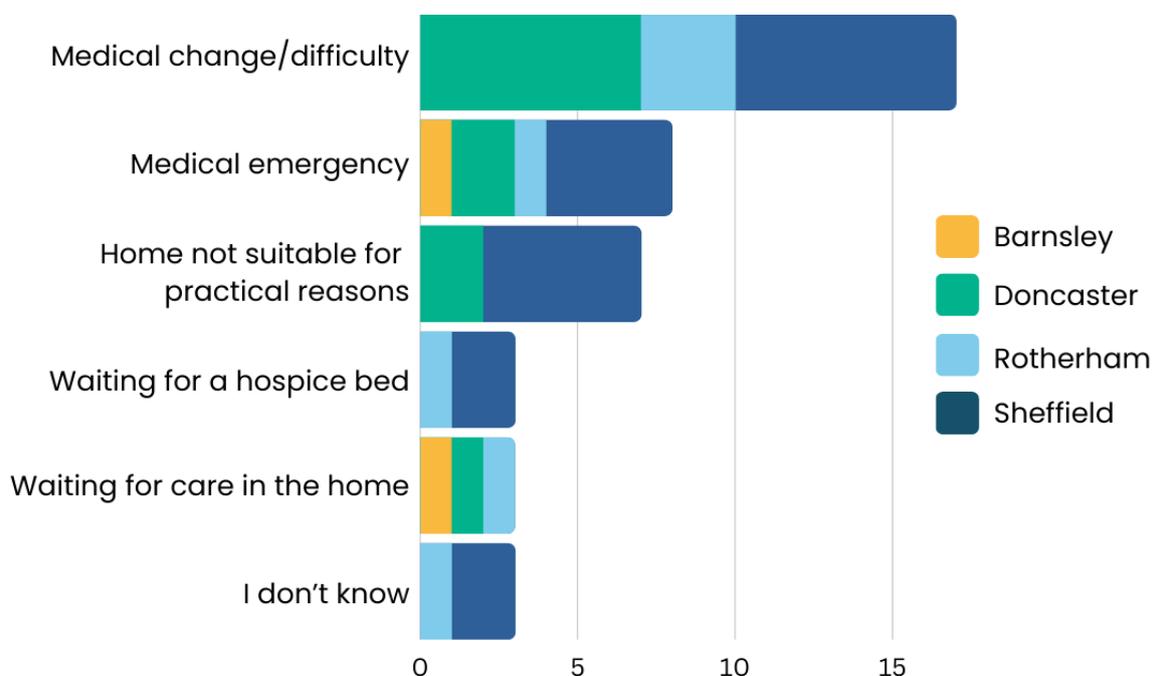
“I wanted my Mum to die in a hospice and was told that would be unlikely. The hospital however were kind and looked after her needs during her final days”

“If I could have taken him to Switzerland I would have done as this was not the death he wanted. We were on a ward with dementia patients (my father did not have dementia & was on end of life care following a head trauma)”

Why weren't people able to die in the place they wanted to?

Around half of those who told us their friend or relative didn't die in the place they want to (37 people) told us why. The biggest reasons were medical – due to changes or rapid deteriorations in the person's condition. There were however some practical reasons too – people's homes not being suitable for hospital beds or other equipment, or that they were waiting for the next steps to be arranged.

Why wasn't your friend or relative able to die in the place they wanted



“Unable to access hospice due to lack of bed availability despite been told there would be a bed. Moving round in hospital from one ward to another, very disorientating and upsetting”

“I asked for her to then at least have ‘hospice at home’ and they said ‘we don't know if she's going to die though’. She was dead within 24 hours and no one made any effort/even started any effort to get her home. Instead they moved her to a busy ward”

Advance care planning insights

We analysed people's responses to the question **'Is there anything else you would like to tell us about advance care planning?'** and other relevant comments throughout the survey, and the interviews to identify 5 main themes.

1. Lack of clarity around whether there is/was an Advance Care Plan (ACP) in place

21 People (27%) said they didn't know whether there was an Advanced Care Plan (ACP) in place, and this was also reflected in what people told us through interviews. Some family and friends knew there had been some discussions or that Do Not Resuscitate orders (DNRs⁷) had been addressed, but were unsure whether there was an actual ACP. Some felt there was nothing recorded that could be accessed by the different services involved in the person's care:

"Some discussions were had but not sure if anything concrete was in place"

"The GPs addressed the DNR process, but I am not aware of discussions about anything else. Certainly nothing seemed to be held in a central place"

"This wasn't clear to family or other services, palliative care were not great at working collaboratively"

One person thought their friend had an ACP, but had not been given any record of it:

"I believe that when the palliative care team nurse visited, details were recorded to produce an advance care plan. However, if this was actually done during the visit, there is no record held by my friend of this plan"

2. Advance Care Planning needs to be timely

The timing of advance care planning varied according to circumstances; it wasn't thought to be possible in some situations. Some people said there that there was not enough time for their friend or relative to have an ACP, whilst others mentioned it happened close to the time that their friend/relative had died and could have happened earlier:

"A plan was not in force, except for her home care support plan, but as the end of life was so unexpected end of life was not on the agenda"

⁷ DNR stands for do not resuscitate. It is also called DNACPR (do not attempt cardiopulmonary resuscitation) or DNAR (do not attempt resuscitation) but they all refer to the same thing; if your heart or breathing stops your healthcare team will not try to restart it.

“No ACP, Diagnosis was delayed so didn't get chance to approach this subject”

“Unfortunately my late husband didn't live long enough to receive an advance care plan”

“As far as I am aware this [DNR] was done on the day he passed”

“We only heard about this towards the very end, would have been useful to discuss it earlier”

Only one person mentioned a ReSPECT⁸ form. It was suggested quite late, and not as part of a wider discussion about advance care planning.

“Family did a power of attorney but no advanced care plan was offered till almost the last few weeks of the persons life when a hospital consultant advised to get a ReSPECT form completed”

3. People want to make informed decisions about whether they want to be resuscitated (DNRs)

Some relatives felt pressurised by health care professionals to agree to a DNR, and highlighted the importance of having a good explanation of why this was being advised, as well as time to talk it over with family:

“On a couple of occasions, I had been approached by GP's that were new to me about a DNR for my husband who has dementia. I felt pressurised & unhappy to agree & refused to do so. I was then visited by our 'named GP' who took time to explain the reasons for agreement & I felt more comfortable in having one for my husband. This same GP then initiated a raft of referrals all of which have been used as needed. I feel well supported & well able to have my husband cared for at home. I think patients, service users etc must be given proper explanations regarding care plans, this takes time & everyone is under pressure but it pays off in the end & saves a lot of distress”

“All the staff appeared to care about was wither or not she had a DNR. Their interest in this was unnaturally keen. it was really quite disturbing, not only among multiple people visiting the house but also one chap who rang up to give advice

⁸ <https://www.resus.org.uk/respect/respect-healthcare-professionals> The ReSPECT process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. These recommendations are created through conversations between a person, their families, and their health and care professionals to understand what matters to them and what is realistic in terms of their care and treatment.

and then rang back up specially to ask where her DNR was. I felt the NHS were MUCH too keen to ensure old people were not asking to be resuscitated”

A relative who cared for a person who didn't live in Sheffield but used services in the city, described her husband's shock when he realised he had signed a DNR form:

“When my husband was in hospital, he signed some forms which to his horror was a DNR, he was shocked about this because he didn't know what the forms were. It was a couple of weeks later that we realised what the forms were and what he had signed. This shouldn't be allowed to happen”



ReSPECT forms

Where a ReSPECT form is filled in collaboratively with the patient and family, it can help them feel assured that their wishes will be respected:

“When my relative was at the end of life the GP called me and told me they look after all their carers. They showed me the RESPECT form and talked through it with me. The form is uploaded and shared with health professionals; it's really good. It records everything the patient and family want. This means if someone goes into hospital the staff can look at the information and do what's requested”

4. People value information about what to expect

Some friends and relatives commented that discussions and information around advance care planning were useful. However, regardless of whether they believed there was an ACP in place, people wanted more information about what to expect and the care available:

“A lot was discussed with the hospital palliative care consultant explaining how things would be as the disease got worse – this was very helpful”

“We needed a bit more information, raising awareness”

“More information on how end of life care works”

“Pink card⁹ – definitely needs to be more information provided to families of religious beliefs”

⁹ A '**Community Administered Medication Record Pink Card**' is required for adult patients in Sheffield prescribed **pre-emptive medications with or without a subcutaneous infusion via a syringe pump**, to authorise community nursing staff to administer these medications for the patient.

