

Chew Valley Needs Analysis for Life Limiting Illness and End of Life Care.

April 2024

Listening and engagement project commissioned by Dorothy House Hospice Care. Project delivered by Community First, registered charity number 288117.

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Acknowledgements

Thank you to Dorothy House Hospice Care for commissioning this listening project for the benefit of communities in the Chew Valley area. Listening to residents in Mendip and now in Chew Valley, demonstrates your ongoing commitment to providing outstanding palliative and end-of-life care to all that need it in B&NES and parts of Wiltshire and Somerset. Many thanks also to our fantastic Community Organisers Katrina Watson, Samantha Lloyd and Heather Pinney, who knocked doors and attended two community groups to listen to residents.

We would also like to thank Killens Estate Agents in Chew Magna who kindly helped our Community Organisers navigate the Chew Valley area. Finally, we would like to extend our gratitude to and appreciation of the 125 individuals who took part in the listening project by sharing their views and their own stories of life-limiting illness and associated loss and bereavement. Your experiences, thoughts and ideas will help Dorothy House Hospice Care shape the offer of support, services and resources for people affected by life-limiting illness in Chew Valley, now and in the future.

Executive Summary

Community First carried out 125 listenings with residents in Chew Valley between January-March 2024. Community Organisers listened to people in six local communities and two community groups.

Demographics

- Overall, more female (66%) than male (33%) residents took part in listening activity.
- Over 80% of all residents were over the age of 45 years, with the highest percentage of listenings carried out with those in the 45-54 (19%) and 75-84 (22%) age categories.
- Amongst residents aged 35-44 and 65-74, the balance of male and female listenings was closer to equal when compared to other age ranges.

Experiences of Life-Limiting Illness

- Almost three-quarters (74%) of the residents who took part in the listening activity had an experience to share around life-limiting illness. Amongst these residents 82% had previously cared for a person who died, 12% are currently caring for someone and 6% are currently living with a life-limiting illness.
- 35% of residents who had experience of life-limiting illness provided care for or are currently caring for a parent or in-law, 24% for a spouse and 10% for another family member.
- Support is/was received from friends and family members (42%), healthcare providers (42%), private carers (34%) and a hospice (29%). 40% of residents stated they were/are the main carer.
- 30% had a positive experience of support, with 20% who felt their experience was negative. Positive factors included hospice care, NHS care and support from charities. Negative factors included feeling let down by NHS services and coordination and standard of care.

- Some residents said their loved one received good care towards the end of their life, but that their own experience of being a carer was fraught and difficult. Some carers suggested they felt forgotten about or unable to access the support they needed at the time they were caring for a loved one.
- 33% of residents said additional support would have been helpful. This included respite care, bereavement support and practical support.

Local Support for Life-Limiting Illness

- As part of the listening activity, residents were asked what support is felt to be important locally.
- Themes included health and care services, communication and signposting, practical support, emotional support (including bereavement) and community groups. A detailed analysis of each of these themes is explored in the report.

Thinking about and Planning for End of Life

- Over half (55%) of residents had previously had a conversation about planning for the end of their life. 28% said they had not had a conversation.
- Amongst those who had made plans, these included a will, DNR request, living will, power of attorney or funeral arrangements.
- Comfort, dignity and peace were the most common themes amongst people asked what matters to them when they think about the end of their life. People would like their death to be quick and as pain free as possible, with family members and loved ones around them.
- Some individuals said they would like to die in their own home, others said they would like to die in a hospice with the support of hospice staff.
- There were several comments from residents in favour of assisted dying. These individuals suggested people should have the right to choose when they die.

Life-Limiting Illness – Community Support

- Over three quarters (77%) of residents indicated support from the wider community was important for people affected by life-limiting illness, with 9% who felt it was not an important factor.
- Despite this, the percentage of Chew Valley residents who suggested they were satisfied with the level of community support or community spirit in their own community was lower overall at 28%.
- There were geographical differences in sentiment towards the level of community support and community spirit in different communities in the Chew Valley area. Residents who attended community groups had higher satisfaction overall.
- Amongst the villages, Chew Magna, Clutton and Chew Stoke had the highest satisfaction level. Bishop Sutton, West Harptree and Temple Cloud had a lower level of satisfaction with community support and community spirit.
- Perception of community support was also (to some extent) age dependent, with older residents reporting a better experience of community support compared to younger residents.
- Groups and organisations like the Death Café, Chew Chat and the widows group were important sources of community support for some residents. Village Agents and Good Neighbour services were also felt to offer a means of practical and emotional support for people affected by life-limiting illness

- Some residents were not in favour of community support for life-limiting illness and felt it was inappropriate. This was due to the complex nature of life-limiting illness (and the need for support and training), as well as a feeling that volunteers may be expected to do too much for the community.

Resources for the Community

- Residents were keen to share their ideas for resources which could help support members of the community who want to help people affected by life-limiting illness.
- Key themes included transport, increased resources e.g. additional volunteers and support for local groups and improved signposting to knowledge and information. A deeper analysis of these themes is explored in the report.

Recommendations

- A range of recommendations for next steps are presented at the end of this report
- These include a palliative and end-of-life care information hub, offering practical and emotional support to carers by building on existing volunteer and community group capacity, developing a community-transport offer for people affected by life-limiting illness in Chew Valley and community mapping to develop a complete picture of support, services and gaps locally.



Photo Community Organisers meet a resident at Clutton Social Club.

Introduction

Dorothy House Hospice Care provides compassionate care and support for people with a life-limiting illness in Bath and North East Somerset (B&NES) and parts of Wiltshire and Somerset. The charity focuses on supporting patients and their families wherever they need care including at home or in hospice and outreach centres. Dorothy House Hospice Care focuses on quality of life, so patients can live well and die well.

In early 2024, Community First was commissioned by Dorothy House Hospice Care to carry out a community-based listening and engagement project with 125 residents in the Chew Valley area of North Somerset. This report presents the findings from the community listening and engagement activity which took place in six village locations in Chew Valley between January and March 2024. The project aimed to engage with Chew Valley residents to understand what support is wanted and needed in terms of life-limiting illness. This might include support to both live well and die well and support with associated loss and bereavement.

For Dorothy House Hospice Care, growing their understanding of the community's aspirations for end-of-life care is important, having recently succeeded St Peter's Hospice in providing care in the Chew Valley area. Despite having a ten-bed inpatient unit and offering care at home, Dorothy House recognises this provision can only ever meet part of what matters most to people at the end of their lives. By listening to residents with lived experience, Dorothy House Hospice Care will gain a deeper understanding of how best to support and offer sustainable solutions to people living with life-limiting illness and their carers in the Chew Valley area.

Community Organising

Devizes-based charity Community First has over 50 years of experience supporting local communities. As well as running several large and established programmes, Community First also works on the ground – at the grassroots and has experience in building and strengthening local communities through active participation and leadership. Community First believes in community ownership by supporting new thoughts and ideas and helping people convert them into reality. The charity also trains local people as Community Organisers and local leaders to improve local spaces and amenities as well as creating lasting social change.

Community First was an early adopter of Community Organising techniques in the South West and uses the Community Organising approach as an open and effective way to meet and talk to local

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people on matters that are important to them, often in their own homes or in other places where people naturally gather such as lunch clubs, groups or public spaces.

Community Organisers are specially trained to reach out, connect and build relationships with people. Whilst the approach has some parallels with traditional research techniques (e.g. focus groups) it should not be confused with market research. Community Organisers believe in an organic approach to engaging with communities. Instead of traditional sampling methods, they go where the people are, knock on every door and gently shape rather than direct conversation. This means they can listen to a diverse range of people and harder-to-reach groups, including people who are marginalised, socially isolated or digitally excluded.

The Community Organising team at Community First is committed to bringing together communities to reflect a range of differing views and issues. This approach produces collective clarity and action that delivers workable solutions to often complex problems. The charity employs a team of qualified and experienced Community Organisers who have delivered a range of community engagement projects including a rural cancer inequalities project for Bath and North East Somerset, Swindon and Wiltshire CCG and an engagement project for BANES Carers' Centre, which aimed to understand the barriers faced by carers in Bath and North East Somerset. Community First also worked with Dorothy House Hospice Care in 2018 to carry out a community needs analysis with residents in the Mendip communities of Coleford, Shepton Mallet and Frome.

This approach produces collective clarity and action that delivers workable solutions to often complex problems.



Photo (left to right) Community Organisers Katrina, Heather and Sam in the Chew Valley area.

Outreach and Engagement

Working with Dorothy House Hospice Care, Community First designed and delivered a programme of listening and engagement activity which focused on door-knocking in six Chew Valley communities and attending two community groups.

Door-knocking is a proactive form of community engagement which aims to reach into the heart of a community or place and speak to people face to face. Door-knocking is an effective way to engage with harder to reach groups and has a proven track-record for reducing isolation, bringing people together and making communities stronger and more resilient. Our trained Community Organisers visit individual houses, knock on every door and speak to local people directly, asking open-ended questions and encouraging people to share their views and experiences.

Listening to Chew Valley Residents

Prior to listening activity, Community First worked with Dorothy House Hospice Care to develop a listening sheet (see Appendix 1). The listening sheet gently shaped conversations in the community, whilst ensuring comparisons could still be made to identify common themes. The listening sheet offered a useful guide to keep the conversation on track and helped conversation to flow naturally, allowing people to talk freely about their own experience of life-limiting illness and associated loss and bereavement.

Whilst many residents were happy to speak at length about their experiences, some listenings were shorter than others or did not cover all of the topics on the listening sheet. This included a small number of residents who were unable to continue with a listening because of a recent bereavement (and distress), or those who chose to expand on one particular theme and not others. As a result, not all residents answered all the available questions, but many people did relate a thorough and (at times) emotional and heartfelt experience.

A total of eight days of outreach and engagement activity were carried out across six locations in Chew Valley between January and March 2024. Community Organisers had with them a leaflet (see Appendix 2) containing information about the project and photographs of the Community Organisers so residents could confirm that the listening project was legitimate and authorised by Dorothy House.

Community Organisers aimed to gather views and experiences from a diverse range of people in terms of age, gender and socio-economic status. To try and capture a range of different views, Community Organisers knock

Our trained Community Organisers visit individual houses, knock on every door and speak to local people directly, asking open-ended questions and encouraging people to share their views and experiences.

on all doors, including larger homes, social housing, bungalows and new housing developments etc. Community Organisers also made arrangements to attend two community groups – Chew Chat in Chew Magna and the Death Café in Bishop Sutton to listen to group participants.

All listenings were recorded on a listening sheet, with Community Organisers noting what was said and basic demographic information about the person being listened to (with their permission). A breakdown of listenings by type and location can be found below:

108

Residents listened to through door-knocking activity in six Chew Valley communities

17

Residents listened to at community groups (Chew Chat and the Death Café)

Location	Type of Listening	Total
Death Café	Community Group	6
Chew Chat	Community Group	11
Chew Magna	Door-knocking	15
Chew Stoke	Door-knocking	17
Bishop Sutton	Door-knocking	25
West Harptree	Door-knocking	14
Clutton	Door-knocking	20
Temple Cloud	Door-knocking	17
Total listenings carried out in the Chew Valley area		125

Community Organisers aimed to gather views and experiences from a diverse range of people in terms of age, gender and socio-economic status.

Listenings were transcribed for a total of over 35,000 words and coded for key themes. The most frequently used words are included in the word cloud on the next page. A coding framework was also created to harvest quantitative data from each listening. In addition to harvesting quantitative data, the responses for each question were reviewed to highlight key themes, especially where accounts featured variations on the same theme. This report contains quantitative and qualitative analysis as well as a selection of verbatim quotes.

Demographics

For listenings with residents of Chew Valley, Community Organisers were able to record basic demographic data (gender and age) with permission from residents.

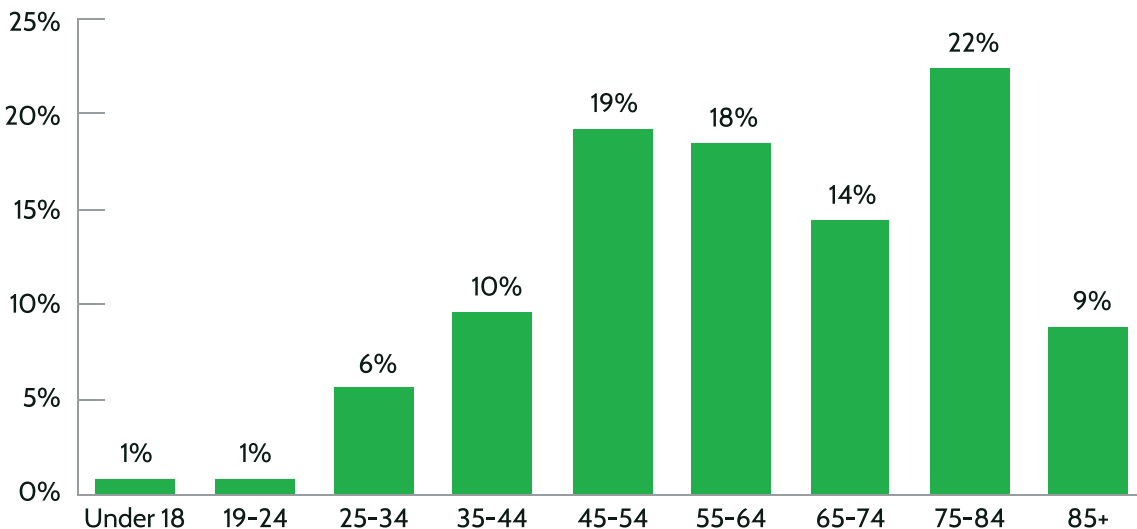
Gender



There were more females (66%) than males (34%) in our sample overall. None of the residents who took part in the listening activity indicated that they were non-binary, transgender or other gender identity/expression.

Over 80% of all residents who took part in listening activity were over the age of 45.

Age Group

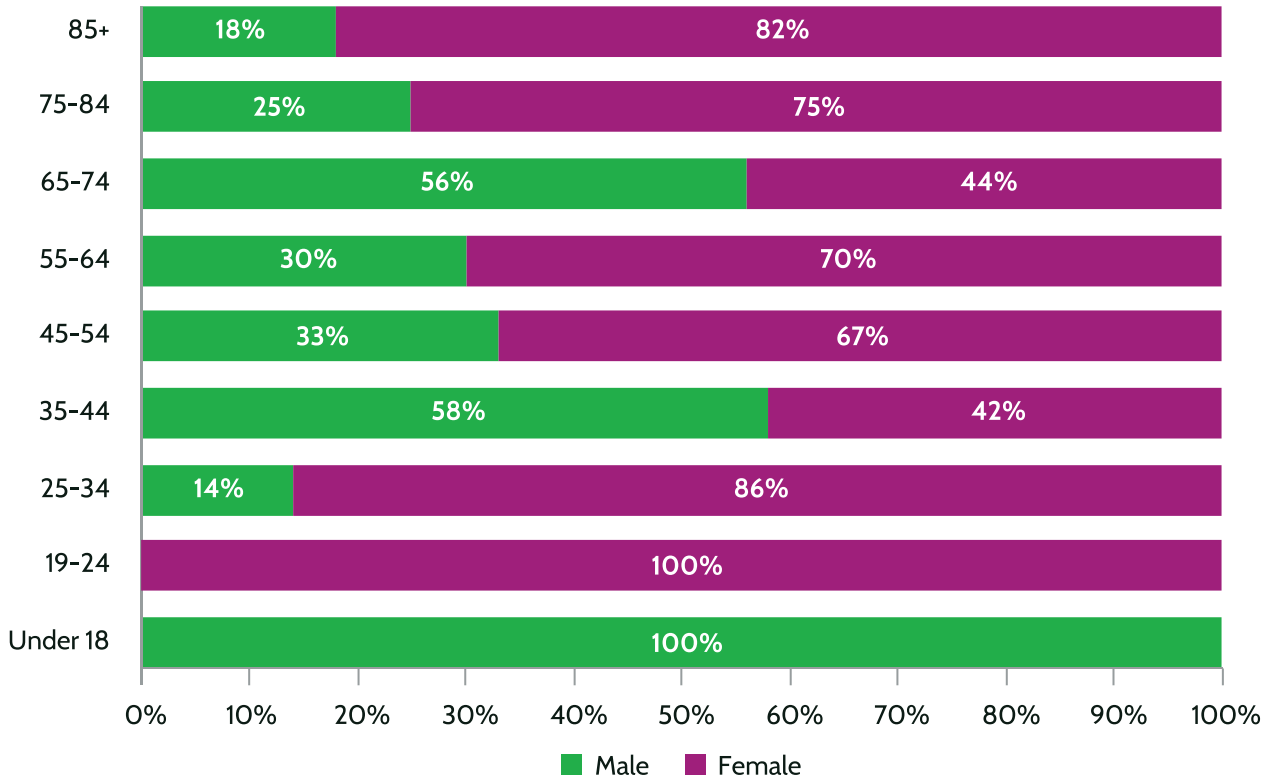


Over 80% of all residents who took part in the listening activity were over the age of 45, with the highest percentage of listenings carried out with those in the 45-54 (19%) and 75-84 (22%) age categories. There were a small number of listenings (8%) with people aged under 35 years.

As with the previous listening project for Dorothy House Hospice Care, the listening activity was carried out during office hours when younger people and people of working age may have been at work, school or college. Amongst residents in the Chew Valley area, older residents were more likely to have a direct experience of caring for someone with a life-limiting illness when compared to younger residents, and therefore may have additional experience and insights beyond what a younger demographic might have to share.

Similarly, the Chew Chat and Death Café community groups were mostly comprised of older residents with experience of life-limiting illness and associated loss and bereavement. Many residents in these groups had lived experience and, having benefited from group support, may have felt more comfortable talking about their experience with Community Organisers.

Gender and Age Breakdown



As previously mentioned, the majority of listenings carried out by Community Organisers in the Chew Valley area were with female residents (66%) and fewer men took part in the listening activity overall.

Amongst residents aged 35-44 and 65-74, the balance of male and female listenings was closer to equal when compared to other age ranges. In residents aged over 85 years, there were significantly more listenings carried out with women (82%) when compared with men (18%). This was also the case with residents aged 25-34, where 86% of listenings were with female residents.

Amongst residents aged 35-44 and 65-74, the balance of male and female listenings was closer to equal when compared to other age ranges.

Project Findings

This section presents the findings from listening activity with residents in Chew Magna, Chew Stoke, Bishop Sutton West Harptree, Clutton and Temple Cloud, as well as group listenings carried out with attendees at Chew Chat in Chew Magna and the Death Café in Bishop Sutton.

Experiences of Life-Limiting Illness

Almost three-quarters (74%) of residents who took part in listening activity in the Chew Valley area said they had previously needed or are currently receiving support because they, a family member or a friend has (or had) a life-limiting illness. This is a significant difference when compared to the 2018 listening activity in Mendip when 47% of residents said they had experience of life-limiting illness.

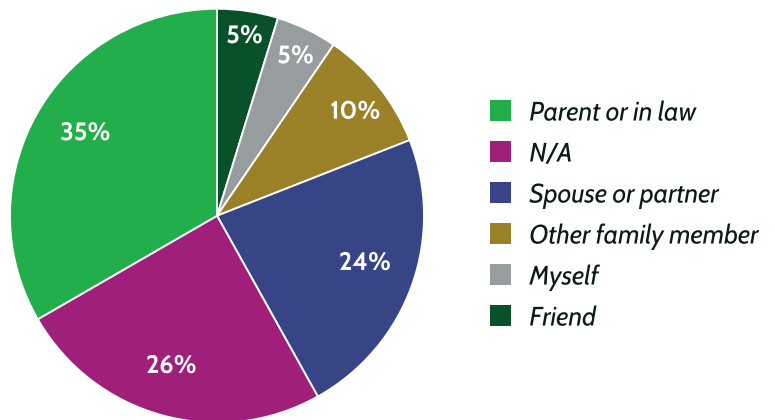


Chart showing who residents care for/cared for in Chew Valley

Amongst Chew Valley residents who said they received support, 82% had previously cared for a person who died, 12% are currently caring for someone with a life-limiting illness and 6% are currently living with a life-limiting illness e.g. cancer. 35% of residents who had an experience of life-limiting illness cared for or are currently caring for a parent or in-law, 24% for a spouse or partner and 10% for another family member (e.g. sibling or grandparent).