“Maybe some better support in understanding palliative care/help would have been good”

“Wish there was more discussion and preparation of what to expect”

“When admitted to hospital we were unaware patient was deemed to be ‘end of life’. Very poor communication regarding care pathway/potential outcome. No evidence of end of life care plan”

5. Family and friends help people communicate their wishes and make sure they are fulfilled

Family members and friends play a key role in supporting people to have the care and death that they want, including dying where they had chosen:

“I know that basic details of where they would prefer to be cared for, and values and beliefs have been conveyed, verbally, to another friend”

“My relative had dementia before the cancer diagnosis, so we'd spoken before it advanced about their wishes”

“I am a mental health nurse and trying to support mum with advanced care planning as we have no idea when she will decline”

“They did have a health power of attorney and I communicated the decisions made to the hospital”



Advance Care Planning – the importance of cultural competency and trusted relationships to support conversations

At a Hadfield Institute session, half the group said they would be open to discussing Advance Care Planning, but for others there were barriers. 30% said they would be hesitant and wanted more information, but this would need to be in a setting that would meet their **cultural and language needs**. The remaining participants struggled with the subjects covered by Advance Care Planning and were not ready for these discussions – they would need more time and support to digest this information.

Gordon's story* – Support to die at home

Gordon was in his 90s when he died. He had dementia, and was partially sighted. We talked with Gordon's daughters who had played a key role in his care.

They began the description of Gordon's end of life journey by talking about the impact of lockdown; they felt his deterioration really began in that time. Before that, he had been very active and mobile – going to football matches and doing the things that he had always done.

When his dementia started deteriorating they felt well supported by church, and by a local voluntary sector organisation. Gordon had been a lifelong fan of Sheffield United and they described how when his sight was deteriorating the club gave him earphones to listen to the matches, and a carers' ticket.

Gordon had not made an advance care plan, but his daughters described that the family was very close and had always put in plans to support other family members to die at home.

“Dad flourished at home, anywhere else he would have died quicker”.

Following a collapse at home, Gordon was admitted to hospital. Family were concerned that he would die there. They don't remember that anyone talked with them about end of life care while he was in hospital; they did discuss a DNR which was put in place, and they understood the reasons for that decision.

When they talked to the hospital about Gordon being able to return home, they felt staff didn't trust that the family would be able to meet his needs. However his daughters had worked in health and care settings and felt confident they had the skills to provide the care.

They received a phonecall to say a rehab bed had been arranged for discharge. They didn't want this and told the hospital it wasn't appropriate – they told us that they felt it was a 'fight' to be able to take him home, and that the hospital wasn't working with them constructively to help this happen. They said:

“They could have had us in to show us and work with us. If they didn't think we were able to do it, why didn't they let us work with them to show what we could do, or they could show us what to do?”

It was agreed that Gordon would return home. This is when the daughters described that some of the challenges began to get everything in place.

“Got great care in hospital but it's not joined up... it's when he leaves...”

A referral was made for equipment – this included a bed, but when it was delivered there was no mattress. They learnt that a nurse in hospital had requested an air flow mattress but this was overruled because he didn't have

any pressure sores. They went to collect a mattress from Rotherham so that it didn't delay his discharge.

The family knew about the need to turn Gordon regularly but said nobody had shown them how or talked about the importance of this before leaving hospital – once home, the district nurses did talk about how often to turn him. Despite this, a couple of days later he developed some red areas.

“A couple of days later I phoned medequip and said he has sores and they said no problem we could have an air flow mattress”

They told us there were other basic things that were difficult to get into place, including his fortisips. Although he had been given them in hospital, he was not discharged with any. They were directed to their GP but it seemed the GP didn't have the information they needed to prescribe, which delayed things.

“It felt like we were begging for things”

In terms of services which visited them at home, they told us the District Nurse was **“really good”** but pointed out that she only came after the they'd phoned the GP about torn skin on his arm. They were told that the physio would visit, but this visit didn't take place until the day that Gordon died, which was 18 days after discharge from hospital, so they weren't able to benefit from physio input.

“Our energy should have been looking after dad not chasing up the GP/hospital”

They appreciated getting 2 visits from the GP at home and said that there were conversations about end of life care.

The other service they spoke about was continence services, which they felt hadn't worked effectively. They said:

“Pads, they waste so much money – they provide the standard offer even though other things are available that would work better”.

Despite the challenges to get things in place, they described that they were able to create a good environment in which to care for their dad.

“Stimulation – music. You don't get that in hospital and that's not their fault that's not what they're there for. But that's why he needed to be at home, touch and movement were really important to him”.

They described a peaceful death for Gordon – the district nurse had been to visit with a view to giving morphine but felt that he didn't need it because he didn't appear to be in pain. They were certain they had made the right decision to care for Gordon at home and that this had enabled him to have the death that he would have wanted.

**Name has been changed*

3. Getting the right care and support

What support was put in place?

As well as understanding people's experiences of each individual service, we wanted to understand how well different needs had been met overall, and how well services had worked together. We asked people to tell how say how much they agreed with a range of statements about the care received – these are shown in the table below which shows the percentages of those who agreed or disagreed. All other responses (not represented in the table) were 'neither agree nor disagree'.

	Number of people who shared their view	% who said they 'strongly agree' or 'agree' with the statement	% who said they 'strongly disagree' or 'disagree' with the statement
They had/have had the equipment they need (e.g. hospital bed, wheelchair)	76	76.3%	10.5%
They had/have had the pain relief they need	77	71.4%	14.3%
They had/have had the treatment they need to manage symptoms (other than pain e.g. nausea or restlessness)	80	68.8%	13.8%
They were/have been supported with personal care needs (e.g. help with washing, going to the toilet)	74	67.6%	16.2%
They had/have had the support they need with eating and drinking	64	64.1%	23.4%
They knew/know where to go for urgent help	73	63%	19.2%

They were/are able to ask for help at any time of day or night	83	62.7%	25.3%
They had/have had support to live life in the way they want to (e.g. social activities, seeing people that are important to them)	63	50.8%	23.8%
Services worked/have worked well together to coordinate their care	75	42.7%	40%

From these responses, we see the highest levels of agreement with statements about meeting basic medical needs – practical equipment, pain relief and other medications. Other types of support are slightly lower – practical help with personal care, eating, and giving information and support. Understanding people’s needs in a more holistic sense features even lower – and perhaps links with low satisfaction scores in the way services work together and see the whole person who is receiving care.