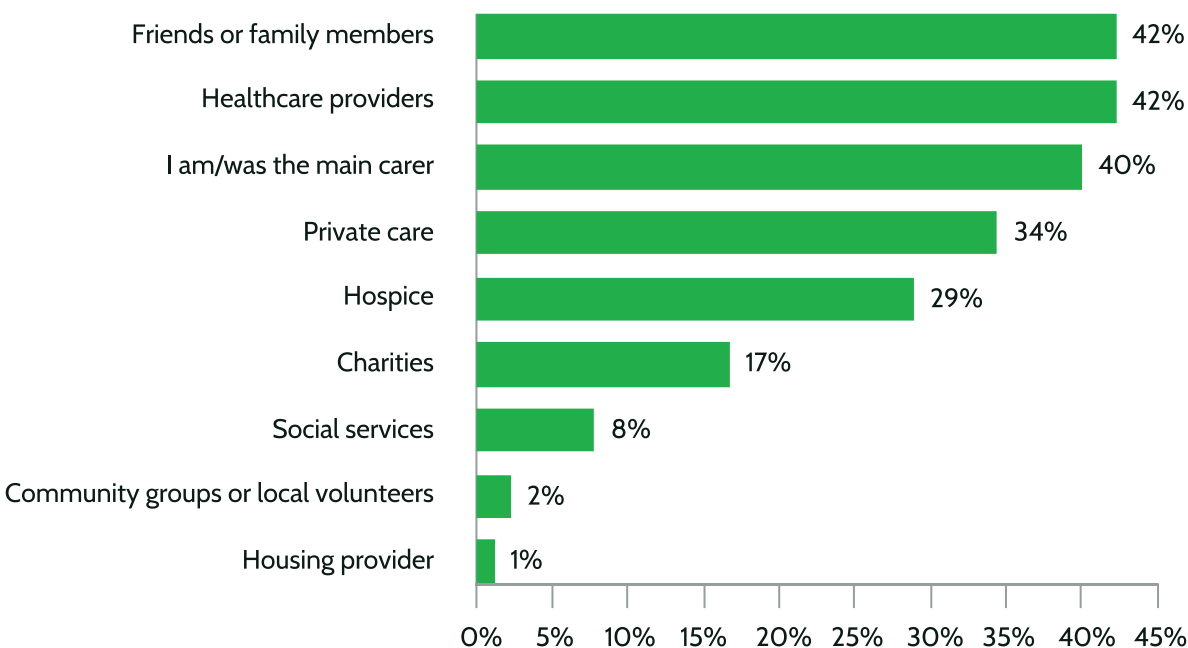


Chart showing sources of support received by people affected by life-limiting illness in Chew Valley

Residents were asked what support and services they had received or are currently receiving locally and from which organisations, groups and individuals. Many people who reported an experience of palliative care and life-limiting illness said they accessed (or are currently accessing) more than one source of support. The chart above shows a breakdown of the types of support accessed locally.

42% had support from friends and family members when caring for someone with a life-limiting illness. A further 42% of support received was through healthcare providers such as GPs, hospitals, district nurses and other NHS staff. The hospitals mentioned included Bath Royal United Hospital and Bristol Royal Infirmary. 40% of all residents listened to said they were or are the main carer for their relative, spouse/partner or loved one and said that the additional support was to help them care for their loved one.

34% had made use of private care services e.g. care homes, private carers or night nurses and 29% used the services of a local hospice. This includes Dorothy House and St Peter's Hospice. Whilst there were some mentions of Dorothy House, residents were more familiar with St Peter's Hospice overall. Some residents had not heard of Dorothy House or did not know the service was free to access.

17% of residents had accessed support from a local or national charity. Charities mentioned were Macmillan, Marie Curie, Cruse Bereavement, Penny Brohn and the Independent Living Centre. 8% said social services had been involved to offer support e.g. offering a carer assessment or helping carers who were unable to cope with their loved one's care needs at home. A small number of people said they had support from community or voluntary groups (e.g. Village Agent, Chew Chat, volunteer drivers, support groups) and their housing or assisted living provider at the time their loved one was ill.

Whilst there were some mentions of Dorothy House, residents were more familiar with St Peter's Hospice overall. Some residents had not heard of Dorothy House or did not know the service was free to access.

"We had Marie Curie nurses and then he went into the hospice. But the nurses that came to us at home looked after him for quite a while before the hospice. We also had district nurses who helped."

"He went into St Peter's Hospice but that was the only support we received other than from the doctor's surgery."

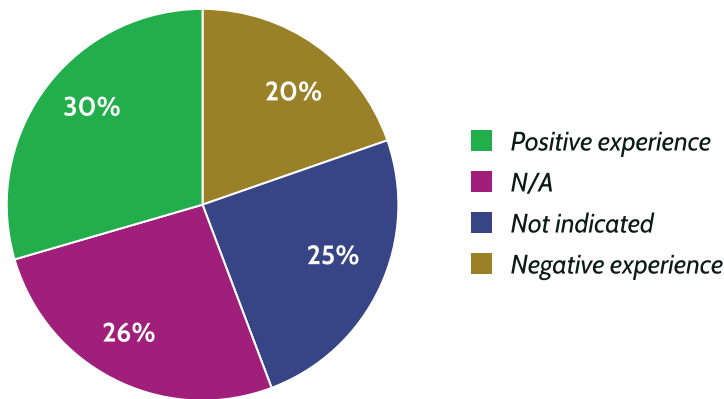
"We had help from the Village Agents and the NHS."

"Dorothy House came and supported him at home. He died at home."

"We have a district nurse come and see her and an outside carer."

"I had been caring for him for some time, but he got taken into a home because he was becoming very aggressive and on occasion (although he didn't mean to) he lashed out and hit me and I got hurt quite badly. Social services got involved."

Sentiment Analysis (Palliative and End-of-Life Care)



Many residents offered their views on whether they felt their experience of care and support was satisfactory. All listenings from people who reported an experience of life-limiting illness were coded for expressed sentiment to better understand the local experience.

25% of residents did not express any sentiment towards their experience of care. These individuals spoke factually about their experience without indicating how they felt about the standard of care.

30% of people who previously received or are currently receiving support indicated they had a positive experience. Positive factors included the care received by a hospice (including home care), private carers, NHS staff (including doctor's surgeries) and the services offered by charities including Macmillan. Some residents mentioned that having a knowledgeable family member e.g. a nurse or a doctor, was a beneficial factor in ensuring their loved one had good palliative and end-of-life care. These individuals suggested this knowledge and experience helped them to navigate the range of support on offer locally.

"He had great support from the NHS but his wife is a nurse so she was able to access groups and organisations that could support locally."

"He had excellent palliative care. The GP was remarkably good and the district nurses were also good and kind."

"The staff and NHS were very supportive and explained everything that was more than likely going to happen with Dad. We did have private carers that supported us looking after dad, which we as a family really needed and benefited from having the carers."

"We had Macmillan nurses who were brilliant."

"St Peter's Hospice was excellent, we felt privileged to be able to use them and have such a great service for mum."

20% of residents who had an experience of palliative care and life-limiting illness suggested they had a negative experience overall. Some individuals felt let down by their experience of NHS services or standards of care for their loved one, this included issues with coordination of care, standard of care, home care, medication and medical staff who were unsupportive or slow to respond. Others said they struggled to access hospice services, in particular, a bed for their loved one when it was needed. Some residents who used the services of private carers suggested it was difficult to arrange care and the cost of care meant their loved one did not have enough care to meet their needs. Some carers said they had a negative experience due to a lack of information and practical/emotional support during the time they were caring for their loved one and after their loved one had died.

“The district nurses weren’t great they just told me how to give the medications and injections they didn’t ask if I was OK to do this or show much compassion. Macmillan were not good at all, I asked them for support with a care plan and they just never came back to me.”

“None of them rated the BRI – they felt like no one cared and they were just another number on the list.”

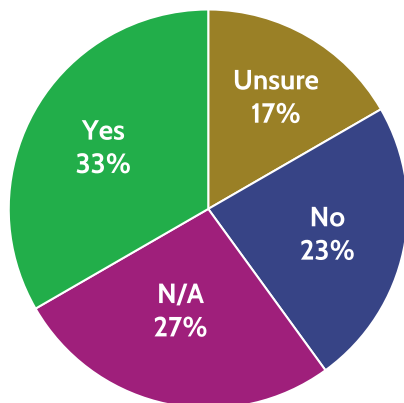
“We couldn’t get any help or support, nobody reached out to us and we didn’t really know where to go. The Hospice were good, but we only got connected with them towards the end.”

“I looked after him myself for as long as I could. I did try and get him into St Peter’s Hospice but they were too busy, so I had to get a carer in to help me. By the time St Peter’s had space, he had sadly died.”

“He needed to be in a nursing home but he was self-funding and couldn’t afford it. There was a Social Worker, but she was terrible and gave us the wrong information.”

Analysis of sentiment was not always straightforward as it related to positive or negative experiences of support for a life-limiting illness. Some residents said their loved one received good care towards the end of their life, but that their own experience of being a carer was negative, fraught and difficult. Some carers said they felt isolated, lonely and stressed and didn’t know where to turn. Some of these individuals felt guilty about leaving their loved one for a short break or felt unable to reach out for additional support for their mental and/or physical wellbeing, because the person they were caring for wanted them to be their sole carer. Other carers expressed regret at not accessing support at the time and reflected that this would have made their experience easier and less stressful.

Additional Support (Palliative and End-of-Life Care)



Residents who had experience of supporting someone with a life-limiting illness were asked whether any additional support would have been helpful. 33% suggested additional support would have been helpful, 23% said they did not need any additional support and 17% were unsure.

Those who were unsure indicated that the care needs of their relative or loved one had recently changed, or they were anticipating needing more support in future as the illness progressed. Comments included:

“So far, all the support has been top-class, although I do wonder if my wife could do with support.”