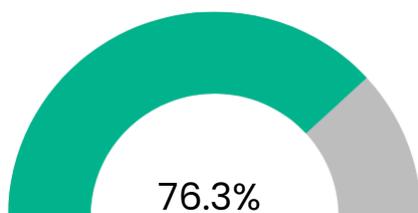
We analysed people’s responses to the question **Is there anything else you want to tell us about the care they had and the way services worked?** and included relevant comments from elsewhere in the survey, including areas asked about in the statements in the previous question, to gain further insight into people’s care experiences.

The green section of these charts represents people who ‘agree’ or ‘strongly agree’ with the statement.



The grey section of these charts represents all other responses – ‘neither agree nor disagree’, ‘disagree’, or ‘strongly disagree’.

Equipment



76.3% of people told us their relative has or had the equipment they need, e.g. a hospital bed or wheelchair.

Some people had difficulty getting the adaptations and equipment they needed in a timely way, and experienced communication issues.

“Really poor for the most part services didn't communicate, adaptations ie stairlift took months to put in place, ramp for main door ended being made by a family friend as no service was able to provide so couldn't get wheelchair out of the door”

“Medequip equipment provider, very poor: communication and delivery of items needed”

Getting the right equipment, and being shown how to use it



In the interviews, carers told us that they had been given equipment, such as hoists and slide sheets, but they had **not been given training** on how to use them.

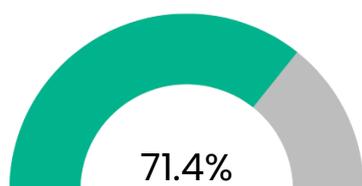
We also heard about situations where lack of clarity about **eligibility and assessment criteria**, and resulting disagreement between professionals, led to people being left without essential equipment on discharge from hospital.



One person emphasised the importance of smaller practical items that facilitate good care for people in their own homes and suggested that more could be done to ensure that families had access to these.

“We also bought quite a bit of kit to make things as comfortable as possible, including baby alarms, medication boxes, food blender, white board, it would have been nice to have been able to pass this pack on to another family to use or a pack being available to families who cannot afford to purchase this type of stuff”

Pain relief



71.4% of people felt their friend or relative has or had the pain relief they need.

Some people did not always get adequate pain relief when they needed it. This was the case in the community and in hospital.

One person felt that pain was managed better in the community than the hospital:

“There was a massive difference between care received at home and care in palliative care, the care at home was great, not so in hospital, not great at

respecting choice and individual need, not great at getting to the bottom of symptoms and managing pain. Not great at getting on top of care needed”

In hospital, we heard how delays in pain relief being administered were caused by staff changing shifts, and a long wait in A&E:

“Pain relief was agreed by palliative care doctor earlier in the day. But was delayed when my father needed it as a new medical team had come on duty and they had to check with person in charge. This took over an hour to get the ok during which time my father was in great pain”

“The only negative experience was a visit to A&E. He was on morphine for pain management and told not to take his medication to hospital but had to wait hours before any medication was given”

Seeing their relative in pain when they were dying was extremely difficult for families:

“My father had a horrible, painful death and I cannot forgive the hospital for this”

In the community, lack of timely pain relief (including access issues) was caused by a variety of factors including poor communication at hospital discharge, drug shortages, and weekend access:

“Even though discussed regularly in TAP and knew multi agency input, and discharge plan in place, discharged on a Friday without notifying rest of professionals in community so inadequate pain relief all weekend and limited access to methadone, awful”

“She left hospital and was prescribed end of life drugs with no communication either with my mum or myself. It was a huge shock when I opened the drugs when we returned home”

“Macmillan nurses... When you phone up for advice on pain relief on a Sunday and no one ever gets in touch it’s not good”

Some people needed to have more information around pain management. One relative had not been properly informed about how to access pain medication at home, and another explained that there is a need for more information about the pink card for the Muslim community, and what to expect when end of life pain medication is given:

“We didn’t know about having end of life drugs in the house in case we had to call someone out in the night. We were told the district nurse would collect the drugs to be used if we had to call someone out in the night, but then the district nurse told us we had to collect them from the GP’s pharmacy ourselves. Thankfully we found out the afternoon before we had to call someone out, and then my dad died the following morning”

“There needs to be a more transparent way of working with families, for example the Muslim community needing more information about the pink card and what that does for the patient. As Muslims need to be able to give the Sha’Hada. The nurses did not explain this in detail and one can appreciate the balance of pain relief but not at the expense of one’s religion beliefs”

Some people felt that GP could have played a better role in helping with pain management:

“Early GP appointment may have facilitated pain been managed at an earlier stage”

“When her health deteriorated the GP was contacted but they did nothing: didn’t provide adequate pain medication”



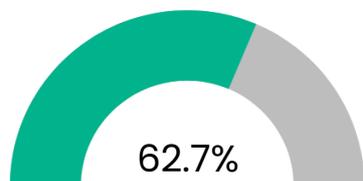
Pain management and social care

In the interviews, we heard about the role of social care staff in ensuring that people received pain relief, and examples of where this didn’t work well.

“The GP prescribed paracetamol, morphine patches and oramorph. Her meds need to be given by the care workers on arrival, to give them time to work, but they [care workers] don’t give her the meds because it will delay them. They want to be in and out quickly. They change her first [in pain] and then ask her if she wants pain relief. Because she’s no longer in pain she says ‘no’. Then they write on her notes that she refused her pain killers, but she doesn’t have capacity. The GP has written to the providers asking for pain relief to be administered on arrival. I don’t complain because I don’t want to ruffle feathers”

“The care workers fill mum’s forms in retrospectively, they’re falsifying information. Mum was overdosed for a few days. I spoke to my GP and was advised to phone 111 or 999 if it happened again. I don’t complain; what am I going to gain? I don’t want repercussions for mum, don’t want to complain whilst mum’s still here [alive]”

Being able to ask for help any time of day/night

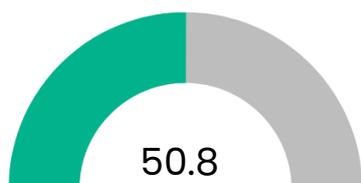


Nearly two thirds of people (62.7%) felt they could ask for help at any time.

The night sitting service was especially valued. A relative supporting someone who was using Intensive Home Nursing, felt they had around the clock access to support if they needed it:

“Knowing I could phone for help or advice 24/7 was a tremendous help”

Support to live life in the way they wanted to (social activities & seeing people who are important to them)



Only half (50.8%) of people said their friend or relative received support to live life in the way they want to, for instance social activities, and seeing people who are important to them.

We heard how one person had benefited from using hospice day services:

“They made such a fuss of her last birthday. Mum also used Clifford House (day centre for St Luke’s) for a couple of years & this was an absolute life line for her”

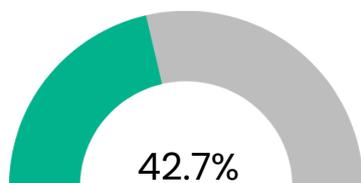
Covid may have impacted some experiences negatively, but some people shared that despite Covid restrictions the hospital made it possible for them to visit. It was not always clear why restrictions had been applied/what the restrictions were.

One family had issues with seeing their dying relative in hospital:

“I begged and cried on the phone to be allowed to bring my son in - who is the best behaved child you have ever met - and was told she wasn’t sick enough and if that changed I would be told.

Nurses was complaining she was disorientated and combative but wouldn’t allow her to see the only person who could recentre her - me”

Coordinated care



Only 42.7% of people felt that services have worked well together to coordinate their friend or relative's care. Of all the statements we asked people's views on, this received the lowest level of agreement.

We did hear some positive experiences of services working together well, and the positive difference this can make to people when it happens.