“We are OK at the moment, we are managing but I do worry about what is to come.”

“I am not sure, it’s a daily struggle and one that we learn as we go.”

“Not at the moment but I am thinking about getting some help with the housework as she gets worse, and I need to spend more time caring for her.”

A third (33%) of all residents who had experience of caring for someone with a life-limiting illness in Chew Valley said that additional support would have been helpful. Amongst this group, some individuals said they would have liked more help and support but felt unable to access support at the time. Reasons stated included pride, refusal to allow outside carers or feelings of inadequacy about accepting help. Some people said they had little access to respite or a break from caring for their loved one which made the experience more difficult. Other carers suggested they would like the opportunity to access respite, but they did not know how to do so:

“Carers would have been a huge help but my mum wouldn’t allow it.”

“She didn’t want to accept any help from carers and didn’t want people in her home. I think it was her pride that stopped her from receiving care sooner.”

“If my in laws and wife had allowed, I would have organised carers for them to give my wife a break. I think they were all a bit too proud.”

“I need a break and I don’t know how to get one.”

Respite and practical/emotional support are felt to be important for people who are caring for a loved one in the Chew Valley area. Some carers indicated their loved one received good end-of-life care, but their own experience of support as a carer was lacking. Similarly, some residents who had cared for a person who died felt that more practical and emotional support for the bereaved would have been helpful.

“I found it emotionally hard and although I have family and friends around me, I didn’t want to put that on family members and I could have done with someone that could relate to what I was going through. I had to learn to live on my own after 50 years and take care of utilities and finances which I hadn’t done before and again it was a journey that would have been easier if I could have reached out to someone that could relate. I do feel the carers are a little forgotten about.”

“I think GPs need to be a little bit wiser to the bigger picture. They have been really helpful to my brother-in-law but not really given much thought or care to my sister’s needs mentally or physically.”

“Yes, we could have done with more support from the GP, we needed carers and we were all struggling, so emotional support would have been good too.”

“My mother-in-law is not in a good place, she cared for him for a while and now she feels at a loss. GP was not supportive with grief and she has been signposted to support groups, but she needs hand-holding through this period, which sadly, we just don’t have the time to do...”

“We struggled to find support with life after he had gone, particularly emotionally.”

Some bereaved individuals said they had been able to find support and suggested that support should be more readily available and better promoted so that others in the same situation can access it easily.

“During the last few months of his life I felt supported, it was only after he had died and the dust had settled that I have felt terribly alone. I have some super friends who know me well enough to know when I am not ok but sometimes its hard to talk about how you really feel if the person you are talking to has not experienced the same thing or similar to you. Some days I just want to be alone but I know that isn't good for me and that's why I joined the death café. We need to promote this group because I am sure there are plenty out there who would benefit from coming along.”

“Since my mother died I have discovered Penny Brohn UK, cancer wellbeing for everyone. This has helped me tremendously and they are very big on the carer being as important as the person dying. This was the first time I had felt understood and they supported me even though my mother had already passed away. I wish I had known about this organisation when my mother was alive.”

“They were really good to my husband but not so supportive for me. There were times when I felt quite alone and there have been times since his death that I have felt 'on my own' and this is why this café is so important to me because I can share my experiences with people that can relate.”

Financial concerns and concerns about the provision of transport were raised by several residents who had previously provided care or were currently caring for a loved one with a life-limiting illness in Chew Valley. Some residents reflected that they were fortunate not to have any financial worries or lack of access to transport at the time they were caring for a loved one, but that the situation and circumstances would have been very different if they had been working, less well off or did not have access to a car.

“We were very fortunate in that money is not an issue, but I dread to think how some people afford the costs of care relief or care homes. One week costs around £1,200!”

“None that I can think of at the moment for me personally, but there are periods when I can't drive and rely on family. So, transport would definitely be an issue for those that don't have support.”

“Community support in driving to and from appointments. We are lucky we don't need it but it falls to my wife and I to transport my father-in-law as my mother-in-law doesn't drive.”

Some residents said they would have appreciated more information in a timely fashion, right from the point of diagnosis. Some people in Chew Valley suggested it is not always easy to find the right information in one place and it can be difficult to know what support and services are available locally for people living with life-limiting illness and their carers.

"A support package should be handed to everyone that receives such a diagnosis and include what is available in your area; as it takes so much time to research, and so many loved ones are having to do this in a very challenging and difficult time, which I think is creating unnecessary stress."

"A system where the care services join up the dots – better signposting, because when you are in this overwhelming situation you can't think straight and need support and advice not constant obstacles."

"More support and signposting right from the diagnosis. You get given this awful news and then almost expected to know how to deal with it and where to go to get support. It throws the whole family into turmoil. Maybe the service is overrun but it was pretty poor in my experience."

"That initial support – we ended up using Google as we just didn't know where or who to reach out to. The GP surgery should provide an information leaflet or at least signpost us to an organisation that knows about all of this."

"We knew it was a smoking disease but we needed to understand more about it. As a family we didn't know what we could do for her or how to get more support."

Some residents also said more practical support such as where to get mobility aids to help with the physical task of caring would have been helpful:

"A one stop Mobility shop, so that everything is in one place, so that all equipment can be delivered at the same time. This would also allow the people providing the equipment the opportunity to get to know you and your situation as they may be in a good place to make recommendations as your disease progresses. Once the person dies, it would also make it easier for the items to be collected promptly so they don't cause the family added stress. My dad's condition had progressively deteriorated, he needed the next model up in a wheelchair, meaning the one that had been delivered only a month ago was no longer suitable for him. Equipment took so long to get delivered and collected."

"Knowing what is available and what to ask for. Learning what is important and how to administer things like a catheter and changing them, if shown, this is a fairly simple task to complete. Where to get supplies from and that could be free, like urine bottles, pads, the sliding sheet when someone is bed bound, also sources to assist in second mobility walking aids etc."

Some carers suggested better coordination, provision and standard of care would have been helpful at the time their loved one was coming towards the end of their life. These residents said it would have been helpful to have the same carers each time, more support from medical staff, better symptom management and access to the type of care (e.g. hospice or home care) that their loved one wanted at the end of their life.

“When she had carers coming into her home, she couldn’t cope with the changes in care providers and changes in routine. She needed the continuity. The agencies didn’t seem to recognise these difficulties and were always sending different carers at different times. It caused a lot of distress.”

“More support and compassion from the district nurses, doctors and Macmillan.”

“Home care where we live, my wife would have preferred to stay at home until the end but that is not always possible.”

“The period of time from being told he had heart failure to actually dying was I suppose quite short but due to Covid, the majority of advice and medication changes and dosages received from the hospital were given over the phone which wasn’t ideal, but little we could do to change it. He was not comfy when he slept, so wasn’t sleeping well at all. No one seemed that interested in that side of it.”

“What would have been more helpful would have been the coordination of the carers’ visits. They came at irregular intervals and, since they were not working in pairs, frequently the first to arrive had to wait for some time for the second one to arrive before they could help, then the first one had to leave for the next appointment so we rarely had the full hour of care, and they often had to rush through the tasks.”

Among residents who said they did not need additional support, there were several positive comments about experiences of palliative and end of life care:

“No, the care she received from Dorothy House was brilliant.”

“We had everything we needed through the hospice, they really were great...”

“None, they were very well supported.”

“Macmillan support was very helpful to all of us.”

Local Support for Life-Limiting Illness

As part of the listening activity, residents in Chew Valley were asked what support is felt to be important locally in terms of life-limiting illness. This might include help to both live well and die well, and support with associated loss and bereavement. This was a broad and open-ended question which gathered views from residents with an experience to share and those who had no experience of life-limiting illness. Feedback can be summarised under the following key themes. Many residents mentioned more than one theme in their listening:

- Health and care services
- Communication and signposting
- Practical support
- Emotional support (including bereavement)
- Community groups

Health and Care Services

A reliable, supportive and proactive NHS service was felt to be an important source of support for people living with life-limiting illness and their carers in Chew Valley. There were mixed feelings among residents in Chew Valley about how well they are served in terms of their GP surgery. The Chew Medical Practice was regarded as excellent by several residents, whereas some residents reported a negative experience with the Harptree Surgery. Some residents suggested that a GP should be more supportive and allow more time for people with life-limiting illness. Some residents also suggested that a member of staff or a Social Prescriber could take on the role of providing information and support from a centralised location (e.g. the GP surgery).

There were mixed feelings among residents in Chew Valley about how well they are served in terms of their GP surgery.

“A good GP! I think they need to start using social prescribers more efficiently. I don’t think a lot of people know what they do or even that they exist but if used effectively, they could help take the pressure off doctors and the system.”

“You need a good GP but again, they are short staffed and a 10 minute appointment window is not enough to obtain the full picture. I think this is how my sister and her husband ended up in the situation they were in. He needed help long before he got it.”

“A point of contact at the surgery – not necessarily a doctor.”

“The GP should definitely be more supportive and be far better at connecting you.”

A local hospice was also felt to be an important source of support for the health and care needs of people with life-limiting illness in Chew Valley. Some residents suggested that an inpatient hospice or hospice at home service should be available for anyone who requests it and that individuals should be able to choose whether they want to die at home or in a hospice (and have that choice listened to and respected).

"I think a hospice is important for people if they don't want to die in their own homes. Sometimes people don't want to put their care onto their families and even with outside support, the family still takes the brunt of it."

"More and more people want to die at home rather than in a hospice. So, help to do that."

"Those with more immediate needs should know that they will be able to access pain-free care in a hospice."

"A good accessible hospice close by."

"Palliative care in your own home should be available but equally I think so should a hospice."

When people spoke about health and care services, either those provided by the NHS or through private carers they felt it was important to have familiar carers, effective symptom management and pain relief when needed. People with life-limiting illness and their loved ones would like to see good, coordinated and joined-up care and support from all providers involved.

"I think you need a good team of carers, but the same carers need to be seeing the same patient. They need continuity and so do the family. You can't build any sort of relationship if you see someone different daily..."

"You need pain killing drugs, not being in pain is very important."

"Pain and symptom control is the most important thing."