We heard how a joint visit from services helped to identify a plan with medication issues and provide respite care:

"Joint visit from Macmillan, District Nurse, social care we decided that to resolve some issues with her medication, give her some therapy and also to give me some respite a spell other 24 hour care would be beneficial. However having seen this in a number of care homes she was not keen. The Macmillan nurse then suggested the local Hospice explaining that it does not just deal with terminal patients"

However, many people thought that services had not worked well together to provide care:

"My experience with my dad has highlighted that end of life care is very hit and miss and uncoordinated"

"Nothing seems to be linked up between the services offered"

"The care and treatment my friend received as an inpatient in hospital, was unfortunately disappointing. There was a clear lack of communication between different departments and services"

"Services did not work together, there was no joined up ways of working and GP/District"

"The GP, specific hospital departments did not work together, and the family were left to muddle There way through the system until the end"

One person described the difficulties they had experienced around a lack of information about what to expect, lack of clarity about who was co-ordinating, and what could be accessed:

"As a family we had never experienced end of life care, and didn't know what to expect or what we could ask for, and essentially how to access the help when we needed it. We didn't know who was supposed to be co-ordinating the care: Doncaster, Sheffield, GP, district nurse. Overall there was poor communication about end of life care with the family and other departments"

The way support was provided

This section of the survey asked people about their experiences of how support was provided – we wanted to understand whether care and support met people’s social and emotional needs, and whether they were involved in making decisions about their care. We asked people to tell us how strongly they agreed with a range of statements which are shown in the box below. All other responses (not represented in the table) were ‘neither agree nor disagree’.

	Number of people who shared their view	% who said they ‘strongly agree’ or ‘agree’ with the statement	% who said they ‘strongly disagree’ or ‘disagree’ with the statement
Staff respected/have respected their privacy and dignity	82	73.2%	14.6%
They were/have been treated with compassion	80	71.3%	17.5%
Their wishes were/have been respected	79	64.6%	16.5%
They were/have been asked about their preferred place of death	69	63.8%	18.8%
They were told about their end-of-life diagnosis in an appropriate way	65	63.1%	24.6%
Their support was/has been culturally appropriate	48	62.5%	14.6%
They felt/have felt able to ask questions	71	59.2%	19.7%
They were/have been given information in a way that works for them	78	56.4%	25.6%
They had/have had the religious / spiritual support they need	42	54.8%	19%
They were/have been involved in the planning of their care	72	54.2%	25%

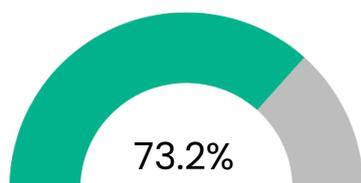
They knew/know what to expect from their care	74	52.7%	27%
Conversations about their care happened/have happened at the right time for them	73	47.9%	28.8%
They had/have had the support they need with financial and legal matters (e.g. benefits, wills, form filling)	55	47.3%	36.4%

The green section of these charts represents people who 'agree' or 'strongly agree' with the statement.



The grey section of these charts represents all other responses – 'neither agree nor disagree', 'disagree', or 'strongly disagree'.

Privacy and dignity



Nearly three quarters of people (73.2%) agreed that staff had respected the dying person's privacy and dignity.

One person told us that their friend/relative had dignity when being supported at home:

"District Nurses made it possible for her to have dignity and support at home for as long as she needed"

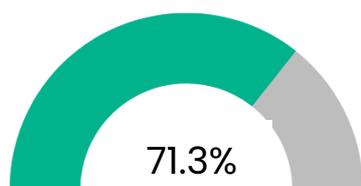
In hospital, a common issue was the lack of a private room for people who were dying, which had a negative impact on the person and their visitors:

"We asked for my father to be moved to a side room so we could spend time in private with him but this was not possible"

"We had to ask for a side room at this point to provide dignity for my family member and privacy for the family"

"The woman in the bed opposite complained 'the place is like piccadilly circus' because I was trying to speak to my mum while she died. It took her approx 5 hours to die in this state and not once did a nurse come near us to wet her lips etc. No one came near"

Compassion



Most people (71.3%) felt that the dying person had been treated with compassion:

“The individuals involved in end of life care are generally compassionate and in the right job, but the processes of getting help need to be improved”

“There was always a person centred, individualised, compassionate and comforting approach, which helped so much throughout such a difficult time”

Where people described a lack of compassion, the concerns included:

- Feeling **rushed** (for example after someone had died)
- Lack of **compassionate language**/communication
- Not feeling **listened to or understood** - including negative judgements due to lifestyle
- **Lack of care in terms of basic needs**, e.g. being offered a drink, or given a comfortable chair

“Two hours before my husband died my daughter-in-law questioned a staff nurse about the fact that the pump delivering meds into my husband’s abdomen wasn’t locked. She screamed that she wasn’t a palliative care nurse!”

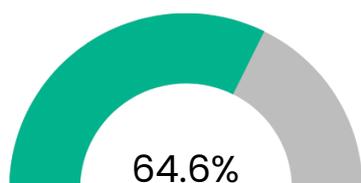
“Nurse said ‘you can stay with her as long as you like, although not too long because we need the bed. We will tell you’”

“I know my friend often felt very frustrated by the at times less than compassionate approach as though she wasn’t being listened to or understood”

“Negative judgements due to lifestyle”

“I think what would improve the situation would be comfortable chair, basic compassion and understanding. The day shift was lovely but night shift was not and we felt rushed after my daughter died”

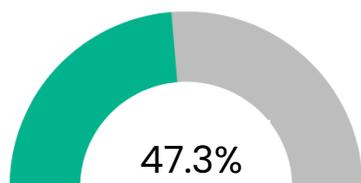
Wishes respected



Nearly two thirds of people (64.6%) felt that their relative/friend’s wishes had been respected. However, we heard some cases where people had been unable to die where they wanted to, or get the palliative care they wanted in the community.

“More could have been done to ensure her wishes were respected”

Financial/legal matters



Less than half the people (47.3%) thought their friend or relative had been supported with financial and legal matters:

“Our family have managed several bereavements and are used to the process. Not sure it would be clear for others. Sheffield Council did provide helpful

pack of information when death was registered”

“I do feel deeper intervention re finances/will drafting would be advantageous as it falls down the priority list for many people living each day at a time”



The financial impact of losing a family member

In our interviews and community conversations we heard about the impact of losing a family member who had been contributing financially, and the enormous strain this placed on bereaved family members:

“I have to find work now because of the job centre. They know my husband died last year and I have 7 children”

“The children have been struggling – they can’t afford to heat the house, it is freezing. They can’t afford food either”

We also heard about the valuable difference a **supportive employer** can make for family carers when their relative reaches end of life.

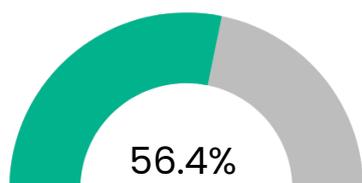
“My manager was really good. She let me work flexi-time and reduced hours when mum became ill. It wouldn’t be the same with the new boss”



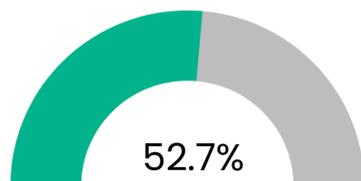
Barriers to dealing with financial and legal matters

In the Hadfield Institute group discussion, people shared concerns around lack of information, knowledge and preparation around these areas – it was also seen as a sensitive area for discussion and people said that many families didn’t feel able to have this conversation.

Information



Just over half of people (56.4%) thought that the person had been given information in a way that worked for them.