Communication and Signposting

Some residents in the Chew Valley area would like to see better signposting and availability of information as it relates to palliative care, life-limiting illness and associated loss and bereavement.

There was some overlap with the theme of health and care services (see above) and some suggestions that the information and signposting could be coordinated by GP surgeries. Residents would like to understand what support is available locally, how to access it and how much (if anything) the service will cost. For example some residents were not aware Dorothy House services are free to access. Some residents felt there was an assumption

that they would have the skills and/or capacity to seek out information for themselves at an already difficult and stressful time. Telephone support e.g. a telephone helpline or list of telephone numbers was felt to be ideal for older residents or those without internet access or digital skills. Overall, residents suggested that signposting and access to resources, information and sources of support were important locally.

"We were very well catered for financially, but it was difficult to know where to go for help. It's a minefield of information and we didn't know what help we were entitled to. I am not one for the internet but, even if I was, that too is overwhelming. I feel a GP should be offering support in signposting people through this journey."

"Package of information and support that is available, with contact telephone numbers, particularly for older people, who want to pick up the phone and speak to another human. Older people find this all very difficult."

"Information on groups that offer help and where people need to go to get this help needs to be more publicly available."

"There should be information available about where to go for help and about what support you are entitled to."

"A pack that gives advice, numbers and what is available to the people that need it, instead of searching a needle in a haystack on Google!"

Practical Support

Some residents said practical support was important for people living with life-limiting illness and their carers in Chew Valley. Transport was the most frequently cited practical support need. Public transport (including Westlink) is felt to be insufficient in the Chew Valley area and there are limited options for people who are unable to drive. This is especially important for residents who have regular medical appointments or who are too unwell, or elderly to use the (limited) bus service. Some residents said they were able to get lifts from a friend or family member or pay for a taxi. Some of these residents also suggested they would be stuck if they were unable to access help with transport from a family member or friend. Some residents said driving their loved one to hospital appointments was difficult to manage with work and other commitments but suggested they had no choice as there was no other way to access health services.

Residents in Chew Valley would like to see more support for local transport initiatives which help people affected by life-limiting illness and their carers to access essential transport for their health and care needs. Residents who attended the Chew Chat group reported that volunteer transport can be arranged by the leader of the group. One group attendee suggested a community transport initiative and a volunteer said the group could benefit from having access to a minibus.

Transport was the most frequently cited practical support need. Public transport (including Westlink) is felt to be insufficient in the Chew Valley area and there are limited options for people who are unable to drive.

"There is no transport here for the elderly or those without cars, although Sam from Chew Chat does arrange lifts."

"Transport was a massive issue as my mother-in-law doesn't drive so was reliant upon family members taking my father-in-law to appointments."

"Transport here needs addressing, there isn't any! I am 92. How can I walk to the bus stop? Even if I wanted to nip out for a few hours, I would have to rely on friends or family to transport me."

"Transport is dreadful here; I don't know how anyone would manage if they couldn't drive."

"So many people are stuck here without transport so some kind of community transport is needed."

Alongside support with transport, residents suggested other practical support needs. This included someone to sit and relieve a person who is caring e.g. volunteer or 'Good Neighbour' service so they can have a break from their caring role and practical support with finances, funding entitlement, form filling and other administrative tasks. Some residents said they had received support from the Village Agents.

"Advice with financial support should be more available to those who have been diagnosed. You are suddenly in a position where you can't work and aren't bringing money in and at times that can impact your partner too. There needs to be more guidance to navigate this as it impacts every aspect of your life."

"Support with paperwork in terms of what you are eligible for and how to access support. Forms for some things need to be obtained through the council and this can be stressful to deal with."

"Volunteers who are willing to give some time to come and chat, make a cup of tea or relieve a carer for an hour or two."

"The local Village Agent came round and introduced us to so many useful things like getting a blue badge and attendance allowance. She calls from time to time to check in."

Emotional Support

When people talked about what support was felt to be important locally, the themes of practical and emotional support were closely linked. There is a general feeling that the provision of care and support needs to consider the practical and emotional needs of the patient and the person who is caring for them at home. Some residents suggested a befriending service (possibly led by volunteers with lived experience of life-limiting illness) which could help to provide emotional support such as a listening ear, a knock at the door, a cup of tea or just being there to offer help. Support with bereavement was also felt to be important for some people who had lost a loved one.

"Someone to support you through those tricky times, to share the ups and downs through the progression of the illness. Someone to help you prepare for what is to come. Some support when your loved one is no longer here. That's something I find very hard now 2 years on and it's hard to find people that can relate. Friends are amazing but can only relate on an emotional level, not an intellectual one as they haven't all experienced what I have."

"Someone who can provide a non-judgemental listening ear. This doesn't have to be counselling, just somewhere you can go to talk and have someone suggest ways of coping. A holistic approach to wellbeing."

"I think you should receive bereavement counselling although you don't feel like you need it at the time."

"I remember grief counselling not being very easy to access and that is very important."

Community Groups

Many residents who took part in the listening activity suggested that access to group support or practical and emotional support through a local community group was important for people affected by a life-limiting illness. These listenings provided a useful summary of the support and services on offer for people who choose to engage in a community group such as Chew Chat, the Death Café and a Widow's Group (they refer to themselves as the Merry Widows). Support from Chew Chat and in particular the group leader Sam Oliphant was felt to be invaluable. Many residents praised Sam and suggested she had been able to offer help with transport and other practical support needs. Chew Chat was described as a 'lifeline' and group attendees had universally positive things to say about the group. Village Agents were mentioned alongside Chew Chat by several residents who took part in the listening activity. Similarly, the Death Café and Widow's Group were mentioned by some residents as offering useful support during and after life-limiting illness and subsequent bereavement. It was suggested the Death Café could expand into other locations to offer additional support:

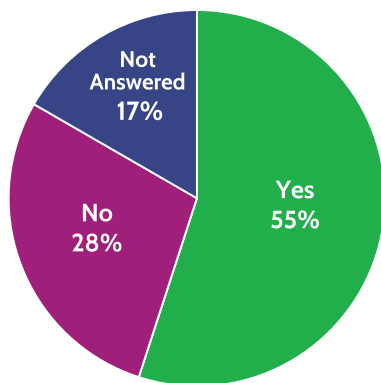
"We are very lucky here in the village there is lots of support available. If you need anything Sam from Chew Chat will organise it for you, including lifts to events and things like that."

"There is the Death Café in Bishop Sutton, I think it is on the third Thursday of the month. It is a place where everyone can talk about death and preparing for death. I think it is really important and we could do something similar here."

"The Death Café have been invaluable in helping me and others through this period. I really would have benefited from something like this during the time my husband was ill."

"We are lucky here as there are some amazing social groups and I just know where to come if I need help. Sam Oliphant is amazing. I wish this had existed when my wife's parents were ill as sourcing outside help can be tricky."

Thinking about and Planning for End of Life



Residents who took part in the listening activity were asked what matters to them when they think about the end of their life and whether they had ever had a conversation about planning for the end of their life.

55% of all residents who took part in the listening activity said they had previously had a conversation about planning for the end of their life. 28% said they had not had a conversation and 17% of residents did not answer this question. This is broadly in line with findings from the Mendip project in which just over half (51%) of residents said they had previously had a conversation about planning for the end of their life.

Amongst people who said they had already made or discussed plans for the end of their life, these included various practical considerations such as a will, power of attorney, living will, Do Not Resuscitate (DNR) request and plans for how their assets or land will be used after their death. Some individuals said they had already pre-paid for their funeral and made arrangements for burial or cremation.

Many people who had made plans for the end of their life wanted to ensure their children and other relatives were taken care of and to ensure that they did not have to worry about planning a funeral or dealing with unnecessary legal issues. Some people reported that a death of someone close to them such as a friend or relative made them realise they needed to make plans for their own death e.g. to avoid similar issues or just for peace of mind. Some individuals said they had a conversation about their end of life wishes with their spouse, children or other family members to ensure their wishes are known in good time and to prepare them.

"Yes, we have made our wills and planned everything that is possible. We did this for our parents because there was no plan in place, and we vowed to ensure our children didn't have to go through the loss and then have to deal with planning everything from scratch."

"We have had conversations. We have made wills, and our wishes are known. I want to be cremated and kept in a box. It's important to me that the family are all ok and are taken care of. I think it is easier for the children if those sorts of conversations have been had."

"After going through everything with mum and dad, we have everything in place. I don't want my children having to deal with it all. We are using just cremation!"

"Everything is planned for me. I have made my wishes known and I have signed a DNR. I'm not afraid of dying at all, I've had a great life. It's important to me that I have a Christian funeral."

"I have had lots of conversations with my family, and I am well prepared. I have a will and power of attorney and a living will with a DNR request."

There were some comments from residents who suggested they did not want to cause a 'fuss' or be a 'burden' on family members and loved ones as they come towards the end of their life. Some residents said it was important to consider practical arrangements for the person left behind after a spouse has died, to ensure they were able to carry out everyday tasks after their loved one has died. These individuals implied this was often overlooked by older couples who had gendered roles within their relationship or household.

"Ensuring the last power of attorney, finances and health is all open, written down and discussed. Even down to gender roles within the household, especially the older generation. He puts the bins out, she does the cooking, shopping and washing etc. He sorts the car out and finances. I think it important that everyone knows what happens in the daily routine of life. There is so much to learn for an older person learning all the new roles they have to take on in a household."

"Instigating better end of life conversations, i.e. do you know how to fill the car up, use the card machine, who your utility providers are and how to access them? It's so important to have this in place before death occurs and before people become ill."

Some people said they had not had a conversation about planning for the end of their life but had made a will. Others said they hadn't given the subject any thought. This was more common amongst younger residents e.g. aged under 40 years. Some residents said they had not had a conversation but, as part of the listening activity, suggested this was something they would consider doing or said they would have a conversation in the future.

"I have not had conversations, but I do have a will and insurance. It's important that the family are taken care of, that they have security and that things are easy for them once I have gone."

"All wills done but I've not really had conversations. I'm quite content with it all. It will happen when it happens there is no use worrying about it."

"I would like to think I would be cared for if I ever need it, but I haven't had those conversations with family yet."

"I haven't had conversations about planning for end of life, I'm far too young."

"We haven't planned any funeral or such wishes, but maybe I should..."

"I would be happy to have a conversation about it, but I haven't yet."

Residents also spoke broadly about what matters to them when they think about the end of their life. Comfort, dignity and peace were the most common themes in the listenings. Residents said they wanted their death to be quick and painless, or as pain free as possible with good pain management. Some people said they would like to be at home with loved ones and some people said they would like to be cared for in a hospice.

"Being pain free, in the most comfortable environment, if at home or in a hospice. Having your last wishes listened to and followed through."

"Quick and painless and in the comfort of my own home."

"I want to be pain free! And I don't want my husband and or son to be left looking after me. I want to die with dignity."

"I don't want to die at home. I would want to be in a hospice for pain relief and the expertise of palliative care and the dying process."

"Having a peaceful and calm environment and having family members around you."

There were several comments from residents in favour of assisted dying. Some residents feel people are generally living for too long with a life-limiting illness and are kept alive by modern medicine past the time it is fair or dignified for them. These individuals said they thought people should be able to choose when they die e.g. through medically assisted dying or by refusing or withdrawing treatment designed to prolong life.

"These days with all the medication that is available they tend to keep you alive too long even when all the quality of life has gone. Under no circumstances do I want that or anything like tube feeding to keep me alive."

"I would go to a country that allows you to choose when you die. The treatment they offer nowadays is good but it's too good and it keeps people alive when it would be kinder to let them die. It's degrading for any human to have to live like that."

"I think you should be able to choose when you are ready to go. Watching people suffer until the end is heart wrenching and at times quite cruel."

"Medication to put you to sleep if that is what you or your loved one wants. We do it for animals, why not allow humans to do the same thing?"

Life-Limiting Illness – Community Support

Chew Valley residents who took part in the listening activity were asked about community support and how members of the community could help support others in the local area who are affected by life-limiting illness. Over three quarters (77%) of Chew Valley residents indicated support from the wider community was important for people affected by life-limiting illness and their carers, with 9% who felt it was not an important factor. This suggests there is a broad awareness of the importance of community support for people affected by life-limiting illness in Chew Valley.

Despite a high level of recognition of community support for people affected by life-limiting illness, the overall percentage of Chew Valley residents who indicated they were satisfied with the current level of community support or community spirit in their own area was lower. 28% of residents suggested satisfaction with the community spirit or level of community support locally, with 9% who suggested it was felt to be lacking. The remaining 63% did not indicate sentiment towards community support or did not engage with this topic as part of the listening activity.

There were geographical differences in sentiment towards community support in Chew Valley. Residents who took part in community groups Chew Chat and the Death Café were more likely to report positive sentiment towards the availability of community support. 64% of Chew Chat attendees and 67% of Death Café attendees indicated they were satisfied with the community support and community spirit locally. This suggests that community groups play an important role in supporting people affected by life-limiting illness in Chew Valley. Listeners with residents in these groups also suggests that participating in group activity offers vital support to older and isolated residents in Chew Valley, even amongst those who are not affected by life-limiting illness and associated loss and bereavement.

Residents who took part in community groups Chew Chat and the Death Café were more likely to report positive sentiment towards the availability of community support.

"We are very lucky in Chew Magna; the community supports one another. We have a member of Chew Chat who is 100 years old and lives on their own. If they need anything there is always someone who can help."

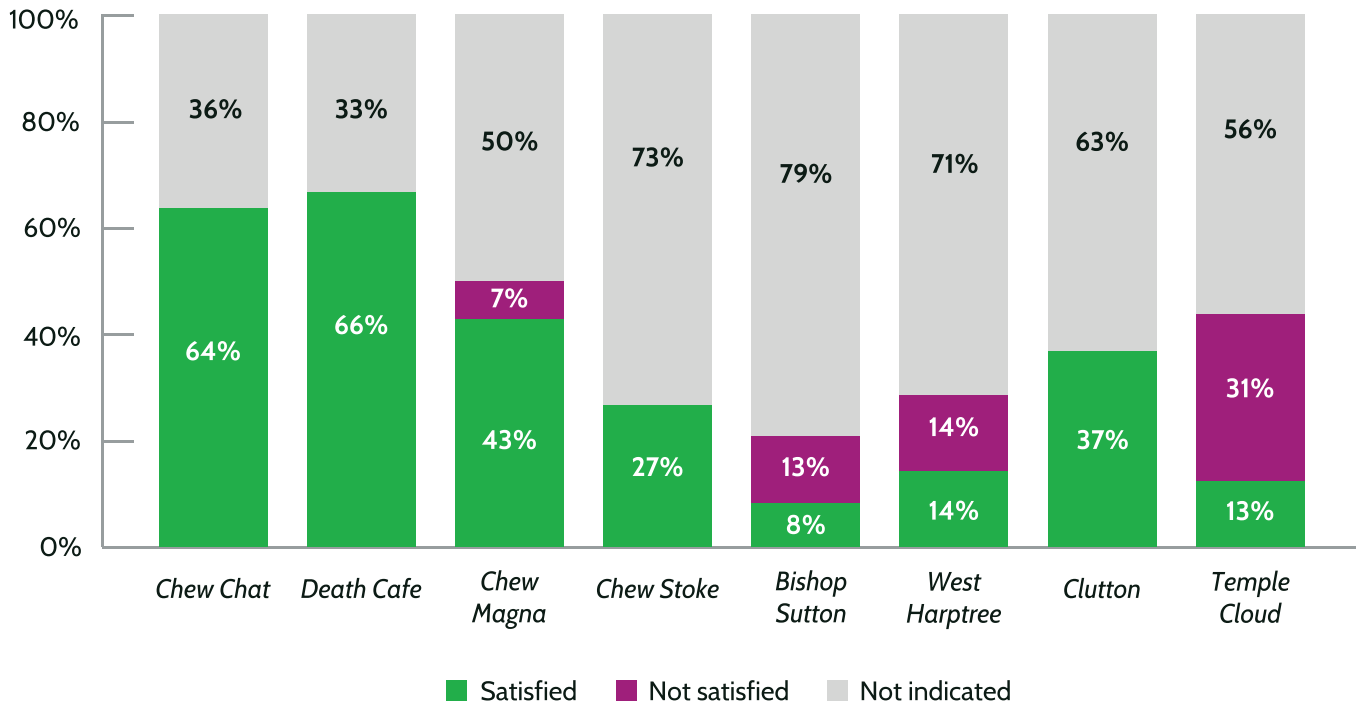
"Groups like this are amazing. This community is amazing, we are very lucky. I know I have people I can call on as well as my family."

"It's nice to live in a good community with good neighbours, there is always local help if you need it. Living in some of the Chew Valley villages you are lucky to know one another as the community is pretty close. It can be more anonymous and isolated in bigger places."

"The Death Café. Somewhere like this has been so beneficial to me and I think would a great source of comfort for many others..."

"Support groups are helpful, and I find this one particularly supportive..."

Satisfaction towards level of community support/spirit by listening location



Of the six villages visited by Community Organisers, Chew Magna reported the highest level of satisfaction with community support and community spirit (43%), followed by Clutton (37%) and Chew Stoke (27%). Residents in Bishop Sutton had a negative view of community support overall (13%), with just 8% of residents who suggested community support or spirit was good. This was also the case with West Harptree where there were equal reports of positive (14%) versus negative (14%) feelings about community support. Overall, residents in Temple Cloud were more likely to report a negative sentiment (31%) towards community support and community spirit when compared to a positive sentiment (13%). This suggests that Bishop Sutton, West Harptree and Temple Cloud residents do not feel community support reflects what is needed locally.

From the listening activity, there was some indication that Covid-19 had impacted upon community groups which had not resumed after the lockdown period came to an end. Other individuals reported that support offered during Covid-19 had improved their overall perception of community cohesion. Some residents felt there was poor integration between new housing and existing social housing in Temple Cloud.

“More community spirit is needed here. There used to be great groups but now the village is split. The new people in the new houses think they are better than us and the friendly caring nature that once was here has gone for many.”

“Covid community spirit was great. The levels people went to help others was amazing. Such high levels of kindness.”

“Community spirit. It’s mixed round here. I think Covid destroyed the community spirit as a wider community. It might be good on one street but not as a whole village.”

“There was a good band of people who helped out during Covid, so similar support to that I think.”

“There are no groups and it’s got worse since Covid. I now feel quite isolated.”

“It’s a shame the community spirit has been lost, not one looks out for anymore and if you live alone it can be very lonely.”

Perception of community support was also (to some extent) age dependent, with older residents reporting a better experience of community support compared to younger residents. This could be because older, retired people have more time to get involved in community activities and groups like Chew Chat. It could also be because older people are more likely to be the target group for community-based support such as that offered by Chew Chat. This includes befriending, volunteer car services, lunch clubs and practical support.

Care should be taken to ensure that the needs of younger residents are also met by community-based initiatives and that they have access to the same level of support as older residents.

How can the Community Offer Support?

Chew Valley residents suggested several ways members of the community (or the wider community as a whole) could offer support to people affected by a life-limiting illness. A variety of groups and organisations were felt to be well suited to this role, including Chew Chat, Good Neighbour services, Village Agents, church congregations or groups and other groups like the Death Café and widows group. Chew Chat and Village Agents were felt to be the most well suited to lead on community support provision locally as they know the individuals in the community and how to offer the kind of help that they need.

Some residents also felt that community outreach should be proactive to ensure that all residents are aware that support is available e.g. a knock on the door or information posted through the letter box. Pride was felt to be an issue amongst some residents in Chew Valley who find it hard to accept help. Some residents also said it can be hard to know what to say or when to approach someone, presumably due to fear of causing offence, being seen to be 'nosy' or overstepping personal or family boundaries.

There was a general feeling that community-based support needs to be tailored to the individual, e.g. one person might need help with transport, whilst another may need assistance with shopping or prescription collection. Residents suggested that community volunteers could step in to offer a variety of practical and emotional support including help with everyday tasks, making a cup of tea and spending time with a carer. Community volunteers could also offer to relieve a carer for a short break from their caring role.