A similar number (52.7%) felt that the person knew what to expect from their care.

Some people needed **more information following diagnosis** and emphasised the need to give people the right information at the right time and follow up with further information:

“Mum has been in and out of hospital this last month with what we now know to be a terminal cancer diagnosis. She was discharged initially without any palliative care referral or understanding of her diagnosis being terminal. She went back in pain to A&E. They pushed several times for discharge until discharged this Thursday without a discharge package in place, no contact numbers and a referral only (as of today) sat with the palliative care triage team. No continuing healthcare fast track forms completed. No contact numbers or anything! It has been wholly disgusting given in discussions the consultant said mum has 3-4 months at best”

“When given their diagnosis they were handed some leaflets about bowel cancer. They were unable to absorb the information because they were in shock. Neither their GP or hospital doctor followed up with them after this point, and they felt discarded and as if no-one cared. They were relieved when I checked in with them to see how they were getting on, as I could reiterate the important information and signpost to charities when they were ready to absorb this information (a few weeks later)”

Some relatives/friends commented that not having **information about what to expect when someone dies/how to recognise signs** makes the situation harder to manage:

“End of life care staff need to bear in mind that for some families this is their first experience of death, and they do not know what to expect and what signs to look for. In my dad’s situation it felt like we got things sorted at the very last moment. It was stressful at times and it sometimes felt like we were letting my dad down”

Communication needs - Information is not always accessible for everyone, which means some people don’t understand their condition or information about the care being offered.

“Had dyslexia – meant it was hard to understand what the nurses were saying about the illness”

“She is poorly informed due to her autism and needs things explaining to her carefully with time to process and ask questions”



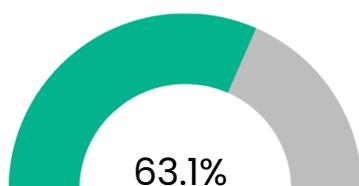
Three people made suggestions to improve care relating to make sure people are well informed:

“I think the only think that would have been useful if we had not come from these backgrounds would have been to have all the information we needed in one place, e.g. info/online training catheter carer, information on nutrition, information on what to expect etc”

“Wish there was more discussion and preparation of what to expect”

“In my opinion, when delivering a terminal diagnosis, hospital consultants and GPs should make follow-up calls to reiterate crucial information/signpost and make sure the patient’s needs are being met and they have a clear idea of what to expect next/where to go (e.g. St Lukes). Alternatively, a designated person from the hospital could make these calls on their behalf. The important thing is that the patient feels like someone cares and is continuing to check up on them and make sure they’re supported. Just because someone cannot be cured, does not mean their wellbeing no longer matters”

End of life diagnosis



Just under two thirds of people (63.1%) felt their friend or relative was told about their end of life diagnosis in an appropriate way.

We heard how one person was told about their diagnosis with **compassion**:

“St Lukes. They gave her the end of life diagnosis which was the only thing that was done with compassion”

Some people experienced **delays** in getting an end of life diagnosis:

“We told professionals for more than a year that something was wrong... we had our concerns dismissed... in the end the diagnosis of a brain tumour came much too late”

Some felt that information couldn’t be taken in when the diagnosis had just been given and there was a lack of follow up in some instances:

“He said he couldn't absorb the information given to him during the appointment (when they informed him of his terminal diagnosis)”



The importance of timely diagnosis

When people were invited to talk about their experiences of end of life care in interviews and community conversations, they often began their story by describing the initial diagnosis of a major illness, which may have been a number of years before the death of their relative. For many people, the experience of that diagnosis, the way in which it was given and received, was an important part of their story. In particular, a delay in diagnosis had an ongoing impact on the care and support which they received towards the end of life – for example leading to rushed decisions, or lack of opportunity to plan while the person still had capacity to do so.

“The dementia diagnosis was hard to get, I knew there was something wasn't right but the GP wouldn't listen to me. They would only talk to my wife and she would say everything's alright”

Elaine's story* - Capacity and care

Elaine was in her 90s when she passed away – her family carer described her as a proud independent Caribbean woman who was focussed on others. She started to experience difficulties with her cognition and was supported by her husband; also proud and independent, he had hidden the severity of this from others. It was only after he passed away that she was diagnosed with dementia; by this time, it was hard for her to convey the nature of her needs due to the way her dementia had progressed. Her daughter organised and paid for her to receive support at home but this did not always go well – on occasions she hid keys to stop workers coming into the home. Family also described that despite her dementia, carers took Elaine's word when they asked about what she needed. If she told them she didn't need anything, the social care workers would leave and not attend to her needs. At times they left her hungry.

Elaine was supported by a local voluntary sector organisation that played a vital role in delivering culturally appropriate food, and advocating for her to get the right care.

Her family carer told us that going into a care home had been Elaine's biggest fear, and family members didn't all agree about whether she should move into one.

Eventually Elaine was admitted to a care home – it was a rushed admission, and she had not been involved in making this decision. The care in the home was poor, with no proper assessment of her needs and as a result the placement broke down and she had to move.

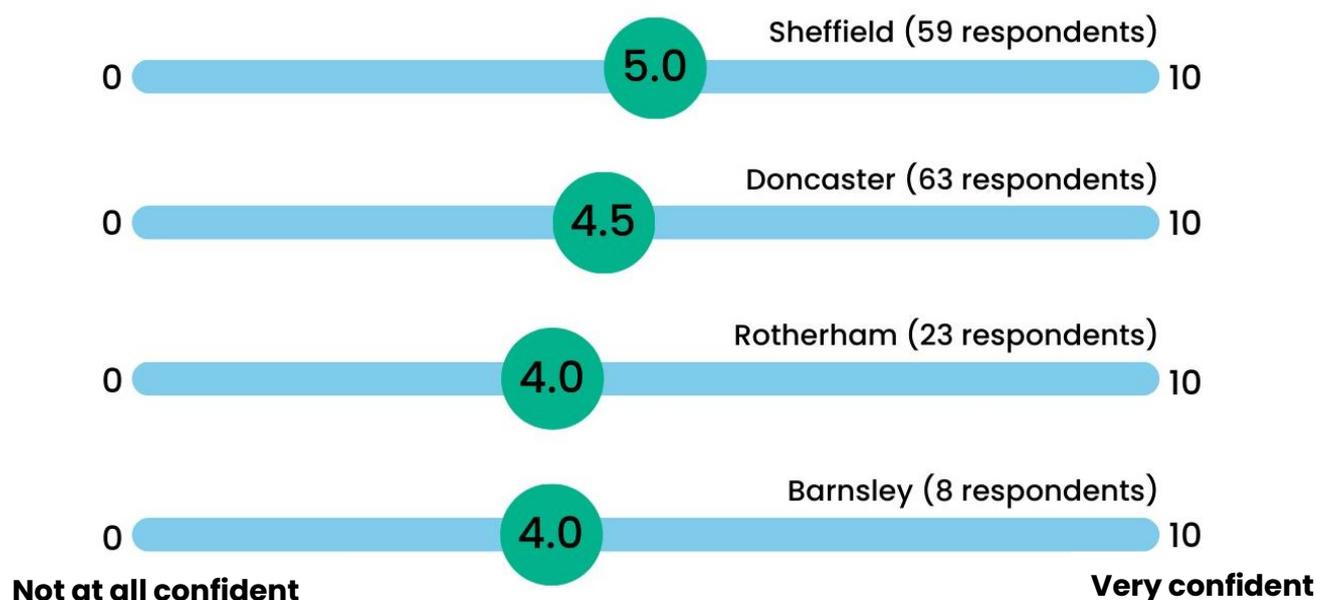
She died in the care home – this is not where she had wanted to die, but due to deteriorating health, and because of her lack of capacity to make decisions about her care, 'everything was taken out of her hands'. Her family carer felt that more could have been done to ensure that Elaine's wishes were respected.