Most people who suggested volunteers could help to support people affected by life-limiting illness, did not suggest that these volunteers take on the health and care needs of the patient or the carer, rather they suggested that the volunteer could offer help and support mostly for the benefit and wellbeing of carers.

Care should be taken to ensure that the needs of younger residents are also met by community-based initiatives and that they have access to the same level of support as older residents.

"By being a helping hand! Even the thought of going to get milk can seem like climbing a mountain some days. You need to know you can nip out and someone is looking after your loved one, even for an hour. That time to yourself is essential to retain your sanity."

"Be a friendly ear, offer a cup of tea, a chat. It's a very lonely time when you care for someone, and you need that lift wherever you can find it."

"Transport and not being afraid to knock and offer help."

"By doing shopping and other odd jobs for them. Just to be around for them, on the other end of the phone."

"Someone that is willing to knock on your door to ask how you are and not be afraid to say the wrong thing. Sometimes people are so conscious about upsetting others it can be more awkward for all involved."

"Good neighbours can offer fantastic support, but I think people are fearful of stepping on toes or being considered nosy."

Sam Oliphant from Chew Chat was frequently mentioned by residents as a key local person who can help to coordinate support locally. Some residents suggested that NHS services e.g. GPs, Social Prescribers and Village Agents should be more proactive in signposting patients and their carers to groups like Chew Chat, the Death Café and the widows group (for those who are bereaved). Some group attendees felt that local groups like Chew Chat and the Death Café should be publicised or expanded so more people can benefit from the support on offer. This may also encourage new volunteers. A small number of residents felt there were misconceptions about the name and function of the Death Café which may be off-putting to some. One resident said it was 'morbid' another said it was a 'terrible name.' If considering supporting new community groups, careful consideration should be given to the naming and promotion of these groups and whether they might give the wrong impression to those could benefit from them.

"There is a Death Café in Bishop Sutton run by Bryony. It is a place you can go and talk about things like how to write a will. It's for people who want to know more about what happens at the end. I went once but found it all a bit morbid."

"People think it is depressing but we talk about all sorts and if someone isn't happy then we can move on to a different topic. We don't sit here and just talk about death."

"There should be training for the people who run the Bereavement Café and the Death Café but that is an awful name!"

Other suggestions for how the community can support people affected by life-limiting illness included coffee mornings led by Dorothy House, support with legal affairs, fundraising for the local hospice and support groups for men who are caring or bereaved as they may struggle to express emotion, cope with grief or reach out for help.

Should the community offer support?

When discussing the topic of how the community could support people affected by life-limiting illness in Chew Valley, some residents were unsupportive of the idea. These individuals suggested it was unreasonable to expect the community to be involved in supporting people with life-limiting illness. Further, sceptical residents said they were concerned that local community members may not have the skills or knowledge to offer adequate support, or that people affected by life-limiting illness might not want to disclose the nature of their condition to neighbours or others in the community for privacy reasons. Some people wondered how much the community should be expected to do. People are working for longer, caring for loved ones or looking after grandchildren and cannot afford to be out of work. Encouraging community-based support could have an impact on communities with a higher percentage of working people who are unable to devote the time needed to support or deliver community-based initiatives.

"How much more should the community be expected to do? People are already working for longer and if they are fortunate to retire early, then chances are they are looking after grandchildren. People can't afford not to work which means there are less people keen to volunteer and therefore less help in the community."

"I am not sure. Is it really fair to put such pressures on to people who are not medically trained or have knowledge of the illness?"

"Should it be a social responsibility? Should people of the community step up? Are they qualified to do so? A lot is expected from volunteers without much support."

"I don't think they should have to help at a time like that. It should not be down to volunteers to help someone dying of cancer."

"I don't think it's up to the community to support others. It's a very private family thing. I wouldn't want anyone interfering."

When considering how the community can support people with life-limiting illness, it is important to understand differences in the perception of community spirit in Chew Valley and willingness amongst more private and reserved residents to attend support groups or reach out for help. Willingness to accept community support may be dependent on a person's desire for social interaction and ongoing relationship with the wider community e.g. whether they want to be involved in groups or prefer not to engage. Whilst community support is felt to be important to residents in Chew Valley, this should be balanced with the needs of those who do not wish to involve the community in their private affairs.

Resources for the Community

Chew Valley residents were asked what resources should be available to support members of the community who want to be able to help those affected by a life-limiting illness. Whilst many residents did engage directly with the subject of the question (resources aimed at community support), many also reflected on what resources they would like to see for themselves or their family members, rather than those for wider community use. Feedback can be summarised under the following key themes. Many residents mentioned more than one theme in their listening:

- Transport
- Support for voluntary groups and organisations
- Knowledge and Signposting.

Transport

Public transport in and around the Chew Valley area is felt to be insufficient to meet the needs of people who do not have access to a private vehicle. Residents said the bus service is limited, and a route (672) had recently been withdrawn. Some residents mentioned the Westlink bus service, but felt it was unreliable as it had to be booked in advance and sometimes did not turn up. There appears to be a lack of viable transport options for people who are elderly, isolated, disabled or unwell, especially if their relatives and loved ones are unable to drive them to hospital or medical appointments. One elderly woman aged 92 said she was unable to walk to the bus stop and could not drive. Another resident was concerned that older people in Chew Valley were driving long past the time it was safe for them to do so because of a lack of transport options.

Residents in Chew Valley would like to see better availability of community-based transport or other affordable, volunteer-led or subsidised transport service for people affected by life-limiting illness and their carers. Some residents said Chew Chat already offers support with lifts but may need additional resources or volunteers to meet the demand. Some residents suggested a community minibus also could be a useful resource.

"We have no buses here into Bristol since they took away the 672. We have the Westlink but that is complicated and unreliable. There is no transport here for the elderly or those without cars, although Sam from Chew Chat does arrange lifts. Sam needs help from people to do the wonderful things she does."

"The work that Chew Chat does is invaluable to people in the community especially the elderly and isolated. I help Sam with Chew Chat. Again, we need a bus. Chew Chat offers lifts with volunteer drivers but there is a limit to how much you can do."

"You need a minibus from the area so people can visit their family when they are in the hospice."

"Volunteer drivers as there are no buses only the Westlink service which is not great."

“Transport is a huge issue here. It is a concern of mine because some people are still driving when they certainly should not be behind a wheel. There are such limited options that people are feeling they must still drive, otherwise they would become quite cut off.”

“We have the Westlink bus service that costs £2 to get anywhere but you have to book that, and it doesn’t always turn up. Transport is a big issue here. So voluntary drivers are a must!”

“So many people are stuck here without transport, so some kind of community transport is needed.”

Support for Voluntary Groups and Organisations

Residents who attend Chew Chat, the Death Café and the local widows group are happy with the support offered to them through these community groups and suggested they could help more people affected by life-limiting illness in the Chew Valley area. Some people said they would like to see central coordination of resources locally which is something the Village Agent and Social Prescriber could work together to deliver. Other residents suggested better awareness of community and support groups with help to promote, advertise and expand the groups locally.

“Groups locally that can offer support or have a connection to a medical set up that can help with advice or signposting. People should not have to be alone or feel they are alone.”

“Forming informal groups, ensuring they have relevant training, DBS checks, safeguarding training and transport would all be excellent resources.”

“A support group to help people going through this and people to spread the word that such a group can/does/could exist.”

“A platform for helpers and those that need help. Social prescribers need to reach out.”

“Someone to co-ordinate a list of volunteers and those who needs support.”

Amongst listenings with attendees at community groups, it was not always clear how much communication (if any) there was between existing groups like Chew Chat, the Death Café and the Widows Group, even if some attendees were aware other groups existed. This presents an opportunity for better coordination and resource sharing e.g. volunteers, as well as an opportunity for groups to expand into other areas.

Knowledge and Signposting

Amongst residents who took part in the listening activity in Chew Valley, a clear and stand out theme from many listenings was of duty and care for loved ones affected by life-limiting illness and a desire to be proactive and seek out resources, information and support. These residents would like to see more 'joined-up' thinking around knowledge and signposting between community groups, healthcare providers and health services as it relates to life-limiting illness and palliative care. Some residents feel there is too much information which is decentralised, scattered and difficult to access. This is especially the case for people who do not have internet access or digital skills. When they are caring for a relative, spouse or loved one who has a life-limiting illness, carers and family members want to know who to call, where to go, how much it will cost, what the telephone number is, how far away it is and how they can get there if they don't have a car.

Chew Valley residents suggested they would like to see Village Agents, Social Prescribers, GPs and other healthcare staff be involved in signposting and sharing resources and information from the point of diagnosis. Resources could include a list of local support services and telephone numbers, what to expect at various stages of a life-limiting illness, when to call for help and where to access medical supplies and mobility aids to help care for a loved one at home. Some residents said it was important for information and resources to be shared with a patient and their carer right from the point of diagnosis, rather than waiting for a crisis point.

When asked what resources could be helpful, many residents suggested a centralised resource hub or knowledge base. This could be a local doctor's surgery, library or other public place. Many different ideas were presented around this theme which included a telephone support line or helpline, a community map of local support organisations and services, an information pack, a list of telephone numbers or a directory-based resource. The common theme in all of these listenings was the need for information to be in one place and kept up to date. This would be a helpful resource for family members, carers and loved ones who are navigating a complex system at an already difficult and stressful time. Some residents were keen to stress that the resource should be accessible to all, including those who do not have a computer or internet access and those who are unable to leave the house.

Some residents feel there is too much information which is decentralised, scattered and difficult to access.

"A one stop shop. It's hard to get information about health, dying, funerals, care and it's all at a time when you need to think straight but can't because it's overwhelming. I think the information and accessibility to it could be made easier."

"A hub of some sort would be hugely beneficial to all. Knowing what you can help with in the local community. Information and the correct information that is updated regularly."

"It's a minefield. Where, who, what, when, cost? You need to know who you can call, and this should be promoted, maybe by the doctors/healthcare professionals."

"A help line for people to contact professionals to enquire about specific issues."

"Information, that is available to all and is kept up to date."



Photo: (left to right) Community Organisers Katrina, Heather and Sam in Chew Valley.