**Name has been changed*

Confidence in the right care and support

We asked people whose friend or relative had died in the last two years to reflect on their confidence in end of life care support now, having supported someone through it in the past. This question was ranked from 0 (not at all confident) to 10 (very confident). Average scores are presented below.

How confident do you feel that you, or someone close to you, would get the right care and support when reaching the end of life?



Insights into confidence levels

Some people gave reasons to explain their confidence ratings. Low ratings were mainly associated with bad experiences. These are the factors that had a negative impact on people's confidence in someone getting the right care and support at the end of life:

- Gaps in/inadequate levels of support
- Bad experiences in hospital, on wards and long waits in poor conditions in A&E
- People not being advised about/linked in with services they need
- Lack of compassionate care
- Things taking too long, including arranging care
- Being unable to die in the preferred place e.g. hospice
- Lack of support for people with Dementia and their families

- Varying quality of care dependent on how much you are able to pay
- 'Postcode lottery' – service varies depending on where you live
- Lack of information about end of life care
- Lack of confidence in a timely diagnosis
- Lack of resources, staff, money, staff working conditions
- Lack of support in the community

Some people were more confident about getting good care. Some people said they had confidence in St Luke's, and one person was confident in the care they would have from their GP.

Some people were confident in care/support in the community but not in hospital.

"I would not wish anyone to go through what we went through. Is like to think it's not happening now but things have got worse recently yet with lack of staff etc. I wouldn't want any of my friends or family to die in hospital"

"St Luke's. And our GP surgery (Nethergreen) were without exception remarkable"



Image: Circle of Life Triptych from the 'Circle of Life' exhibition, created by Ignite Imaginations artist Ali Bird in a collaborative visual arts workshop with Firvale Community Hub.

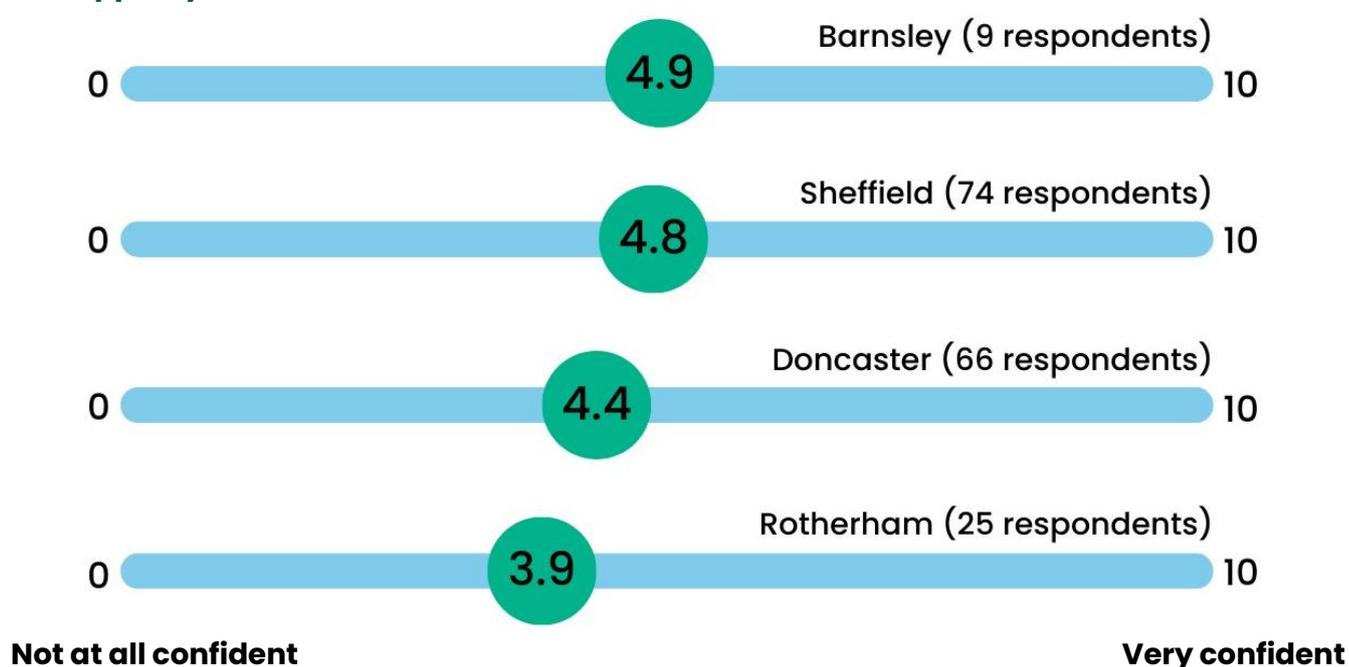
Inspiration came from thinking about the symbolism and use of flowers in death rituals, combined with words chosen by participants which held meaning for them. The words in Arabic in the central circle are: "From Allah we came and to Allah we return"

Section 4 – Support for carers

Friends and relatives play a key role in caring for and supporting people at the end of life; we wanted to understand people’s experiences as a carer, and learn whether they received the support they needed.

We asked people how satisfied they were overall with the support they received as a carer. This question was ranked from 0 (not at all confident) to 10 (very confident). The average scores across each area of South Yorkshire are shown below.

Overall, on a scale from 0 to 10, how satisfied have you been with the care and support you’ve had as a carer?



We also asked them to say how much they agreed with a range of statements which are shown in the table on the next page.

All other responses (not represented in the table) were ‘neither agree nor disagree’.

	Number of people who shared their view	% who said they 'strongly agree' or 'agree' with the statement	% who said they 'strongly disagree' or 'disagree' with the statement
I knew that my relative or friend was dying*	57	86%	12.3%
I feel able to discuss my experience with friends and family	76	76.3%	11.8%
I am part of a community where people support each other in emotional and practical ways	69	58%	18.8%
I knew/know where to access support and advice	82	56.1%	26.8%
I am part of a community where people are willing to have conversations about death and dying	71	53.5%	29.6%
I feel supported practically/I felt supported practically when my relative or friend was alive	71	49.3%	33.8%
I feel supported emotionally/I felt supported emotionally when my relative or friend was alive	73	47.9%	38.4%
I felt supported emotionally after the death of my relative or friend*	54	37%	42.6%
I felt supported practically after the death of my relative or friend*	53	35.8%	49.1%

Statements marked with an asterisk (*) were only presented to people who said their relative or friend had died.

From these responses we can see that many people felt supported by their friends, families and communities. We can also see that some of the support people receive while their relative or friend is receiving end of life care, doesn't extend as well into bereavement, with fewer people feeling supported both physically and emotionally once their loved one has died.

Insights from carers

We asked carers **'Is there anything else you would like to tell us about your experience as a carer?'** and analysed their responses to this question, along with relevant comments in other free text responses. The key themes that emerged are presented below.