Photo: (left to right) Community Organisers Sam, Heather, Katrina and Killens Estate Agent staff member in Chew Magna.

Recommendations

Work with local organisations, groups and health care providers to improve information and signposting in Chew Valley. Consider a palliative and end of life care information hub or helpline.

Residents in Chew Valley are proactive and highly motivated to help a loved one affected by life-limiting illness. Patients, carers and family members would like comprehensive, centralised and easy to access information about palliative and end of life care and associated loss and bereavement. This information should be kept up to date and be easily accessible both online and offline. The information should also include telephone numbers with a person at the end of the phone rather than an automated service. A helpline service could be considered. Information, advice and guidance should be provided to all patients affected by life-limiting illness and their carers from the point of diagnosis.


People affected by life-limiting illness in Chew Valley want to know who can help them, where they can go, how much (if anything) it will cost and what to expect at each stage of the illness. If they are caring for a loved one at home, carers and family members would also like to know how they can access supplies and mobility aids. Similarly, when a loved one has died, people in Chew Valley who are bereaved would like to know how they can access emotional support to help them come to terms and cope with their loss e.g. a support group or counselling.

Dorothy House Hospice Care could explore the creation of an information hub which could be located at a doctor's surgery, library or other public location e.g. an information bus. Alternatively, Social Prescribers, Village Agents and community volunteers could be trained to deliver information, advice and guidance to people affected by life-limiting illness, with support from an organisation like Dorothy House. This could negate the need for a physical hub (and associated costs) and ensure that people with no internet access or digital skills can still receive information.

Offer practical and emotional support to carers in Chew Valley by building on existing volunteer and community group capacity.

Whilst the focus should always be on the person receiving care for a life-limiting illness, some people who are caring for a loved one can become isolated and feel forgotten about. Several residents who took part in the listening project said that they (or another carer known to them) had reached a crisis point before being offered support. Careful attention should be paid to the practical and emotional support needs of carers to ensure their needs are adequately met. 40% of residents who said they had an experience of end-of-life care were also the main carer for their spouse, relative or loved one, often without a regular break. Carers may feel guilty about

Patients, carers and family members would like comprehensive, centralised and easy to access information about palliative and end of life care and associated loss and bereavement



asking for help or be in a position where the person they are caring for does not want to accept help from outside sources. This could be due to pride, embarrassment or potential cost, even when help is desperately needed. Doctors, healthcare workers, Social Prescribers, community members and other organisations involved in supporting people affected by life-limiting illness should be aware of the practical and emotional support needs of carers and signpost to the appropriate service.

Organisations like Chew Chat and similar 'Good Neighbour' or befriending services could offer an effective community-based support system for carers in Chew Valley. This could include help with small tasks in the home or garden, sitting with a patient so a carer can have a short break, collecting shopping or prescriptions and spending time with a carer to offer emotional support and company such as a cup of tea and chat. Care should be taken to ensure that isolated carers e.g. those who cannot leave the house due to their caring role, are not left behind. A postcard, a note through the letterbox or a knock on the door will help to identify those carers who are most isolated and in need of support.


Dorothy House Hospice Care could consider direct outreach to local community groups like Chew Chat and the Village Agent service to identify whether a community-based 'Good Neighbour' service can be developed or expanded in the Chew Valley area. Resources may be needed to identify and train new volunteers. Volunteers may also have lived-experience of caring for someone with a life-limiting illness and thus be aware of and sensitive to the needs of carers in Chew Valley.

Develop a community-transport offer for people affected by life-limiting illness in Chew Valley.

Lack of transport is a significant barrier to accessing healthcare, support groups and other essential services for residents who do not have a car. Similarly, a lack of public transport may mean older and unwell residents in Chew Valley continue to drive even when it is unsafe for them to do so.

Access to community-based transport services can provide a lifeline for people affected by life-limiting illness in Chew Valley. There are a number of community transport organisations in the Chew Valley area. Chew Valley Community Transport has approximately 40 volunteer drivers and provides door-to-door transport for medical appointments only, with around a week's notice required to arrange for a volunteer driver. There is a mileage charge to use the service. Parts of the Chew Valley area are also covered by community transport providers SWAN Transport and Midsomer Norton and Radstock Dial a Ride, however there may be gaps in provision locally.

Dorothy House Hospice Care could consider working alongside existing community transport groups to expand community-based transport services for people affected by life-limiting illness. This could be a minibus or resources to support new or existing volunteer car services in Chew Valley.



Access to community-based transport services can provide a lifeline for people affected by life-limiting illness in Chew Valley.

Consider a comprehensive community mapping exercise to develop a complete picture of support, services and gaps locally.

This listening and engagement project is an important first step in understanding what is felt to be needed in terms of life-limiting illness and associated loss and bereavement in Chew Valley. In some listenings with residents, there was a lack of awareness about groups and services in their local area, even if groups and support services existed in these areas. If local residents are not aware of what is on offer locally, there is limited scope to map these services based on listening activity alone.

Similarly, some individuals suggested that services did not communicate effectively with each other or that there were gaps in provision locally. One Chew Valley resident (a GP and a volunteer) who took part in listening activity and a subsequent telephone follow-up call, said that Chew Valley is situated in an area at the boundaries of several regional hospice services and multiple health services with computer systems that do not communicate effectively with each other. In some cases a patient with a life-limiting illness may have a GP in one area, a hospital visit in a second area and hospice services in a third area. Similarly, transport services and community groups may cover a particular village e.g. Chew Magna, but not Clutton. Transport providers SWAN Transport, Midsomer Norton and Radstock Dial-a-Ride and Chew Valley Community Transport may only cover specific postcode areas within the Chew Valley community. This means there may be whole areas of Chew Valley which have limited (or no) community-based transport services. Some support groups such as the Death Cafe and the service offered by Chew Chat are also geographically limited.

A comprehensive community mapping exercise is beyond the scope of this project, but Dorothy House Hospice Care could consider community mapping of the Chew Valley area to gain a better overview of the range of support and services on offer. This could include the precise number of groups, volunteer services, charities and organisations, community transport services, public transport services, Village Agents, Social Prescribers and other identified sources of support. These services could be plotted onto a map of the local area, with their boundary areas, coverage and capacity, to identify specific parts of Chew Valley that are well-served and under-served in terms of support for life-limiting illness and associated loss and bereavement. This could also provide useful information for the proposed information hub (see page 37).

Community First has previously worked with Macmillan Cancer Care and Bath and North East Somerset, Swindon and Wiltshire CCG to identify and map services and can provide more information and support with this if required.

A comprehensive community mapping exercise is beyond the scope of this project, but Dorothy House Hospice Care could consider community mapping of the Chew Valley area to gain a better overview of the range of support and services on offer.

Appendices

Appendix 1: Listening Sheet

Appendix 2: Information Leaflet

Transcribed listening sheets for all listenings with residents in Chew Valley are included as a separate document alongside this report.

Appendix 1

Listening Sheet

Age

Gender

Location

1. Have you ever needed support because you, a family member or friend has or has had a life-limiting illness? (last 1,000 days of life)

i. What support/services are you experiencing/did you experience locally and from which organisation, groups or individuals?

ii. Would any additional support have been helpful?

2. What support do you think is important locally in terms of life-limiting illness? This might include support to both live well and die well and support with associated loss and bereavement

3. What matters to you when you think about the end of your life?

i. Have you ever had a conversation about planning for the end of life?

4. How do you think members of the community could help support others in the local area with or affected by a life-limiting illness?

5. What resources should be available to support members of the community who want to be able to help those affected by a life-limiting illness?

Appendix 2

Information Leaflet



Who we are.

Community Organisers from Community First are working to deliver this project in the Chew Valley area on behalf of Dorothy House Hospice Care.

For more information about Community First or this project contact:

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Community First (Wiltshire) is a registered charity and a member of the Action with Communities in Rural England (ACRE)

Dorothy House Hospice Care

For more information about Dorothy House Hospice Care, please contact our Communications Team on 01225 721392 or visit: dorothyhouse.org.uk



A society where death is part of life.

Share your experience and help us understand what support the Chew Valley community needs in terms of life-limiting illness.



dorothyhouse.org.uk

Dorothy House Hospice Care
Winsley, Bradford on Avon, BA15 2LE
Telephone: 01225 722 988

Registered Charity No. 275745



Hello.

We are working with **Dorothy House Hospice Care** to talk with local people in the Chew Valley area about what support is felt to be needed in terms of life-limiting illness.

We popped by today to drop off this leaflet and let you know that we'll be door-knocking in your local area over the next few weeks.

Dorothy House has recently taken over from St Peter's Hospice as the palliative and end of life care provider in the Chew Valley. Dorothy House wants to hear from the local residents regarding what they feel their area wants and needs.

We have included more information about our project in this leaflet and we hope to speak with you when we are in the area.

Katrina, Heather & Samantha

Community First
Community Organisers

Dorothy House Hospice Care Community Engagement

In partnership with Community First, Dorothy House Hospice Care is undertaking a listening activity within the Chew Valley community to better understand what is felt to be important locally in terms of life-limiting illness: This might include support to both live well and die well and support with associated loss and bereavement.

For Dorothy House, growing their understanding of the community's aspirations for end of life care is important, having recently succeeded St Peter's Hospice in providing clinical care in the area. Dorothy House has a ten bedded in patient unit and offers care in people's own homes through a dedicated local team, but this can only ever meet part of what matters most to people at the end of their lives.

Our mission is that everyone in the area has access to outstanding palliative and end of life care, fully acknowledging the vast amount of end of life care that is provided by local services, neighbours and loved ones. We can only achieve that mission together.

Community First is an early adopter of Community Organising techniques and uses this approach in an open and effective way to meet and talk to local people on matters that are important to them. It is the first step in seeking to understand what can be achieved by building on the strengths that already exist in communities across the Chew Valley.

Community Organisers will visit Chew Valley in January and February 2024. They hope to talk to local people and find out what they have to say. Community First and Dorothy House will then feedback what has been heard before working with the community to agree the next steps.



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Chew Valley Needs Analysis for Life Limiting Illness and End of Life Care.

Project commissioned by Dorothy House Hospice Care,
working in partnership with Community First.

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