1. Supporting people at end of life can take a toll on people's physical and mental wellbeing

People found having to chase things up stressful and some felt like they were left alone to manage. Some carers had their own health problems to manage alongside their caring responsibilities:

"Had to ring GP and nobody answered. Rang 55 times. This took toll on me the carer. I was just so tired, doing everything on my own"

"I found it very hard work and lonely whilst coping with my own illnesses and trying to look after my own welfare needs to keep myself healthy to be able to look after my hubby properly as he wished me too"

Having someone to help provide care for relatives staying at home, makes a big difference to carers, particularly at night time:

"I never had a full night's sleep for at least 2 years before the Intensive home nursing gave me a night sitter as often as they could. This has made a great difference & enabled me to deal with daytime issues in a better way"

2. Bad experiences of end of life care and support can have a significant impact on people's mental health

Lack of information, poor care and a lack of compassion were all linked to people suffering emotionally, with the effects being felt for some time afterwards:

"My experience of my relatives end of life care was explained in a lot of ways but not in other I didn't realise that when they started the syringe drive with the

medication in that I would never hear her speak again which I have found hard to deal with”

“There was also another female patient who sat for over an hour with my father telling staff she was his wife. The staff believed her and told me when I went to visit that his wife had been to see him – I had to tell them that his wife, my mother had been dead for four years! This was very distressful for me especially under these circumstances”

“I honestly think I have PTSD from the pain of my mothers death and the lack of humanity shown to her in her final days on earth. I can't move on from it, it is a physical pain in my heart. I'm crying writing this”

“My father had a painful & traumatic death. We complained to the hospital but we're all too traumatised to take it any further”

3. Mixed experiences of the level of support and where it comes from

Some people felt more supported than others. Some people talked about only just coping and needing more support:

“My mum did an excellent job but would have benefited from greater support being offered rather than her having to initiate it. She was exhausted and I think it makes it hard to keep seeking help. Things have been so much better since St Luke's admitted my dad”

“At the end of everything, as a family we look back and feel we coped with most of the process on our own, and we are thankful that my dad was able to die at home. We feel we managed – but only just”

“No referrals have been made we as a family are managing this totally alone”

Families of people with Dementia in particular described a need for more support:

“Memory service diagnosed then basically left my friends to their own devices, there were times when the person was distressed/aggressive to family carer contact for advice/support was never answered”

“I also have past experience with my Mum who died of dementia. Where is the care and support for patients and families living with dementia?”

“My friend was caring for her husband with Alzheimer's 22 hours a day and was palliative herself no support was given to her, she was told she isn't ill enough she has 5 cancers how can we say that it's disgusting she was on her knees”

Some people felt well supported by services involved in their friend/relative's care:

“The Transfer of care team and the palliative care team at the Northern were very helpful and gave us lots of information and support. District nurses also amazing”

“Our doctor only asked me once how I was coping when he made a home visit I had requested as I was concerned for my hubby's deterioration in his health when he was hospitalised immediately by him on arrival”

“Bereavement counselling via St Luke's was excellent”

“Everyone [in the hospital] was so respectful and provided all that could be provided in very difficult circumstances”

“Persons from adult social care have been supportive”

“This would be dependent on where the person was – I had amazing support when losing a relative at St Luke's Hospice, not so much when another relative died in hospital”

4. Varied family involvement in care planning and decision making

27% of people didn't know whether their friend/relative had an Advance Care Plan in place and some people didn't feel they were well informed:

“These services have not been explained and not been offered”

However some relatives felt involved in their family member's care:

“Mum died with advanced dementia. Not able to communicate or understand, but family were well informed and consulted”



Mental capacity and decision making

Some people described situations where different views on whether their relative had capacity to manage their care, led to **lack of clarity** around who health professionals should be talking to and when.

“The GPs are always phoning me and my brother for decisions. They decided she has mental capacity so why are they asking me. They should ask mum; I'd only do what she wants anyway. They should leave me out of it. I think they want to involve me in decisions; out of courtesy. I don't think mum has mental capacity any more and I think it suits the NHS to say she has”

Someone else emphasised the importance of **involving the person with a dementia diagnosis in the best interests process**¹⁰ – where this doesn't happen it makes them feel “less than human”.

¹⁰ If a person has been assessed as lacking capacity then any action taken, or any decision made for, or on behalf of that person, must be made in his or her best interests (Principle 4 of the [Mental Capacity Act 2005](#))

5. Lack of the right information at the right time

Several people did not feel well informed about what to expect and how best to care for their friend/relative:

“Worked well for what he needed but less support for family. We needed information as to what to expect and how best to support him. Death took 5 days and he was unaware for all of it but we needed help”

“Communication and time to explain what was happening and what could happen, what signs to look for, how to keep him comfortable”

“We were told that we should have been given an information pack we did not receive this, it all added to the trauma”

“We were in a side room that was very uncomfortable, we didnt know what to expect and we was very frightened. We were left alone and nobody explained anything. I asked one nurse what would happen and she actually said she will just stop breathing,It was horrendous it was the most traumatic experience ever”

“I have recently found The Carers Centre and will be able to access information not available to me previously. My friend had never heard of the Carers Centre and is not aware of any support available to her carers”

6. Families fill the gaps in care and support left by services

We heard many examples of families and friends stepping in to provide support and care where services had not provided what people needed:

“Unfortunately services let us down and we did most of the care ourselves.. up till the hospice involvement”

“Really poor for the most part services didn't communicate, adaptations ie stairlift took months to put in place, ramp for main door ended being made by a family friend as no service was able to provide so couldn't get wheelchair out of the door”

“They were relieved when I checked in with them to see how they were getting on, as I could reiterate the important information and signpost to charities when they were ready to absorb this information (a few weeks later”

“Not enough intensive home nursing, carers 4 x per day leaves gaps between visits, lots of emphasis on family to care between gaps and advocate for the patient”

One person suggested it would be better if: “Families [were] able to spend time with their loved ones without having to advocate for appropriate care/medication”



Bereavement Support

We heard how bereavement support works well for people well it is located in places/organisations they are already connected with.

Where **culturally appropriate bereavement support** is offered this is valued, but some people aren't aware how or where they can access this.

"I saw my GP...They have arranged some counselling and I have that every week. The lady I see at the surgery...is originally from Zimbabwe. She understands my culture, that has really helped. She has helped me stop blaming myself after my husband's death"

"Even after many years people are still living with a huge sense of loss, and never having accessed support for grief/bereavement"



Lack of bereavement and mental health support for children after death of a family member:

"My daughter has not had much help. We have someone from MAST. They have offered her help but it is in Rotherham and that is too far for us to go. She needs counselling but there isn't any here"



Ideas to improve support for carers:

"A guide to navigating health and social care: who to contact when"

"End of life care would be improved by more support given to mum whilst she was caring for dad at home, particularly from the Drs surgery"

"More information given to patients and families about what is available for them without having to find out for themselves through charities"

"More explanation of end of life care and how it works"

"Open conversations with families about when their relative is reaching end of life"

"If someone is at end of life families should be told with sufficient time for wider family members to travel there"

"Greater support for family carers"

"Addressing the gaps - such as care at night"

Marala's story* – Importance of cultural and religious practices

Marala is a mum with school age children. We met with her through a mental health support group which she regularly attends – she spoke to us about the death of her father, and her experience as a key family member who had to support him through his illness, as well as manage his affairs after his death.

Marala's parents came to the UK from a country in southern Africa. In his 60s, her dad developed a number of health conditions including (among other things) prostate cancer, and a heart condition. Marala told us that having multiple health conditions could make managing his care difficult and led to a lot of delays in treatment:

“Dad was under 9 consultants. So a referral had to take a very complex route when leaving the GP”

Despite his multiple health conditions there were not conversations about end of life, she told us:

“I couldn't really have conversations about end of life with my parents as my dad would say, you trying to kill me off. He didn't make a will....”

Her dad's GP had prescribed him Oromorph, and Marala believes that he was secretly drinking alcohol while taking this. On a family trip to their home country, he had a fall and went into hospital – after 10 days he discharged himself and died in the house. Although they had not had direct conversations about death, Marala felt that he had died in the place that he would have wanted. She described how they were able to follow the practices that related to their religion:

“My parents were both [...] a certain type of Hindu religion. After death that religion buries the body, unlike other forms of Hinduism, where they have to be cremated [...] He was buried with his mother and brother which is what he always wanted.”

When back in the UK, it fell to Marala to deal with the practical matters relating to his death. She described poor communication with health services, telling us:

“I asked dad's GP for a summary of his notes, after his death and that just took forever. They weren't very helpful. They [GP surgery] didn't let the 9 consultants know of dad's death and we got a phone call asking to speak to dad which was upsetting for my mum.”

“I tried to use the governments Tell us once service so I wouldn’t have to have rung around everyone. They said because dad died abroad and there wasn’t a death number, we couldn’t use the service. In the end I didn’t mind, as I know if I did it all myself it was definitely done and not just like what happened with the GP. It was a lot for me to deal with as I was still in recovery from my own addictions and have the two [children] too.”

Marala was referred to a bereavement service, but didn’t manage to access the service:

“Their referral process was s*. They never rang me and after 4 months on a waiting list they sent me an email, and because of my depression I missed it and then they said I only had one more chance to reply before they withdrew any support”**

She had a more positive experience with Sheffield Mind who she was already connected to – they offered her their own bereavement support.

“[The group] referred me to their own bereavement support lady. I saw her 6 times and she was brilliant [...] it was hard but she did help me, it was limited to just 6 weeks”

**Name has been changed*

5. Cross cutting themes

Throughout the survey responses, the interviews and community conversations we have identified a number of cross cutting themes. These themes are ones which are repeated in relation to different services, and different aspects of care. They are shown below.

<p>Access to services</p> 	<p>Identification of serious health conditions and end of life diagnosis needs to be timely. Delays have negative impact on later care.</p>	<p>Follow up and proactive checking in on people is important but often doesn't happen</p>	<p>Difficult to navigate care – confusion around what is available, and lack of information and support to access it</p>
<p>Information</p> 	<p>Support to understand information is important. People need to understand their condition and the care they are being offered</p>	<p>Information is not always in suitable formats – eg for autistic people or dyslexic people</p>	<p>Lack of information for carers about how to navigate the system; what to expect, how best to care for their friend/relative</p>
<p>Compassion and understanding</p> 	<p>Importance of sensitive communication and appropriate language</p>	<p>Traumatic experiences of death have an ongoing impact on people's health and wellbeing after bereavement</p>	<p>Treating people with compassion is important, for instance by providing time and space for privacy</p>
<p>Quality of care</p> 	<p>Praise for staff – across the system we heard about staff who had delivered excellent care</p>	<p>Care in the community was generally preferred, and often described as better quality</p>	<p>Services working together – we heard examples where this did not go well, but also the difference this can make when it happens</p>
<p>Equity</p> 	<p>Culturally appropriate care is important but not always available</p>	<p>Some people, especially those facing other barriers to care, don't know what services are available, or how to access them</p>	<p>Voluntary sector organisations play a vital role in linking people to support and advocating for them</p>
<p>Carers</p> 	<p>Relatives and friends help people access services and equipment that they need</p>	<p>Relatives and friends provide support where there are gaps in services</p>	<p>Families and carers need support themselves – the biggest gaps are after bereavement</p>

6. Ideas to improve palliative & end of life care

We asked people 'Is there was anything else they would like to tell us about their experience, including what would improve palliative and end of life care?' Below is a summary of the actions people suggested.

Information

- A guide to navigating health and social care for end of life care
- Knowing what support is available and how to access it – who to contact and when
- Understanding what to expect from the care you receive

Coordination/joined up working

- Teams and professionals working together to coordinate care
- Being clear about which services are involved and who is doing what

Advance Care Planning

- More consistently work with families and individuals on end of life plans
- Support greater knowledge and understanding of Advance Care Planning within community settings – including an emphasis on culturally appropriate conversations

Communication

- Better communication with individuals and families
- Better communication between services

More community support

- Increase the amount of community care and address the gaps in care (e.g. care at night)

Family involvement

- Open conversations with families when their relative is reaching end of life
- If someone is at end of life, families should be told with sufficient time for wider family members to travel there

Follow up after diagnosis

- Ensure people follow up/check in on people after an end of life diagnosis is given

More palliative/end of life care knowledge in the wider workforce

- More specialist carers, but also better education for staff working on mainstream wards, or within the community

More support for carers

- Greater support for family carers, enabling them to spend time for relatives without having to advocate for appropriate care

Recommendations

1. A focus on equitable and inclusive care

- a. In the context of Sheffield's changing population, continue work to understand needs across all communities. Develop inclusive ways of hearing and acting on people's experiences of palliative and end-of-life care on an ongoing basis, in order to improve services.
- b. Develop services which meet people's cultural and religious needs – this includes culturally appropriate care, and processes which support and enable religious and cultural practices to be observed after death e.g. a place to wash the body, timely certification of death.
- c. All services to place equity and inclusion at the centre of their improvement plans and service delivery.

2. Developing services which meet people's needs and deliver good quality care

- a. Develop community services to enable more care to take place outside of hospital.
- b. Improve access to practical elements of support such as equipment and continence services.
- c. Work to ensure better, more consistent access to the right pain management in all settings.
- d. Consider ways to increase privacy within hospital settings – where separate physical spaces are not possible, staff should be mindful of taking steps to minimise unnecessary noise and intrusion.
- e. Develop alternative routes to access urgent care; people with an end-of-life diagnosis should know where they are able to access support out of hours, with a focus on supporting people to avoid A&E where possible.

3. A joined-up approach to ensuring good care across the system

- a. Improve multi-disciplinary working- at key points (such as hospital discharge) bring professionals together with the patient and family to make plans for their care.
- b. Take a system approach to strategically plan, develop and fund joined up services where care is well co-ordinated.
- c. Improve access to specialist palliative care provision, and use good practice from specialist services to inform staff knowledge and skills across all health and social care services.
- d. Support voluntary sector organisations in the broad role that they play in end-

of-life care; involve them as partners in the planning and delivery of services in the city.

4. Ensuring people get good and timely information about treatment and support

- a. Develop online information that will enable people to understand what services are available and how to access them – these resources should be accessible in different languages.
- b. Provide information in different formats, in a wide range of places, including community settings.
- c. Information resources need to cover a wide range of topics and signpost people to a broad range of services. This includes information on specific areas (e.g. legal and financial issues) but also wider sources of support in the city (for example the Sheffield Carers Centre, Sheffield Mental Health Guide).
- d. Ensure patients and their carers are given good information about what to expect as the illness progresses, and also about signs and stages of death.

5. Involving people in decisions about their care and supporting them to plan

- a. Ensure patients are told clearly, compassionately, and in a timely way about their end-of-life diagnosis; opportunities for follow up conversations are also essential.
- b. Support greater awareness of Advance Care Planning, with particular focus on communities where there is less awareness and/or cultural barriers to talking about death.
- c. Give staff training to support compassionate conversations with patients and their families about key decisions such as DNR and Respect forms – where possible, these conversations should be led by professionals already known to the person.

6. Improving support for family members and carers

- a. Develop services which support carers to stay well. This includes more options for respite care in the city, but also access to broader support such as benefits advice, and peer support groups.
- b. Commission a range of bereavement support options, including services which are located in community organisations where trusted relationships are already established and cultural needs can be met.
- c. Increase awareness of available support services for carers, including bereavement support.
- d. Offer training and support to carers to enable them to feel equipped for their caring role.



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